



Canadian Addison Society La Société Canadienne Addison

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A d d i s o n I n f o

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What a wonderful year the Canadian Addison Society has had! Check out our new **Logo!** We have reached many more Addisonians, in our own country and around the world and hopefully helped each to gain more information, understanding and meet others and perhaps become part of a support group either in their own province or in some cases, in their own country.

It is with great pleasure that I announce that our next newsletter will be the work of **Francisca Swist**, a Canadian member from Edmonton, Alberta and I know that we all will give to her our total support and encouragement.

Our annual meeting was a success and one of the main issues addressed was that we would include ALL of the Canadian members in our decisions for next year. Most major issues were "carried over" to next year with that in mind, so that we can ALL decide and be a part in shaping our future. We will soon have our own Canadian Addison Society Website! It should be well in place by January 1999. Thank you again for your continued support. **Don't forget to renew your 1999 membership!**

Sincerely **Joan Southam**

President's Message by Mrs. Greeta Fraser

We are now 4 years old. We have come a long way in that time. I would like to thank all of our support branches and thank them for all the work that they have done and sincerely hope that we can continue to work together towards the same goals. Again, let me remind you that all officers of the local support group **MUST** be members in good standing of the Canadian Addison Society. Thanks to Francisca for her help with the next newsletter. I urge all of you to get involved. In my opinion, it always seems to raise our own self-esteem as well. Continue to send us your stories. We all have different stories to tell and others enjoy reading about them as well.

I am planning an **OPEN HOUSE** at my home in Trenton on **November 14, 1998** from 1 to 5 p.m. Everyone welcome. Please **RSVP** if you are planning to attend. Contact me at [<ggfraser@lks.net>](mailto:ggfraser@lks.net) or call me at 1-613-394-4644. Thank you.

Sincerely **Greeta Fraser**

Highlights from Local Meetings

If you wish to start a support group in your area, contact us at the Canadian Addison Society for any information, guidelines or supplies that we may be able to give you, call 1-519-753-1271 or e-mail Joan at <jsoutham@worldchat.com>

Quebec:

If you wish more information about the Quebec support group, contact Sophie at 1-514-528-3291 or e-mail her at <sola@colba.net. > or call Sybil at 1-514-486-9817

Ontario:

Eastern Ontario:

On July 11, 1998, a group of 7 Addisonians and family met in Perth at Patterson's Restaurant, in the interest of starting a support group in Eastern Ontario. The meeting began with self-introductions, with diagnoses ranging from 18 months to 43 years. We elected a President - **Elaine Hall**, Gloucester, Secretary - **Mieke Turner, Kemptville**. Mr. Bill Eckersley donated \$100.00. After lunch 2 more Addisonians and families joined us for the speaker, Dr. Silverman, endocrinologist from Ottawa. He spoke about the history of the disease, the difficulty of diagnosis, common tests used and treatments. He also talked about the management of illnesses and treatment in case of adrenal crises. Dr. Silverman then answered questions from his audience. Minutes submitted by Secretary - **Mieke Turner**

On September 26, 1998 a meeting was held in Ottawa at Robbie's Italian Restaurant in Ottawa's East End. A new board member Kim Dufresne was added. Issues decided: a) term length will be 3 years b) two meetings spring/fall a year c) meeting should be both formal and informal) the meetings should have a guest speaker e) perhaps lunch or areas of interest for a social event f) group will continue to submit to the National newsletter g) ideas for raising money discussed (perhaps an added fee to the national fee h) use e-mail to cut down on costs.

Issues still pending 1) Hospital Emergency and Paramedic services for Addisonians. We can contact the CMA or nurses association as a way to inform medical personnel of the dilemma affecting Addisonians in emergency situations. Perhaps Addisonians could contact their MPP to inform them of the situation.

2) The suggestion was presented to carry an emergency pack, including your medical history in order to give to doctors in the emergency room and emphasize to as many people that this may be the vital key to their health in an emergency.

Guest Speaker was Dr. Mira Wasilewska, a member of the Academy of Naturopaths and Naturetherapists. She spoke regarding the holistic approach to wellness. She centered her talk on the endocrine system and explained to the group some of the natural products that could be used with safety for those with Addison's Disease.

Dr. Wasilewska suggested that Addisonians should never use only the natural approach to their disease. She suggested however that we could improve our immune system by taking natural products such as Vitamin B, Ontario Ginseng, and St. Johns Wort (also good for stress) and improving our diet with avoiding fatty foods and additives.

Submitted by President - **Elaine Hall**

For more information about this support group contact Elaine at <grahamhall@sprint.ca>

Southern Ontario:

The October meeting of the Brantford and District Addison Society was combined with the Annual meeting of the Canadian Addison Society on Saturday, October 17, 1998 at the Brantford Police Station meeting room. There were 52 present at this meeting. We accepted with regret the resignation, due to ill health, of Mrs. Isabel Rathbun, one of the

founding members of the Brantford support group. Mrs. Lois Bleth and Mrs. Karen Harvey have offered to help Mrs. Ruth Ann Kruger.

Self-introductions were made with several members and guests coming from Montreal, New York State, and Michigan State as well as many parts of Ontario.

Speaker for the afternoon was **Dr. Robert Volpe**, a Toronto endocrinologist who spoke on "Clustering of other diseases with Addison's Disease." (See Annual meeting report)

Our next meeting will be in late January or early February -see exact date in our next January newsletter. The speaker will be an Emergency Doctor arranged in conjunction with the Brantford General Hospital. (The doctor could not verify a date at this time). This speaker will speak about the Emergency treatment received, what to expect and how we as Addisonians can help ourselves when we are admitted in an emergency situation. Plan to attend.

Alberta:

The Alberta Addison Support Group held their support meeting on June 27, 1998 at the Royal Alexandra Hospital, Edmonton Alberta with 12 in attendance. The meeting began with the review of guidelines and voluntary introduction.

It was agreed that the group develop an "Addisons Information Package" which will include 1) a list of doctors in Alberta that have Addison patients 2) a Brochure 3) Health Monitoring 4) What to do in an emergency situation 5) A list of contact persons and Addison Group members from Alberta and Canada 6) Membership Solicitation. It was agreed that Colleen Lane and Elisabeth Mol head a committee to gather and create this "New Addisonian" package. It was agreed that Bill Rees provide a draft copy of the NADF Addison brochure. It was agreed that Richard Evans request a copy of the information package from the Canadian Addison Society as there will be overlap from the Alberta info and the Canadian info.

Funding was discussed. It was agreed that an account for the group was to be opened by treasurer Peter Little and an annual fee of \$15-\$20 was agreed upon and will be required from all members. Fees were volunteered by some meeting attendees and were collected by Peter Little. It was agreed that Mr. Little will provide receipts to those individuals who submitted their fees as well as to track paid and all outstanding membership fees. All costs/spending must be recorded and tracked for audit purposes.

An open discussion followed with the next meeting being decided on for October 24, 1998 to be held between Edmonton and Calgary to try and facilitate the attendance of Addisonians in Southern Alberta. This will be arranged with assistance of Rosemary Brown.

A meeting to be held October 24, 1998 at Innisfail Hospital with the speaker, a Clinical Pharmacist was cancelled due to lack of interest. The next meeting will be announced at a later date.

For more information about this support group contact Peter at 1-403-922-5307 or E-mail him at <little19@ibn.net> or call Ginny at 1-403-939-3730

British Columbia:

New Westminister Support Group

On July 11, 1998 a meeting was held in New Westminister with 9 in attendance. For three, it was the first time meeting others with Addisons Disease. One had been diagnosed 15 years, another less than one week.

Topics of discussion included a preloaded syringe, as shown by Florence Weeks from Victoria. Other topics included the definition of Addison's, future guest speakers, osteoporosis, and the need for a bone density scan for future reference, Fosamax, or

Digernal/Etigernate and future guest speakers. Sandra Denisuk, with her previous experience and involvement with asthma, volunteered to assist with fundraising and awareness.

Our guest speaker was Ms. Jetha from CPP who explained Disability Pension and its recent changes. To recap - everyone in Canada since it began in 1966 and upon turning 18, pays CPP if they are employed, until the age of 65. There are three kinds of benefits, **Survivor**, which includes spouse or children's benefit, **disability**, which is a pension and paid to children under 18 and over 18 if going to university. The amount is determined by the amount paid into the fund and the time. You also have to fit the disability criteria i.e.; cannot perform any kind of work and it is indefinite. If you are disabled prior to 1998, the previous criteria apply. Two pieces of ID is required, SIN, or a birth certificate or a picture ID. The onus is on the client to provide good objective medical information. An Adjudicator decides if you meet the described criteria. The child portion under 18 is not taxable but once a child turns 18, the benefit is taxable for the child. If you are to go back to work, you will still receive benefits on 3 months trial, if you cannot work and it is less than three months work deemed unsuccessful job entry. You are allowed to do volunteer work but a course of study or accreditation will be reassessed to see if you have gained transferable skills. The "fast tracking process" is in place if you returned to work and cannot continue because of the original disability within 5 years and within 6 months of stopping work your application for disability benefits will be fast racked. After 5 years you have to reapply for original process. The Appeal Process has three levels and all stages have a 90-day appeal limit.

The next meeting will be November 14, 1998, followed by March 13 and July 10, 1999 from 1-3 p.m. in the Sherbrooke Lounge of the Sherbrooke Centre in the Royal Columbian Hospital, New Westminster.

For more information about this support group call Judythe at 1-604-936-6694 or E-mail her at <bugbee@direct.ca>

Victoria Support Group

The meeting of the Vancouver Island Support Group was held October 3, 1998 at Victoria General Hospital. There were 8 in attendance. Members compared the use of various Glucocorticoids such as prednisone, cortisone acetate, Cortef etc. not only as a daily dosage but also as to how they, as informed patients decide when to increase the mounts on their own in stress situations.

Discussion of the Addisonians' enhanced risk for osteoporosis ranged from the need for bone-density testing at regular intervals to treatment by estrogen replacement, calcium supplements, exercise, and drugs such as Foxomax. Attendees compared notes on coping with full-time employment, insomnia, hunger-induced hypoglycemia, refusal to do jury service and irritability resulting from untreated stress. A report was heard on the latest attempts to have the pre-filled syringes of Dexamethasone brought into Canada for sale to Addisonians for emergency use.

The next meeting will be held on February 6, 1999 in the Victoria General Hospital at 1:00 p.m. We hope to have an endocrinologist as speaker and answer questions about various Addison's topics.

For more information about this support group contact Jim at 1-250-656-6270 or E-mail him at <wx699@victoria.tc.ca> or contact Florence at 1-250-598-0321 or E-mail her at <fmweekes@mail.islandnet.com>

The Annual meeting of the Canadian Addison Society

The Canadian Addison Society held their 4th annual meeting on October 17, 1998 at the Brantford Police Station Meeting Room in Brantford, Ontario. For our morning business

meeting, there were 32 present. The highlights of the business meeting included approval of a new logo, which you will find on our newsletters, business cards, letterhead and more and voted to have both the bilingual names and address on the letterhead. We also voted \$100.00 to have a technician set up a website for us. The question of helping new groups start up was discussed in conjunction with the increase of our fees, some of which would go back to the local support groups. It was decided that this remain as is for the coming year but in the summer newsletter, an agenda would be published for the general meeting and the Canadian Addison Society would accept written proposals how the membership wishes to have this handled. A proposal was submitted by Joan Southam on behalf of Judy Stanley, B.C., that the Canadian Addison Society accept information regarding the self-injected pre-filled syringes and will consider a blanket policy. All agreed. Judy also proposed that the name of the Canadian Addison Society be changed to the Canadian Adrenal Society and this would include all those with Cushing's Disease and those with Congenital Adrenal Hyperplasia, and others. This would also help them as well as our organization when we become a charitable organization. This too was one of the items that we decided to put to the whole Canadian membership since it is "your" decision to make as well. Joan also presented a letter from an Ottawa member regarding the closing of one of the Ottawa hospitals. It was voted that this was a local problem and the members did not feel that it was an area that we should get involved in or set up a precedence. We then broke for a potluck lunch and the rest of the meeting was combined with the local Brantford and District Addison group.

In the absence of the secretary, the minutes were taken and submitted by Greeta Fraser.

Minutes of the combined meeting of the Canadian Addison Society and the Brantford and District Addison Group

Our guest speaker for the afternoon combined meeting was Dr. Robert Volpé, an endocrinologist from the Wellesley Hospital in Toronto. He is also a professor at the University of Toronto.

Dr. Volpé pointed out that approximately 85% of all Addison's Disease today are autoimmune destruction. However, in Third World countries, TB is still the most common cause. There are also a growing number of Addison cases caused by the AIDS virus. A more virulent form of Addison's Disease can occur in infancy.

Schmidt's Syndrome is when two or more related or hormonal diseases occur. By far, the commonest is thyroid involvement, followed by diabetes, pernicious anemia, vitiligo, ovarian failure, baldness, and candidiasis. Less common are those with lupus, hepatitis, myasthenia gravis which affects the muscles and rheumatoid arthritis, celiac disease, asthma with allergies which are marginally related. Forty percent of Addisonians have no other disease leaving 60% that will develop some other affliction. Dr. Volpé stresses the need for all patients with Addison's Disease to be checked periodically for other conditions, the most common, especially among females over 50 is for thyroid involvement. A TSH test will show these levels.

Female hormones can adversely affect the immune system. Low parathyroid or hyperthyroidism can result. Severe hypothyroidism causes aches and pain in the muscles. With the cessation of menstruation, the ovaries could become destroyed. Addison's is more common in females on a ratio of 4:1. As Dr. Volpé explained, our immune system is designed to ward off bacteria, germs, fungi, and viruses by making antibodies to fight these invasions. There is tolerance to our tissues and with no destructive tendencies towards our own cells. In most people, cells don't attack the host. Suppressor cells prevent inherited abnormalities in the genes from attacking within.

Genes are thus a minor cause. Something else affects the system such as stress, infection, trauma, smoking, drugs and aging linked with the genetic background can cause the response. The genes for these diseases are closely related and therefore more likely to occur. Scientists now know where on the genetic code they appear. Dr. Volpé recommends that one be checked once a year during regular checkups for associated diseases.

A test called ANA (anti-nuclear antibody) can be high in many diseases, one being lupus and another thyroid.

Long before the adrenals completely fail, as our cortisol levels decline, ACTH goes up. This is why the disease can progress fairly slowly before being set off by some trigger, which can then quickly become a critical condition. Dr. Volpé pointed out that because the cortisol levels vary from minute to minute, the only way to determine cortisol levels is the 24-hour ACTH profile.

Other issues were discussed the injectable emergency syringes, use of extra salt, dosage of medication, twins, too much cortisol, compared to too little cortisol, differences in types of medication and more.

Dr. Volpé also mentioned that he has a new medical textbook available in the spring. It is called The Autoimmune Endocrinopathies.

If you wish more complete minutes regarding this presentation by Dr. Volpé, contact the Canadian Addison Society at the above address or e-mail.

Please Note: Our annual fees are due January 1, 1999.

Minutes for this meeting were submitted by Recording secretary - Angela Timms

Logo Search

Thank you for your entries. Thank you particularly to Patti Nauta and her family from Saskatchewan and Dave Steadman from Ontario. All appreciated your participation. Thanks as well to the entries sent without return names. We hope that you like our choice.

Computer Bytes of Information

Hopefully in the next newsletter, we will be able to include the address of our own website! We are listed officially now as supporting members of the **ACIF (Addison and Cushing International Federation) out of Holland.** Look at <http://www.spin.nl/nvap0302.htm> for the updated Canadian information. Shortly a French language translation of this information will also be added, thanks to the hard work of Canadian member Sophie Lapointe from Montreal.

We do send our heartiest congratulations to the **Australian support group.** They now have their own web site at <http://www.addisons.ml.org>

Still one of the popular and easily understood sites for information for family or oneself is the **NADF** site (National Adrenal Diseases Foundation) at <http://medhlp.netusa.net/www/nadf.htm>

The website at **NIDK** (National Institute of Diabetes and Digestive and Kidney Disease) has some good information as well at <http://nidk.nih.gov>

There is a very interesting and informative site at the **NIH** (National Institute of Health), which includes a 9-page booklet that can be printed out for your own reference at http://www.cc.nih.gov/cc/patient_education/ai/aifinal.html

This booklet is about "**Managing Adrenal insufficiency**" and includes in that, 4 pages of written information as well as pictures, to show how to give yourself an injection.

Another site is Joan Hoffman's, editor of the Addison News Newsletter. Joan H. lives in Michigan U.S.A. Her site is at <http://www2.dmci.net/users/hoffmanrj>

Still a very important website is www.rxlist.com to check out the properties and side effects of our medications, as well as those of our family and friends. It is excellent site for reference.

Francisca sent us this one. It is the website of the WebDoctor at <http://www.gretmar.com/webdoctor>. It is a comprehensive index of medical resources on the Internet produced in Canada.

For the more experienced in medical terminology, there is always the New England Journal of Medicine at <http://www.nejm.org> where you can obtain copies (sometimes free of charge, other times for a fee) on certain medical papers. Another site is the Mayo Clinic site at <http://www.mayohealth.org>

Tidbit Section

DHEA study: DHEA is *Dehydroepiandrosterone*, an androgen of the adrenal cortex and the ovaries/testes. The one-year research study taken part in London, Ontario by initially 65 Ontario Addisonians is finished for some or nearing completion for others. ***Do we*** or ***don't we*** are the questions that we will be asking but for some of us, those questions will have to wait another six months. There has been a 6-month extension added on to the one-year study, during which time the active medication (DHEA) will be offered for all subjects who wish to remain in this extended study.

Those of us that continued with the active medication (DHEA) will again be followed up with testing at 3-month intervals with blood samples, and questionnaires.

For more information about the DHEA program contact Dr. Jeff Mahon at 339 Windermere Road, London, Ontario Canada N6A 5A5.

The Addisonian Book Store: There are still a few copies of the book "***Addison Patients in the Netherlands***". The books sell for \$25.00 which *includes* the postage. Please send 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 her kind generosity.

Specialists Recommendations:

We are still asking you to send any recommendations for specialists for other Addisonians who are searching. It is so hard to find a specialist that understands Addison's Disease and its treatment and care. If you have such a doctor, please send along his/her name, address, and telephone number to share with other Addisonians.

One kind member sent us these names of Endocrinologists that are also Pediatricians - In Hamilton - ***Dr. J. Holland***, McMaster Medical Centre, Head of Pediatrics - telephone him at 1-905-531-2100 Ext. 5606

In Toronto - ***Dr. D. Doneman***, Hospital for Sick Children, telephone him at - 1-416-813-6217

In London - ***Dr. C. Clarison***, telephone she at the Children's Hospital of Western Ontario. Telephone 1-519-685-8516

Your Stories:

We are still looking for "your story" of life with Addison's Disease and the difficulties you may have had coping. We all have something to add, whether it be trials and tribulations or individual little triumphs. All stories are needed. Send your written stories, for possible publication in our newsletter, to the Canadian Addison Society.

Please note: Membership fees are due January 1, 1999 and the cost is still the same - \$20.00 per year. Enclosed please find a renewal form, to update your information to be sent back with your payment, to make sure that we have the latest address, telephone and e-mail address for you. Please do not miss the next copy of the Canadian Addison Society newsletter!

International Interest

I have been corresponding for several months with an Addisonian lady by the name of **Toril Olsson** from **Norway**. She is also a local support group leader. I asked her to send us some information about her local group for me to share in our newsletter with our Canadian members. She very kindly sent us back this information.

We are a small local support group in the east of Norway. Today we number 23 members, including one Endo in our local hospital. Our group includes all patients with Addison's Cushing's and Acromegaly. The local support group's purpose is to first of all "Make an activity plan for the present year, Arrange social meetings, Give information about the disease, Apply for subsidy, Recruit new members and support members. We have an annual meeting every year in February. At this meeting we make an activity plan for the present year. We try to arrange 3-4 meetings a year including participation in the Norwegian Addison's Society's Annual meeting. This lasts for one weekend and there are different speakers invited. This is also the height of the year about news and science and other related information. In the summer we invite the members and their families to a barbeque day at the beach. This is a very popular day and our spouses have a great opportunity to share experiences too. In the autumn we often have a meeting with a speaker. Last year, an Endo visited us and we could ask him all the questions we don't have time for at a busy consultation. In October/November we go to the capital of Norway - Oslo - to see a show and afterwards go to a restaurant for eating. We enjoy three trips also together with our spouses. Within the year, the executive committee has 3-4 meetings on our own. Our information folders we bring to the pharmacies, GP's offices, and the local hospitals. We have written in the newspaper as well about Addison's Disease. As we all know this is a great challenge especially to the hospitals. It seems the doctors, both physicians, surgeons, and nurses and not to forget the ambulance staff, need even more information. We are lucky here in Norway and get subsidies both from the state and the country. We then have to send applies for our projects of the year. It's very important to give support especially to new members who have a lot of questions and how to meet them in their grief and suffering. Two persons of our local group have participated in two courses on how to meet these people. In October/November this year we will have our third course on this subject. After all I think it's very important to meet other Addisonians and hear their experiences. We still learn most from people who suffer from the same disease as ourselves. Of course we are all different and react in different ways but we also have much in common.

I hope this tells you a little bit of what we are doing here in Norway.



Medical Questions and Answers
With
D. Killinger, MD, PhD, FRCPC

Q: I have been told by my family physician that because I take replacement cortisone, I am much more susceptible to fungal infections and that this is one thing that we as Addisonians must be very careful of.....Catherine

A: People taking cortisone or prednisone for reasons other than Addison's Disease are usually on high doses. This can cause high blood sugars in some individuals and this will predispose them to fungus infections. Individuals on physiological doses should not be more susceptible.

There is a childhood form of autoimmune endocrine disease that is associated with "systemic candidiasis". This is a fungus infection that can involve the gastrointestinal tract. This does not occur in adult onset Addison's Disease.

An Interesting News Article from Saskatchewan

The following is a news article sent to us by Audrey Mackenzie and Elizabeth Hill both from Saskatchewan

This article came from ***The Leader-Post Regina Wednesday, June 3, 1998 by reporter Mike O'Brian of the Leader-Post***

Nearly seven months after their son died of a mysterious illness, a Regina couple has learned what killed him. But that knowledge hasn't erased all the frustration stemming from their son's death. "It's always better to know," Krysztof Gebhard said Tuesday. "But because he died of a treatable disease, in many ways it made it worse."

Damian Paul Gebhard died in Lethbridge on the morning of November 14, 1997. The Leboldus graduate was studying at Lethbridge College. The 18-year-old had felt ill for several days and visited a Lethbridge physician on November 13. He was sent home and told to take over-the-counter medication, according to his father.

"The morning of the 14th, he called us and said, "I'm really sick. Come get me." Krysztof and Vicky Gebhard started driving but the Lethbridge hospital called them on their cell phone as they approached Swift Current and informed them that Damien was dead. He had been found dead in his room. The initial autopsy failed to identify the cause of their son's death and was according to Krysztof Gebhard, full of errors.

The Gebhards were convinced their son's death was connected to his diabetes. The family lobbied the Alberta government to review the case. The province's Chief Medical Examiner agreed to conduct a second autopsy.

Last week, the Gebhards learned the results: their son died of an Addisonian crisis. Because the body's autoimmune system damages the adrenal glands, the body is unable to produce cortisol, a natural and necessary chemical. "It's an acute adrenal failure," Gebhard said. "Only one out of 100,000 people will have it....The coroner was emphatic (it) was not anything related to diabetes."

The Gebhards had filed a complaint with the Alberta College of Physicians and surgeons because they believe the doctor failed to act to prevent their son's death. "He had more than flu-like symptoms. He had a heart rate of 125....He was vomiting for three days."

While the latest autopsy identified the cause of death, Gebhard believes a proper diagnosis could have saved his son's life. Addisonians disease is treatable with medication to replace the missing cortisol. "It's not easy to diagnose, but people are diagnosed with and manage to survive," Gebhard said.

The family is waiting to hear the Alberta College's decision before deciding what they will do next.

This story is very sad but perhaps can serve to show us that it possibly could have been avoided. If you are not happy with your family physician's decision, or even your specialist's decision, seek other means of help - a second consultation or even emergency treatment. We must be aware of the consequences that could develop if we do not pursue another avenue in our search for good quality health care.

To all of you - take special care of yourself. Each of us is a special and totally unique person that may need some extra care at times. Be especially tolerant of yourself. Special thoughts to all of you from Joan 😊