



The Canadian Addison Society
La Société canadienne d'Addison

8 Francis Street, Brantford,
Ontario, Canada N3R 7C4

ISSUE NO.10 (abridged)

Addison Info September 1997

We have just returned from the Annual General Meeting in Trenton, Ontario and what a success!! We have a new Executive, Board of Directors, a set of By-laws (courtesy of Don Archi) and. new President - Mrs. Greeta Fraser. Congratulations to all of you,

who helped make this possible. Our membership is growing rapidly - now over 200!

Executive

President Mrs. Greeta Fraser
Vice-President Mr. Don Archi
Secretary Mrs. Joan Southam
Treasurer Mr. Richard Moore

Board of Directors

Mr. Pierre Corbeil
Ms. Sophie Lapointe
Mr. Al McConnell

We wish all of our new executive the very best in the coming three years.

President's Message by Mrs. Greeta Fraser

My warmest greetings to you all. It is quite an undertaking and certainly an honor but together we will succeed. We are all so excited with the progress that we have made as a national group. We are now "officially" bilingual, and we have our own set of bylaws, the next step to becoming a possible charitable organization. The next three years will see even more growth in numbers, in local groups and certainly as a strong, visible national organization. We all need each other and we encourage the growth of the local groups for more personal support with a strong link to the national organization. The group in Brantford, Ontario has grown not only in numbers but in the visible placement in the community, helped by the excellent newspaper articles published recently. Thank you for the trust you have placed in me as your president.

Highlights from the Annual General Meeting - September 27. 1997 in Trenton

- A banner designed by Joan Hoffman, U.S.A. has been kindly donated for use at our meetings. It symbolizes many aspects of the disease with white background for salt craving; beige for skin color; blue for coast to coast; our title and purpose. Terrific!
- Ms. Sybil Harrison read a letter from our out going president, Ms. Isabelle Clift, who declined to stand for office again because of poor health. Ms. Clift emphasized a wish for the continued support of the bilingual documentation.
- Mr. Al McConnell, our outgoing treasurer spoke about the future direction he would like

to see the Canadian group take and suggested video-conferencing of future national meetings, alignment with key hospital and/or medical personnel and also cautioned rapid expansion vs. quality support. He also suggested the rotation of national meeting places throughout Canada to serve all of the Canada membership.

- Through the generosity and talents of Brantford lawyer Don Archi, a fellow Addisonian, we have our own by-laws, one of the first steps necessary for charitable status.
- A local Quebec group is in the planning stages. With the addition of our bilingual name, and their wish to provide resources in both languages, Ms. Sophie Lapointe, an educational psychologist and fellow Addisonian, is confident the Quebec branch will become a reality with the help of other interested Addisonians in Quebec. They also stressed the desire to preserve a strong link with the Canadian Addison Society.
- An added purpose of the Canadian Addison Society was emphasized: "to promote the establishment of local branches of the Canadian Addison Society throughout Canada". It is recommended as well that a "designated link" be appointed to serve as a liaison with the Canadian Addison Society." The link for the local organized Brantford Ontario group is Mrs. Angela Timms.
- Mrs. Joan Southam has been in touch with several new Edmonton, Alberta members, 8 in number, and we hope that a local group will be forming there soon.
- Mrs. Joan Southam presented a draft of our brochure on Addison's disease. This will increase awareness of our rare disease and doctors can use this as a hand out to new patients with Addison's disease and make them aware of our support group.

Guest speaker: Dr. Charles Bird

- Dr. Bird began his talk by describing basic adrenal function and spoke of the "peaks and valleys" of the cortisone actions on the body. He explained why it was high in the morning, lower in the late afternoon and he believes that the replacement medication should mimic this pattern for optimum benefit.
- It is accepted that the major cause of Addison's disease is classed as auto-immune but can also be caused by tuberculosis, cancer, severe infection, Aids, and hemorrhage with surgical removal of the adrenals.
- Dr. Bird stressed the importance for all Addisonians to wear a Medic-Alert bracelet and carry a health information card/letter, particularly when travelling.
- He also felt that regular check ups should investigate any possibility of other auto immune diseases starting and include a check for bone loss in post-menopausal women.
- Dr. Bird felt that getting the "perfect dose" of medication was essential. Over medication can lead to increased blood pressure, "moon face look", stretch marks all over the body, thin bones, thin, papery skin, muscle atrophy, and weakness.
- Our speaker also talked of the DHEA study being carried out by his colleagues, Dr. Don Killinger, Dr. Jeff Mahon and others in London, Ontario. DHEA may improve the quality of life for Addisonians in areas such as blood lipids, blood pressure, muscle mass, bone density etc. It was noted that several of our members have already volunteered for this study.
- Questions from the audience included finding the right doctors and/or specialist, upping ones cortisone for short-term burst of energy but with disastrous long term effects, recommending of flu shots, and how the Canadian Endocrine Society would be a very

good contact for to reach out the medical and/or specialist community.

An executive meeting of the Brantford and District Addison Group was held September 8, 1997 with Don Archi, Joan Southam, Ruth Ann Kruger, Isabelle Rathbun, Lois Jensen, Mike Southam and Angela Timms (recorder) present.

The main focus of the meeting was to work out a draft of the by-laws to be presented to the General Meeting the end of September in Trenton. The recent newspaper article about Addison's Disease written by Mr. Donald Chang in the Brantford Expositor was discussed and the fact that it has also been reprinted in Edmonton Alberta, Owen Sound Ontario and Waterloo Ontario, so far to date. Joan Southam, Don Archi and Isabelle Rathbun were interviewed for this article. Response from all across Canada, and parts the U.S. has been very favorable.

***Please note: Complete and full minutes of all these meetings are available on request as well as a video made of our general meeting.**

Computer "Bytes of Information"

- Many of us or our families now have accessibility to the Internet and there are a few areas that may be very interesting to Addisonians and those with other auto-immune diseases as well. One of the most "user friendly" is the Addison and Forum at www.healinglight.com/addisons. There is information from other Addisonians across North America and it is very easy to "ask" a question, read or make a comment on someone else's questions. It is very informal. There is also a "chat page" connected with this as well. There are also connective links to NADF(National Adrenal Diseases Foundation USA) and to NORD (National Organization for Rare Disorders, Inc. USA) at www.pcnet.com/~orphan and also NIDDK(National Institute of Diabetes and Digestive and Kidney Disease of the National Institutes of Health .U.S.A. see Endocrine & ~ Metabolic diseases). These will give you a "surfing" start. There is a lot of information available to us out there. If you find anything interesting - let us know!
- One thing that is of great interest to us all is a North American Addisonian Survey at the NADF website. It must be completed and sent in by October 31,1997 so there is some time left to print off a copy for yourself and any other Addisonian you know and send it off. It will provide valuable research information that may help us all in the years to come. You can remain anonymous if you wish. Look for it!

Local Group Meetings

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The Brantford and District Addison Group will hold their next meeting at the Brantford City Police Station Meeting Room at the corner of Wayne Gretzky Parkway (off of Hwy 403)

and the corner of Elgin Street on Saturday November 1, 1997 at 1:30-4:00 p.m. We will have as our speaker. Dr. Don Killinger, Professor of Medicine at the University of Western Ontario in London. He will speak about "All you wanted to know about Addison's Disease but your doctor was too busy to tell you (or just didn't know)!" Dr. Killinger will be answering several questions that we have "collected". He will also speak about the DHEA research project soon to get underway in London. There are a variety of tests that they plan to carry out on the volunteers and we would like to know what they are looking for in these tests.

Some of the suggested topics for speakers over the coming year for our group include A Naturopath -what they can add to the quality of our life; A Dietician - what they can tell us about what food would be best for us as Addisonians, a Kinesiologist - who can demonstrate some key exercises that most all of us can do to improve our well being and level of fitness, a Pharmacist who can tell us all about the various medications we take - the side effects and much more . Anyone having any other ideas - let us know - we would be glad to hear from you! Contact Joan at 1-519-753-1271 for more info.

Question Time?

Do you have a question to which you cannot find an answer? Perhaps one of our fellow Addisonians has the answer! Write your questions to c/o "Question Time" and we will share them in later issues for our membership to comment on and answer!

The Addisonian Book Store

We are hopeful that in the near future, we will be able to offer various items of interest for purchase by our fellow Addisonians. The items that we are thinking of specifically would be specialty books, and articles. There is an excellent book, the Dutch Report, put out in Holland, a book for Addisonian children and there are also several books available on DHEA that are both informative and thought provoking. We are thinking as well of special international items that would not be readily available to the average person but could be ordered in "bulk" through our group. There are many international newsletters that are available as well. Would anyone be interested in this service? Any comments? Let us know!