The Canadian Addison Society
La Société canadienne d'Addison

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The year 1997 has now ended and a brand new year has begun. We hope that each and every one of you has felt some special success from this past year and is looking forward to 1998 \\ith renewed optimism. The year 1997 has seen many advances for the Canadian Addison Society, not only nationally and internationally but at the local levels as well. With us all working together for our common goals and supporting each other in our shared quests for improved health and up to date information, we will have much to look forward to in the coming year. The Best in '98!

Sincerely Joan Southam

President's Message by Mrs. Greeta Fraser

I sincerely wish a Happy New Year to each and every one of you. I too look forward to the challenges in the coming year. With us all working together, we can achieve success. I will end the news of 1997 on a sad note. Our Canadian treasurer, Mr. Richard Moore, died very suddenly on Boxing Day, in London, Ontario. He will be sadly missed. Our condolences to his wife Joanne, and their family. Mr. Don Archi, Canadian Vice-president will carry out the duties of Treasurer, until a permanent appointment can be made at our next national meeting. For 1998, it will start on a more positive note with the appointment of Dr. D.W. Killinger as our official medical advisor for the Canadian Addison Society. We are very fortunate to have Dr. Killinger working with us and send a warm welcome and our heartfelt thanks to him on behalf of all the members of the Canadian Addison Society. Thanks also to all of you for your cards, letters and most importantly your support and encouragement over this past year.

Highlights from Local Meetings

Quebec:

An informal meeting with Sophie LaPointe, Sybil Harrison, Isabelle Clift and Al McConnell was held in Montreal. The group has been working hard to reach other Addisonians in and around Montreal. Sybil put ads in the English speaking paper while Sophie put ads in the French speaking papers. The response was not overwhelming. We had a good meeting though, with lots of support for each other and we have taken some positive steps for the future. We will try to reach more people through the Community television as well. We will continue to send out letters to editors and continue to give telephone support for anyone in and around our area. We will have another meeting in three months. For information about the Montreal group, call Sophie at 1-514-288-7268 or Sybil at 1-514-486-9817.

Ontario:

A meeting was held November 1, 1997 at the-Brantford Police Station Meeting Room in Brantford. There were 43 people in attendance. Our guest speaker was Dr. D.W. Killinger, professor of medicine at the University of Western Ontario, and Endocrinology and Metabolism at St. Joseph's Health Center, London. He gave an informative lecture to help those who may have had some previous knowledge about Addison's disease, and wanted more in-depth answers to long-standing questions about this disease. Dr. Killinger did this superbly, by focusing on some physiology, his area of research in the DHEA study and some of the testing methods being used and why, the pros and cons of various drugs and treatments used in Addison's disease and more. He explained how, even though our cqrtisol blood levels are at acceptable numbers, we may have "too much" medication at the cell level. It was a very informative two hours. Our next meeting will be held again at the Brantford City Police at the corner of Elgin and Wayne Gretzky Parkway on Saturday, January 31, 1998 from 1:30 to 4:00 and our guest speaker will be Alfred Hauk, Doctor of Naturopath. It has been requested by several members that representatives of Alternative Medicine be included in our programming. Dr. Hauk's background includes 3 years Pre-Med., plus 4 years at the Naturopath College in Toronto. He had built up a very active practice in Brantford over the last 7 years. We know that Addison's disease is not curable but we can do a great deal to make our bodies healthier to help cope with this chronic disease. His presentation will also be of interest to "care givers" of Addisonians as well. Because of space, this is only a condensed version of the minutes of our meeting but full and complete minutes are available on request, courtesy of our excellent recording secretary, Mrs. Angela Timms. For information about the Ontario group call Joan at 1-519-753-1271.

Saskatchewan:

An informal meeting was held in Saskatoon at the home of Belle Messier with Belle, Jean Sage and Elizabeth Hill present. We discussed new treatments available, our stamina, how stress affects us and, of course, fatigue and how we deal with it. It was a good beginning. For information about the Saskatchewan group call Elizabeth at 1-306-236-5483.

Alberta:

A group is forming in Edmonton, under the capable hands of Peter Little. He is presently contacting known Addisonians in and around Edmonton to try and arrange a meeting. We certainly wish him good luck. For more information about the Alberta group, contact Peter at 1-403-922-5307.

British Columbia:

The first meeting in British Columbia was held November 8, 1997 at the Royal Columbian Hospital in New Westminster. It was very successful with 14 people attending. We had arranged for an endocrinologist, Dr. Priestman to come and answer questions regarding Addison's Disease. She answered questions about autoimmune diseases, medication dosages and when to take them, hereditary possibilities and what to do in an Addisonian crisis. As well, we had Ms. Elizabeth Grant, a paramedic and a Paramedical Medical Dispatcher who also discussed what to do if you are in a crisis and need to call an ambulance. In B.C. paramedics are not allowed to administer a shot of cortisone, even if you had one available. We will further discuss that protocol. She also suggested that you inform the ambulance dispatcher that you have an electrolyte imbalance describing any severe symptoms, e.g. a possible drop in blood pressure and also have an up to date information sheet available with medication info. Our next meeting will be at the Royal Columbian Hospital as well on March 28, 1998 from 1:00-3:00 at which time we will have a pharmacist and someone from the Public Health Unit teach us how to use a needle in an emergency situation. For more information regarding the B.C. group call Judythe at 1-604-936-6694.

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

Logo Search

We are STILL looking for a logo for the Canadian Addison Society. We would like some entries to take to our next national meeting for approval. Put your creative thinking caps on and "pen us a winner". We would like to get a logo printed on our letterhead as well as for our pamphlets. It would also look smashing on our newsletters and on our new Canadian Banner! Think Canadian!

Computer Bytes of Information

- We hope that you have enjoyed the site Addison and.Forum at www.healinqliqht.com/addisons. It is a very user- friendly site.
- The NADFsite is still a good information choice as well as the NORD and the CORD sites. We are listed as a support group in all three areas!
- There is also a site for prescription drugs. It is called www.rxlist.com and this will give you information about each drug, the pros and cons. It is a very valuable tool for everyone's use.
- Be sure to check out the new Addison & Gushing International Federation (ACIF) web pages from Holland at http://www.spin.nl/nvap0300.htm. There is a special area about Canada there as well as our Canadian support information. We are in the midst of translating the same Canadian information into French with Sophie LaPointe and Raymond D'Astous's help.
- We wish to thank the efforts of Mr. Laurens Mijnders, Holland and also Mrs. Joan Hoffman, U.S.A. for all the work that they have done to make this international website a reality. Mrs. Hoffman also has a newsletter the "Addison News" which is very informative with the latest in up to date information, nationally and internationally. Check out her website as well. You will find mention of us, as a support group there too at http://www2.dmci.net/u5ers/hoffmanrj.
- There is also a most interesting article called "Just in Time" in the New England Journal of Medicine website at http:///www.ne1m.orq/public/1996/0334/00pl/0046/l.htm. I found it very interesting and in fact, ordered a copy of the actual article and put it in our

archives this past summer. Isabelle has mentioned this information site as well. It is about a 15-year-old girl, from Houston that nearly dies before they finally diagnose her as Addisonian. Since I was 14 years old when I was diagnosed, it brought back a lot of very unhappy memories for me. In some ways, medicine has not improved as much as we would like to think.

Tidbit Section

A study is currently underway by Dr. Noel Maclaren. pediatric endocrinologist. on APS1 and APS2 (autoimmune polyglandular disease) hi southern U.S.A. He is particularly interested in Addison's disease appearing in childhood, APS1, which may affect siblings. I have had some correspondence with Dr. Maclaren and he will be happy to answer any questions that parents may have about their children with Addison's disease. E-mail Dr. Maclaren at nkmaclaren@aol.com or for more information contact Joan at 1-519-753-1271 for a complete mailing address and phone numbers for Dr. Maclaren.

Men - BEWARE! Men on steroid replacement run the risk, as well as women, of osteoporosis! Be sure to inquire about a bone density study, a simple painless test that will check the state of those bones, whether they are male or female!

DHEA Study: Several of us from Brantford , as well as other parts of Ontario are involved in a study of the effects of DHEA on the Addisonian patient. We are divided into two groups and one is given DHEA and the other group is given a placebo. The doctors in charge of this yearlong study believe that it will improve the "quality of life" of Addisonian patients. There are still several places still available for other qualifying Addisonians from Ontario still wishing to take part in this very worthwhile study. Contact Dr. J. Mahon at 1-519-663-3756 and they will kindly explain about the study and give you more information. Give is some careful thought.

Story Time: We want your stories about "your life with Addison's disease" and how you are coping , the problems you are having and anything you feel like writing. These "stories"' will be kept in our files and hopefully one day will be made into a booklet for "new Addisonians"' to read, or "old Addisonians" to gain strength and insight from. We would prefer that you also give permission for these stories to be published as we would like to include some of them in our up and coming newsletters as well.

The Addisonian Book Store: I just received information that die Dutch Report Books ordered from Holland have arrived at Joan Hoffman's house in Michigan. We are in the midst of arranging for delivery to Canada. We calculate at this time that the price will be around $25.00 each Canadian funds. I have a copy of this book and there is certainly a lot of worthwhile and interesting information in it.

Specialists: It is so hard to find a "good" and informed doctor when you are looking for one, particularly if you have just moved to a new region. Word of mouth is one of the tried and true methods that most people subscribe to. Shirley, an Addisonian from Ontario wrote and wishes to recommend her specialist's name, a doctor in Oshawa, Ontario. Shirley says that this woman is not only good as a doctor but knows a lot about Addison's disease as well. Truly a gem! If anyone else has a specialist, either an endocrinologist or internist that they would recommend let us know and we will add it to a list, and if anyone from that area is in need of a doctor, it will certainly make the search easier.

Old Newsletters: We have had a request from Shirley in New Zealand asking for copies of all of our previous newsletters so they can be added to their New Zealand Addison's Disease Archives. When we went searching, we found we did not have any of the old copies left. If anyone has any copies of the original newsletters, please let us know and we can arrange to have copies made that we can keep for our own archives as well as send out to interested people in Canada and others around the world.

Acknowledgments: We have many people to thank for making our life easier. Thanks to Don and Angela for donating a "lovingly cared for" file cabinet. I can actually "find" stuff now instead of searching through envelopes and boxes and piles of papers and it stays in the same place! Thanks for many of you who also included "extra" when paying your membership dues. These kind people include Don Jacobson, Sophie Elton (for Justin), Allan Walters, Donald Johnson U.S.A., and Roger Guselle. This only includes the ones that have recently sent in their renewals.

Remember: Renewal time is January 1, 1998. Because of the postal strike, we are extending the renewal time to include this newsletter. This non-profit group is self-supporting with only your membership dues to cover expenses at this present time. To those that did renew –Thanks.

Renew-It may be the best and healthiest $20.00 you spend in "98.

Many of us have wondered HOW or WHY our autoimmune Addison's Disease occurred. I hope this will help to answer some of those questions.

Medical Update

(Reprinted from the National Organization for Rare Diseases, Inc)

Molecular Mimicry and Autoimmune diseases

Although our understanding of the complexities of the immune system continues to grow, most scientists agree that we have much to learn about "normal" immune responses as well as misdirected immune system attacks, generally termed "autoimmune diseases"'. It is widely accepted that an autoimmune disease begins when the immune system mistakenly identifies the body's own cells as "foreign invaders" (such as viruses or bacteria) and sets about to destroy these cells. Scientists who study the immune system believe that some of the answers about the nature of autoimmune diseases, such as Juvenile Diabetes and Lupus, may lie in the controversial theory- of "molecular mimicry". This theory, which may help to explain how autoimmune diseases are triggered, suggests that certain common diseases-causing agents (e.g. bacteria or viruses) may initiate a mistaken autoimmune response causing the immune system to attack the body's own tissues as well as the invading offender (the "'mimic"). Molecular mimicry does not attempt to explain the role that genetics (i.e., genetic susceptibility) or other environmental or hormonal factor may play in the autoimmune disease process.

Certain specialized cells of the immune system known as T cells (or killer T cells) mature in the thymus and are released into the blood stream where they play a major role in immune functions. These cells are able to "recognize" the body's own cells (self-proteins) as well as the proteins of foreign invading agents (antigens), hi most cases, during a normal response, the immune system appropriately destroys the invading agent, disregarding the body's own cells.

For example, when a person has a respiratory infection, the virus "makes a home" in the lining of the throat. During a "normal" immune response, specialized "defender'" cells (e.g. macrophages or B cells) surround the invading virus, eventually "chopping it up" into tiny protein fragments (peptide chains) that are strung together like a necklace. Some of these fragments eventually make their way to the surface membranes of these specialized immune cells where they park themselves in ridges (clefts) on the cells - in effect announcing to the body that an invading virus or bacterium is present. Scientists suspect that those fragments that make their way to the surface of the cells may be determined, in part, by our genetic makeup. It is believed that the presence of these protein fragments on the cell's surface evokes a response from the "'killer" T cells of the immune system. Though present by the millions, each T cell is uniquely shaped and different so as to recognize a specific protein fragment. T cells that "match" the protein sequence of the surface fragment "anchor" onto the viral protein. Thus begins the process of destroying the cell that contains the virus.

Scientists believe that this normal immune response may go astray when protein fragments from invading viruses or bacteria "mimic" or are very similar to one of the body's own proteins. The result may be the beginning of an autoimmune response, when the immune system attacks its own tissues. Essentially the immune system is fooled and responds inappropriately because it is unable to distinguish between the "mimic" protein on the surface of the "defender" cells and the body's own proteins. Researchers believe that this may be the case in certain diseases such as Juvenile Diabetes. The cells of the pancreas that produce insulin (islet cells) contain a "normal" protein sequence (GAD) that is similar to the protein fragments of a virus, such as Coxsackie virus. The immune system may target the virus "mimic" and then mistakenly destroy the cells of the pancreas that have a similar protein sequence on the surface of the island cells.

Many mysteries have yet to unfold as scientists unravel the sequence of events surrounding normal and abnormal immune responses. Many questions remain and skeptics believe that the theory of molecular mimicry requires additional scientific investigation. However, proponents of the theory of mimicry believe that unraveling the triggers of the autoimmune disease process, which genes may be involved, and how specific T cells are activated may well hold the clues that may lead to new treatments and possible prevention of autoimmune diseases in the future. Much of the important new information that scientists have learned about the immune system was made possible through the study of HIV and AIDS. This knowledge is now becoming applicable to other diseases.