



***The Canadian Addison Society***  
***La Société canadienne d'Addison***

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**ISSUE NO 4 (abridged)**

**Addison info**

**Fall 1995**

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**Minutes of Meeting Sept. 30th, 1995 (Summary)**

The first anniversary meeting of the Canadian Addison Society was held at Evelyn Paul's house at Perth, Ont. 11 people were present with newcomers Don and Angela Timms and son Geoff, who has been diabetic with Addisons since 11 years old. Stories were exchanged and several items discussed.

Brochures are being looked at, with Isabelle trying to get permission to use one from NADF.

Isabelle reported taking 100 letters to the Canadian Endocrinologist / Metabolism Society meeting in 8ept, 80 taken.

Suggestions were made for getting us known in the community, to contact hospitals and colleges, wallet cards and prices.

Vaierie Atyeo's letter discussed; possible follow-up.

Al reported he has \$1420.00 on hand & opened a group bank acct.

Globe & Mail ad for \$56.62.

People asked if we should waive fees; All said no,

Greeta asked if we should twin with another Addison group (thru Joan Hoffman), All agreed,

Louise explained about using liquid cortisone for emergency; that it has an expiry date, & to ask doctor about it before travel.

Suggestion for just one Ouebec/Ont annual meeting and more regional meetings vetoed for reasons of clarity of purpose.

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At the Annual General Meeting, it was found that a number of Addisonians suffer from a variety of other ailments; this is borne out by results in the Dutch Study. Therefore, in upcoming issues, we will be featuring articles on some of these related issues as a way of helping our fellow members. If you have any particular concerns which you feel have not been addressed, we welcome your comments and suggestions.

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## Associated Autoimmune Disorders

Roughly half of the patients with Addison's Disease also have another autoimmune disorder which usually affects another hormone producing organ. The table below gives a summary of the autoimmune disorders which are most commonly found in combination with Addison's Disease. In most of these cases there will also be antibodies directed against the body's own organs (e.g. thyroid, ovaries, etc.) present in the blood. There are two multiple autoimmune disorders in which Addison's Disease is also always present. These combinations are known as polyglandular (i.e. relating to more than one hormone-producing gland) autoimmune syndromes (P.A.I.S.).

P.A.I.S. type I consists of Addison's Disease, parathyroid insufficiency and chronic fungal infections of the skin and/or mucous membranes, sometimes accompanied by other disorders. It is a rare hereditary disease, which is mainly found in children.

P.A.I.S. type II occurs rather more often than type I and is found mainly in adults. It is a combination of Addison's Disease, a thyroid disorder (usually thyroid insufficiency due to Hashimoto's Disease) and/or type I (insulin-dependent) diabetes mellitus.

### Table

Autoimmune disorders which regularly occur in combination with Addison's Disease

- thyroid disorders
  - enlarged thyroid (goitre)
  - increased function (hyperthyroidism, Graves' Disease)
  - decreased function (hypothyroidism, Hashimoto's Disease)
- premature menopause In women
- insulin-dependent diabetes mellitus (type I diabetes)
- parathyroid deficiency
- pernicious anemia
- spots on the skin with less or no pigment (vitilligo)

This article has been taken from *Addison Patients in the Netherlands 1994*

## Greetings to Fellow Addisonians

My name is Dorothy Frewing and I have had Addison Disease for 31 years. I am 68 yrs old. My husband Douglas and I have been married for 47 yrs. We have one daughter and 2 granddaughters. Our daughter was born in 1950 and in 1952 I thought I was pregnant, as I had quit menstruating. I had severe pains and doctors operated from the navel down, removing my appendix. At age 22, I went through the change of life.

My life changed drastically in 1964 when I was diagnosed with Addison Disease. In

1962, I was losing weight, excessively tired and unable to keep food/water down. Our family doctor treated me for arthritis, ulcers and hepatitis. By 1963, I was spending more time in bed and had dark spots around my mouth. On Easter of 1964, I was put in hospital, having gone from 150 to 86 pounds. Days and nights ran into each other. My sister, a registered nurse, and my husband searched books, found out Addisons fit the bill and told the doctor. He called Dr. Earl Plunkett in London, and within a week I was in London where they started me on an IV with cortisone. Next day I ate a full meal and kept it down. I stayed in hospital for the next 2 months.

The worst part of coming home was when my dad, who had been very ill, died on Father's Day. To see me through, my cortisone was increased during the crisis and reduced afterwards. During the next year, I was diagnosed with low thyroid, salt depleted, so now took synthroid and florinef with the cortisone. Doctors now believe the Addisons Disease began when I was 22.

The past few years have been very stressful. I come from a family of 10 and several of us have had serious illnesses, some fatal, including cancer of the pancreas, lupus and osteoporosis. I have had numerous illnesses that include appendicitis, blocked nerves in both elbows, Meniere's Disease, knee replacement last August, arthritis and osteoporosis deterioration, bladder dilation from 1 to 2 point for a bladder control problem, and recently experienced spotting and bleeding.

I wish I had kept a record of the Addison Disease, as several times I became dehydrated and needed hospitalization, the last in Dec. 1989. I am so grateful for my husband standing by me all these years, not always able to understand my aches and pains and need to rest. To my friends and neighbours, I put up a good front, thinking I was alone in this. The letters from Greeta Fraser and the newsletter have helped my family to understand more. 3 years ago I weighed 200 pounds; today I weigh 128.

Thank you for the opportunity to tell my history.

I take:	prednisone	0.5 mg	x 2
	Florinef	0.1 mg	x 1.5
	Levothyroxine	0.2 mg	x 1
	Indomethacen	25 mg	x 3

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## HAPPY HOLIDAYS!!

This year has been an extremely rewarding one for many reasons. We have successfully passed our first anniversary, gone through a name change, raised funds and reached out to several new members. In the metamorphosis, much hard work has gone into organizing and raising awareness between ourselves, our families and communities. Despite growing pains, we have emerged a capable and determined

group concerned about the well being of our members and community at large. For this, we have many dedicated individuals to thank, too many to mention individually, but all who deserve our gratitude. We rely upon each of you to provide us with the insight and direction to take. More challenges remain, but for now, some names deserve recognition for a job well done:

- Isabelle Clift, our president who persevered during time of illness
- Greeta Fraser, secretary, keeping the lines of communication open
- Al McConnell, treasurer, for guiding our fledgling finances
- Evelyn Paul, in providing her home and hospitality for meetings

If anyone else can lend a hand to some of these dedicated volunteers, they would be most appreciative. Also, our funds are really limited, so in the spirit of giving at this time of year, donations are especially welcome.

Be happy and enjoy the holidays!!

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## **What's My Risk!**

### **Thyroid Disease**

People with type I diabetes are about five times as likely to have thyroid auto-antibodies and thus are at five times the risk for developing thyroid disease as are non-diabetics. Anywhere from 8 to 20 percent of children and adolescents with type I diabetes will have thyroid autoantibodies.

Thyroid auto-antibodies are not as common in blacks with type I diabetes as in whites (5.5 percent vs. 20 percent).

Women with diabetes are affected with thyroid autoimmune disorders at least twice as commonly as men with diabetes. About 10 percent of new mothers who have type I diabetes will develop thyroid disease soon after giving birth (postpartum thyroiditis), versus only 5 percent of non-diabetic moms.

Half the people who have thyroid auto-antibodies in their blood will develop thyroid disease over time. Of those with thyroid disease, chronic lymphocytic thyroiditis is four times as likely as Graves' disease.

### **Gastric Parietal Cell Disease**

About 8 percent of people with type I diabetes are positive for parietal cell auto-antibodies (PCA), which is triple the rate in the general population. Women are twice as likely as men to be positive for PCA; 10 percent versus 5.4 percent. Blacks have a

slightly higher risk; 9 percent versus 8 percent in whites.

These autoimmune diseases run in packs: if you have one, you are at increased risk for the others. If you are positive for thyroid auto-antibodies, you have a 20 percent chance of being positive for PCA.

### **Adrenal Gland Disease**

Adrenal auto-antibodies are markers of an autoimmune attack against the adrenal glands. They occur in people with type I diabetes five times as commonly as in the general population: about 1.6 percent versus 0.3 percent.

Among people with diabetes, women are four times as likely to have adrenal auto-antibodies as men. Blacks are half as likely as whites to have them.

About half of all people with adrenal auto-antibodies will have evidence of adrenal gland dysfunction. And, once again, we see packs: if thyroid auto-antibodies are detected, the risk of having adrenal auto-antibodies more than triples to about 6 percent.

By William E. Winter, M.D., associate professor in the Departments of Pathology and Laboratory Medicine, Pediatrics, and Immunology and Medical Microbiology; and section chief and medical director of Clinical Chemistry at the University of Florida College of Medicine, Gainesville

Our thanks to "Diabetes Forecast", a publication of the American Diabetes Association for this.

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# CANADIAN ADDISON SOCIETY

Montreal. September 11, 1995

Doctor,

Living with a rare disorder is not easy, though physicians do everything possible to treat it. Patients have many questions that a physician cannot answer. The most important one of them is: "Can I lead a normal life?"

People with Addison's disease are no different. They too have questions that health care professionals cannot always answer. They have problems coming to terms with this illness. Sometimes, it is very helpful to speak with others in the same situation. With this idea in mind, we have founded The Canadian Addison Society, a nonprofit organization.

The Society was created in September 1994 and has contacted forty persons so far. Its main goals are to provide mutual support to people with Addison's disease, help those who have problems accepting it or living with it, and bring Addisonians together by organizing meetings where they can meet and share their feelings. We want to provide literature on Addison's disease for those who need it. We do not intend, under any circumstance, to provide medical advice.

I am writing on behalf of the Society in the hope that you may help us bring Addisonians together. Since the illness is rare, it is difficult to locate them and let them know of our existence. This is why we need your assistance. We are aware that you are bound by the confidentiality of the medical act and that you cannot provide us with the names of patients suffering from Addison. However, it is possible for you to let them know of our existence and give them our address. They could then decide for themselves if they wish to contact us. You will find a notice enclosed. We would be very grateful if you could put it up on your bulletin board.

Finally, I would like to reassure you about our intentions. Our only goal is mutual support and assistance. If you want more information, do not hesitate to contact us. I thank you for your attention.

We would be very grateful for your support.

Yours truly,

Isabelle Clift  
President, Canadian Addison Society

Greeta Fraser  
Secretary, Canadian Addison Society

# SOCIÉTÉ CANADIENNE D'ADDISON

Montréal, le 11 septembre 1995

Docteur,

La vie n'est pas facile lorsqu'on souffre d'une maladie rare, même si les médecins font tout leur possible pour apporter un traitement efficace. Les patients se posent plusieurs questions auxquelles leur médecin n'a pas de réponse. La première est sans doute: « Vais-je pouvoir vivre une vie normale? »

Les victimes de la maladie d'Addison sont dans ce cas. Ils se posent plusieurs questions auxquelles les professionnels de la santé ne trouvent pas toujours de réponse. Ces gens ont parfois des problèmes d'adaptation. Il est parfois très rassurant d'échanger avec d'autres personnes qui partagent la même situation. C'est avec cette idée en tête que nous avons fondé la Société canadienne d'Addison, un organisme sans but lucratif.

La Société fut créée en septembre 1994. Depuis elle est entrée en contact avec une quarantaine de personnes. Ses principaux objectifs sont de fournir un support moral à ceux qui souffrent de la maladie d'Addison, assister ceux qui ont des problèmes à l'accepter ou à s'y adapter, et à susciter des réunions où les Addisoniens pourraient se rencontrer et partager leurs sentiments avec d'autres. Nous souhaitons pouvoir fournir à ceux qui en ont besoin de la documentation sur la maladie d'Addison. En aucune circonstance avons-nous l'intention de donner des conseils d'ordre médical.

Je vous écris au nom de notre société dans l'espoir que vous pourrez nous aider à réunir les victimes de la maladie d'Addison. À cause de la rareté de cette maladie, il est difficile de les localiser et de leur faire connaître notre existence. C'est pour cette raison que nous sollicitons votre aide. Nous sommes conscients du fait que vous êtes lié par la confidentialité de la loi de la santé et que vous ne sauriez nous fournir une liste de patients souffrant de la maladie d'Addison. Il vous est possible toutefois de les informer de notre existence et de leur fournir notre adresse. A ce moment, ils pourront décider d'eux-mêmes s'ils veulent nous contacter. Nous joignons un avis à cette lettre. Nous vous serions reconnaissants si vous pouviez l'afficher à la vue de vos patients.

Finalement, permiettez-moi de vous rassurer encore une fois quant à nos intentions. Notre seul objectif est le soutien et l'assistance mutuelle. Si vous désirez de plus amples renseignements, n'hésitez pas à nous contacter. Je vous remercie de votre bienveillante attention.

Nous serions reconnaissants de votre appui.

Bien a vous,

Isabelle Clift  
Présidente, La Société canadienne  
d'Addison

Greta Fraser  
Secrétaire, La Société canadienne d'Addison