

The Canadian Addison Society La Société canadienne d'Addison

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President's Message:

Dear Fellow Addisonians,

After being diagnosed in 1989 I had experienced a fairly even life in regards to Addison's until this past year. I had stopped taking Florinef as it seemed I didn't need it and it only caused swollen ankles; so my doctor said to try it.

After six months of nausea and not being able to keep food down, I started experiencing extreme bouts of lower intestinal problems, and gradually feeling very ill. I went to emergency on two separate occasions and had saline [and other meds.] intravenously to bring down the high potassium levels.

I went on a holiday to a cottage, and found I had trouble walking very far, [weak legs and shaking]. My friend brought me home to hospital, where they discovered I was having an Addison Crisis. I was in hospital 5 days [4 on intravenous]. I came home feeling better than I had for a long time.

I am telling you all of this in case some of you are having the same problem. My doctor was on holidays, but I received excellent care from the staff doctors and nurses. They contacted a specialist and my family doctor, who is an internist and also a gerontologist. I am now back on Florinef 1/2 of a. Img tablet daily, and not having too much swelling in my ankles.

I hope you all have a healthy 2002. If I can help anyone please contact me at: gf raser@dsisp. net or through our head office in Brantford, Ontario.

Regards,

Greeta

Please support your local groups and the Canadian Addison Society

PLEASE TAKE NOTE - OUR ADDRESS HAS CHANGED

Due to a situation beyond our control, The Canadian Addison Society has undergone changes to our e-mail address and website address effective November 22/01.

The new e-mail address is as follows: jsoutham@rogers.com.

The new website address is as follows: http://members.rogers.com/jsoutham.

Please adjust your records and we sincerely apologize for any inconvenience this may have caused you.

Have you paid your 2002 dues yet? For your convenience, there is a membership form attached to the back of this newsletter. Please return yours along with a cheque or money order for \$25.00 as soon as possible. Thanks to all who have sent in their dues.

Welcome New Editor in Training

It is with great pleasure that we announce the addition of Heather Nicholson as "editor in training" to the newsletter staff of the Canadian Addison Society. Heather is a member from Bradford, Ontario and will work with our present editor, Helene Perry, with a gradual change over of responsibilities until Helene's term officially ends December 2002. Our new member of the team has introduced herself to you through the newsletter on the "Letter to the Editor" page of this edition and with her recipe on the "Let's Hear It For Life" page. Heather brings with her an enthusiastic attitude and a wonderful gift for wanting to step up to bat and help.

Please join me in wishing Heather all the best as she gradually takes over the job of assisting us by sharing and learning from each other through our newsletters. Heather can be reached by mail at:

P.O. Box 1417, Bradford, Ontario, L3Z 2B7 Or Addison_editor@yahoo.ca

Helene Perry can be reached by mail at:

75 Wendover Dr. #218, Hamilton, Ontario, L9C 2S7
Or
hperry@interlynx.com

Medical Questions and Answers

Dr. Donald Killinger, MD, Phd, FRCPC

Dr. Donald Killinger, from London, Ontario, who is the Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Questions and answers that may be of interest to everyone will be published in the newsletter. Dr. Killinger has asked that we not write him directly, but to address your questions by letter/email or fax through The Canadian Addison Society and they will be forwarded on to Dr. Killinger.

P 1 e a s e - If you are pleased with your endocrinologist - LET US KNOW! We have many requests not only from recently diagnosed Addisonians but other Addisonians from all parts of the country, who may be moving from one area to another and require the services of an endocrinologist knowledgeable about Addison's disease and its treatment.

In our last issue of the newsletter, there was a question for Dr. Killinger from a member of the Canadian Addison Society, by the name of Glenda George, who lives in Australia. She wrote about her daughter, Vanessa, who has Addison's and facing eye surgery. We are pleased to pass along an update from Glenda that her daughter has come through the surgery just fine. Her doctors will be watching closely for the next 3 to 6 months for signs of rejection. The Canadian Addison Society would like to send Vanessa our best wishes that she will have a complete and successful outcome.

If anyone would like to have a poster to put up in their doctor or specialist's office, (with their permission, of course), then The Canadian Addison Society has some available and can send one to you free of charge. Please contact the office at the address on the front of this newsletter with your request. It's an excellent way for you to help spread the word around that we are here.

Possible Cortef Supply Shortage Alert from Florence Weekes & James Sadlish

It seems that there is more than a shortage of doctors to keep on top of. We have had word from our friends on the west coast warning us of a temporary shortage of hydrocortisone (Cortef) tablets. James Sadlish has contacted Pharmacia Canada, who supplies this medication to their area. They expect to have the 10 mg tablets available about January 14/02 at their Toronto center. The 20mg tablets should be available about February 11/02 at Toronto. Drug wholesalers on the west coast will receive supplies somewhat later due to the time necessary for shipping. This shortage is also occurring in parts of the United States.

Some of our membership may have to switch to Cortisone Acetate or Prednisone on a temporary basis should your pharmacy run out of Cortef. Please check with your source and contact your doctor if their stock has run out and arrange for a temporary alternative.

Thank you Florence Weekes and Jim Sadlish for sharing this vital information with us all.

ACIF WEBSITE URL CHANGE AND NEW BULLETIN BOARD

ACIF stands for the Addison and Gushing International Federation, informally established at the first, (and only, so far), international conference of support groups for Addison's Cushing's and Acromegaly in Oslo in 1996.

For the past five years, the Dutch Addison and Gushing Association, (NVACP), Laurens Mijnders in particular, has maintained ACIF contact information on its website, and helped enquirers find support groups or found new ones — now nearly 20 countries. The Canadian Addison Society is also an active participant.

The NVACP has a new website at www.nvacp.nl. It includes some English language pages. On 1 November an English-language bulletin board was launched for a trial period.

How the ACIF will evolve is currently being discussed between participants. It is likely that the NVACP web site will continue as the location of a comprehensive ACIF register of international groups.

Recent Publication

The Canadian Addison Society has been given permission from authors, Katharine White and Sarah Baker of the UK Addison's Disease Self-Help Group to offer photocopies of the newly released "Living With Addison's Disease". This is a very worthwhile read by Sarah and Katharine, in collaboration with endocrinologist Professor J. A. H. Wass. It aims to provide the reader with information to help fine tune steroid replacement therapy and to make informed choices about lifestyle, together with practical ways of managing some of the challenges that can be experienced.

The \$10.00 (Canadian) per copy price consists of our expenses of \$5.00 for copying, slide folders, envelopes, postage etc., \$2.50 for copyright royalties and \$2.50 for The Canadian Addison Society. Each support group will receive one copy from the Canadian Addison Society at no charge if you wish to look it over, but these must not be copied. If you wish to obtain a copy of your own, please send a \$10.00 cheque or money order made payable to The Canadian Addison Society and mail to Joan Southam at the head office in Brantford Ontario.

The Canadian Addison Society would very much appreciate any donations of Canadian Tire Money that you would be willing to send in. These would be used to benefit us all by helping to supplement the various costs of running the organization. Any help to get the message out by sharing resources is gratefully accepted. Thank you.

Joan Southam reports that the Canadian Addison Society has received notification from Charities Division of the Canada Customs and Revenue Agency in Ottawa, stating that our application for Charitable Status has been received and they are reviewing all the submitted information.

The Canadian Addison Society would also like to express a sincere thank you to the family of the late Helen Thomas for their generous donation in her memory. Our sympathies go out to her family and friends.

FOOD ALLERGIES AND THE IMMUNE SYSTEM

Who gets food allergies? They're most common in children and decline over the first 10 years of life. However, allergies can and do begin in adulthood. Food intolerance is not the same as allergies and does not involve the immune system. Instead, the body fails to properly process certain foods. A person with lactose intolerance, for example, lacks an enzyme needed to digest the sugar in milk. This is not the same as an allergy to milk.

Even if you don't have a food allergy, you may occasionally have a dinner guest who has one or you or someone you love may have this problem. It is also possible to have an allergy to more than one food product. Allergy experts emphasize that food from any source; the grocery store, restaurants, school lunches, potluck suppers or picnics can hold hidden hazards for those with allergies. Ask what is in the food and how it is prepared if you have an allergy. Any time you did not prepare the food yourself, it could contain hidden hazards that can really put yourself or some unsuspecting sufferer at risk. Some symptoms of food allergies are: a rash, rapid heart beat, a drop in blood pressure, abdominal cramps, vomiting, swelling of the tongue or throat, breathing difficulties, loss of consciousness and, in some cases, death.

Some labels have improved in recent years, but those with this immune system problem, need to be diligent in reading labels and become familiar with industry terms and what they are actually buying. Having Addison's Disease and a food allergy makes this even more of an important quest when you are grocery shopping.

Below is a list of some industry terms used to describe ingredients which are the most common allergy triggers:

- MILK OR MILK COMPONENTS: casein, whey, lactose, ammonium caseinate, milk protein, whey protein concentrate, magnesium caseinate, butter fat, rennet casein, lactalbumin.
- EGGS OR PARTS OF EGGS: albumen, globulin, livetin, simplesse, egg substitute, egg white, egg yolk, powdered egg, egg solids and words beginning with "ov", such as ovalbumin and ovomucin.
- PEANUTS: nuts, peanut oil, peanut flour, natural flavoring.
- WHEAT AND PARTS OF WHEAT: gluten, malt, modified food starch, dextrin, distilled vinegar, wheat germ, bran.
- SOY: lecithin, soy protein, textured vegetable protein, natural flavoring

Also watch for the phrase, "may contain". This hides sloppy manufacturing practices, such as cross-contamination of one food produced on the same machinery as another that contained a common allergen.

If you suspect yourself or your child has a food allergy, speak to your doctor about an allergy test. To ignore the warning signs could be disastrous, especially for someone with Addison's Disease. Scout out sources of foods you like that don't contain your allergen; egg-free baked goods, for instance, if you're allergic to eggs. Your local library is an excellent source of recipes to help avoid your specific trigger.

Submitted by Helene Perry:

Information source: Seattle Children's Hospital & Regional Medical Center, Food Allergy & Anaphylaxis Network.

The Hamilton Spectator, October 24/01

Highlights From Local Meetings

Vancouver Island Support Group (Nanaimo) - October 20/2001

Submitted by Christy Lapi:

A small meeting was held on October 20/2001 at the Nanaimo Regional General Hospital. Sharon Erickson chaired this meeting. Christy and Barbara were unable to attend.

For information on upcoming meetings to be held in Nanaimo, please contact: Christy Lapi at **clapi@mail.island.net**, or 250-245-7554 or Barbara Hunn at **bhunn@telus.net or** 250-756-4385.

Vancouver Island Support Group (Victoria) - November 24/2001

Submitted by James Sadlish:

The Vancouver Island support group of The Canadian Addison Society met November 24th at Victoria General Hospital, Room 1814, for general discussion. Eight attended, six Addisonians and two spouses of members.

Subjects ranged over a wide range of general concerns, including types and amounts of medications, recurring symptoms, doctor/patient relationships and education of ourselves and others. As usual in our group's discussions, attending spouses made helpful contributions. Partners can not only notice symptoms a patient might not, but can also help in reminding of a need for extra cortisone in stress situations, or in injecting an emergency dose of Solu-Cortef.

DHEA is being tried by several of the group and those taking it report improved sense of well-being, along with a leveling-out of cortisone-dosage response. Acne and excessively oily skin can be a problem with it, and dosage of DHEA and other corticosteroids are having to be adjusted to suit each patient's response.

Members reported a wide range of dosages of both glucocorticoid and mineral corticoid hormones, some taking the "standard" amount of 30 mg/day of hydrocortisone (or its equivalent of 37.5 mg cortisone acetate, or 7.5 mg prednisone) and some taking as little as one-third of that. Fludrocortisone dosage ranged as widely. To some, it appeared that DHEA can make a difference in the amount of other hormones required for general energy and health. One member reported on the efficacy of certain Chinese herbs in these same areas.

Several expressed concern about osteoporosis and about the importance of bone-density testing. Hope was expressed that a new test, which provides an indication of the current level of bone resorption, will soon become readily available for Addisonians and others with like concerns. This test, called NTx, shows whether bone is being lost and requires only a urine specimen.

Nothing new has been heard from the U.S. doctors of pharmacology who were checking into the possibility of creation of an under-the-tongue emergency cortisone tablet, (buccal method), that could be used instead of the cumbersome Solu-Cortef injection, but members expressed hope something like this can eventually be found.

It was decided to reduce the number of meetings this year to two in Victoria and two in Nanaimo, with dates to be arranged and announced later.

For further information: Victoria meetings: **Jim Sadlish at x699@victoria.tc.ca** or 250-656-6270, or Florence Weekes at **fmweekes@telus.net** or 250-598-0321. Nanaimo meetings: Christy Lapi at **clapi@island.net**, or 250-245-7554 or Barbara Hunn at **bhunn@telus.net** or 250-756-4385.

BC Lower Mainland Support Group - October 13/2001

Submitted by Judy Stanley:

The October 13, guest speaker was Ifigenia Fasogiannis, Human Resources Development Canada, Outreach Officer, Income Security Programs Branch. Ifigenia recommended that you not carry your S.I.N. card or give out your number over the phone due to the large amount of fraud in Canada.

Old Age Security - OAS - you may receive one year retroactive if applying late - 2001 is \$442.62/month. Between the ages of 60 - 64, the spouse of a pensioner can apply for an allowance (old survivor benefits) which must be renewed each year. Survivor and supplement benefits are non-taxable. For those in the 'sandwich generation' if one of your parents is living in a retirement home due to ill health and the other is maintaining the family home they can claim as individuals for tax purposes which will put them into a higher deduction bracket.

Canada Pension Plan - CPP - Can be collected any country in the world with reciprocal agreement. The employer will match (2201) 4.3% of your earnings paid. If self-employed you pay double that amount. 2002 rate will be 4.7%, 2003 - 4.95% where the rate will be frozen. CPP started in 1966 and contributions will be calculated to current value for higher pension. You cannot contribute after age 70 but can claim after age 60 - pension will be 30% less than at age 65 but will even out amount earned by age 71. Drop out provisions are provided for - Period of Disability - CPP disability only, company disability years do not count towards CPP, raising children - 7 years will be disregarded. If someone has to go on disability from their place of work they should also contact an Outreach Officer regarding CPP disability. CPP is taxable. As of May 2001 you can now earn less than \$3800 per year, do volunteer work and collect CPP Disability. You can assign or share your Retirement Pension with the lesser earner for a better tax bracket. You can now apply for survivor benefits under 35 and can remarry. Bill C-54 allows for a late application of disability benefits but you can only collect one year retroactive.

This is a very short recap of any hour and half talk with numerous questions asked by members. I have many handouts for anyone interested. It is well worth contacting an Outreach Officer in your community to go over the rules and regulations which pertain to all parts of Canada. Each individual will have a different amount of pension due to them after all the calculations are made.

Next meeting is February 16, 2002. Guest speaker will be Dr. Jerilynn Prior, Professor of Medicine / Endocrinology, UBC. Dr. Prior has created a video called the Puzzle of Perimenopause, which comes with a diary. If you have any endocrine related questions or Addison/ Cushings research questions for Dr. Prior, please e-mail them to me (note new e-mail address — bugbee@shaw.ca) and I will forward them to Marilyn. She will be calling Dr. Prior mid-December to discuss topics. If anyone in the Canadian Addison Society has questions they would like to ask Dr. Prior, we are open for suggestions.

May 25, 2002, Tentatively booked Dr. Saul Pilar, Medical Doctor who also practices Environmental Medicine. He will be contacted again in January to finalize his participation. Other possible speakers: or your suggestions welcome: Yoga Instructor, who would really like to come to speak to our group. Director of PR, Paramedic Association, Voder School re: Lymphatic Drainage.

Thanks go to Marilyn for arranging speakers and doing such a great job. For those at the meeting to update you on Marilyn's trek over to maternity after the meeting; Marilyn and Keith are the proud grandparents of a baby girl Avery Sloane who was born 3:27 am on Sunday. Congratulations.

The next two meetings will be February 16 and May 25, 2002. All dates are Saturday from 1:00 to 3:00 p.m. at 330 Columbia St. E, Sherbrooke Lounge, Sherbrooke Centre, next to Royal Columbian Hospital.

Saskatchewan Addison Support Group

There are no meetings on the calendar at the present time. If you are from this area and wish to make contact with the group, please call Elizabeth Hill from Meadow Lake at 306-236-5483.

Southern Ontario Support Group

The next meeting for the Southern Ontario Support Group is booked for February 09/02, starting at 1:00pm, at the Brantford Ontario Police Station on Wayne Gretzky Pkwy. The format for this meeting has not been confirmed, but should be of interest to everyone. If you wish further information on this meeting or any upcoming meetings, please contact Lynda Daniels in Toronto at 416-538-4978 or e-mail at vfdaniels@hotmaii.com

Alberta Support Group

For information regarding any upcoming meetings, please contact Francisca Swist of Edmonton at 780-488-8540 or e-mail at fswist@powersurfr.com

Eastern Ontario Support Group

Minutes for the October 13/2001 meeting were not available at press time. If you require information on this meeting, please contact Elaine Hall.

Meetings are held twice annually at the following times:

<u>MAY</u> - The first Saturday following the Victoria Day weekend. The group meets at Robbies Italian Restaurant on St. Laurent Boulevard, Ottawa at 12:30 for an informal lunch.

<u>OCTQBER</u> - The first Saturday following the Thanksgiving weekend. The group holds this meeting at a member's home and a "pot-luck" lunch is arranged. A speaker is invited to this meeting.

Please contact Elaine Hall at 613-824-0160 or grahamhall@sprint.ca for further details.

Quebec Support Group - September 15/01

If you would like information about upcoming meetings, please contact Sybil Harrison at: 108 - 6950 Fielding Ave. Montreal, Quebec, H4V 1P7 514-486-9817 or Sophie Lapointe at 514-521-6538 or e-mail sophielg sympatico. ca

What is more mortifying than to feel that you have missed the plum for want of courage to shake the tree?

Logan Pearsall Smith

We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop.

Mother Teresa i

The three hardest tasks in the world are neither physical feats nor intellectual achievements, but moral acts: to return love for hate, to include the excluded, and to say, "I was wrong."

Sydney J. Harris Pieces of Eight

I would like to take this space to wish you all a peaceful new year, wherever and however you find it and to thank you all for your continued support and friendship in the past. You make the job of editor very rewarding for me and I can assure you that I receive much in return for my contribution to this very helpful and caring organization.

Helene Perry



Letter from the Editor

In this edition, I would like to share my experience with Addison's Disease. I feel that this would be a great opportunity for you to get to know me and hope that it will inspire you to share your experiences, thoughts or feelings.

When I was 20 years old, I underwent a lot of stressful challenges. My house had been broken into; I had broken up with my boyfriend so I thought it would be a great idea to go away for my 20th birthday to Dominican Republic. Prior to the trip, I had been suffering from colds, flues, constant asthma attacks, and appeared to be losing a tremendous amount of weight. I continued to plan and book my trip and decided to get medical insurance since my health was very unstable.

When I arrived at the island, my tan appeared almost instantly and I had never tanned so dark in my life! By the second day, I felt extremely fatigued and irritable. However, I wanted to enjoy my vacation so I became very adventuresome on my birthday and decided to go parasailing. When I landed I felt extremely dizzy and nauseous. I blamed it on the alcohol that I drank. I became extremely ill and decided to make a visit with the doctor, as my symptoms became worse. He gave me a bottle of Pedialite and told me to drink lots of water as I was suffering with dehydration. It didn't help; I was becoming weaker and could barely walk from the pain in my back and abdomen. I went back the next day and they injected me with an enema; I had no idea if the needles were sterile or what they were doing or saying as they spoke in Spanish and mine was limited!

I was later admitted into a hospital where a doctor advised me that I had some sort of ulcer and needed bed rest. He also reminded me that I couldn't fly home until I felt better. I was due to leave back to Canada in 3-4 days! I convinced my doctor that I was fine (myself too) and I was released 2 days later.

When I arrived home, I met with my family doctor and told her about my experiences while staying in the Caribbean. She had made numerous appointments with specialists determined that something would show up. I was becoming weaker, thinner and more and more lethargic as time went on. I was a fitness instructor and eventually had to give up my classes because my energy levels were so low. I also had a part time job as a cashier and spent my breaks on the bathroom floor, as I was so dizzy and hot. The tile felt so soothing on my back.

After being admitted and discharged what seemed to feel like every weekend, I was finally admitted for bronchitis that affected my asthma. I went on Prednisone to treat the infection. I felt much better to my surprise. After being "cured" of bronchitis, back in the hospital I went. The pain was unbearable; doctors were questioning if I was anorexic, I saw a psychiatrist who put me on Paxil because I "appeared" to be depressed. Demerol became my new best friend and was the only thing that put me at ease.

My mother continued to stay by my side the entire time. Whether it be stroking my hand, brushing my hair, or encouraging me to walk just a few steps a day. This felt like a marathon to me; in reality it was only a few steps.

After every "possible" test was completed my internist had suggested performing one more test. The results had come back positive! Addison's Disease. I had no idea as to what this meant. Would 1 have to give up my teaching? Could I have kids? Was I going to die? What did this really mean?

After analyzing this for the past 3 years, it means that I have to look out for myself. I have to take care of myself. I must learn to manage the stress in my life and find ways to control it. I must listen to my body and know my limitations.

The last few years have been challenging for me, as "no" has never been an option. 1 have always done what I set out to do. Having Addison's disease hasn't enabled me from doing these things, it just means that extra care must be taken! After all, my doctor reminds me, "Heather, just because you're Superwoman doesn't mean that you have to prove it!"

I continue to teach fitness classes and have even taken up yoga for both personal and instructional. I now work a job that has flexible hours and allows me to work as little or as much as I want, when I want.

I have met a wonderful friend over the internet who has Addison's Disease. She is from Chicago and we are close in age. We met for the first time last year and shared our personal experiences. This year she flew into Toronto to meet me again. We talk about our progress and most of all, how we enjoy our lives. We have educated each other of our symptoms; doctors' advice and news from each other's support groups.

To this day, I truly feel blessed to have this disease. I have allowed myself to try new things that I wouldn't have in the past. I sincerely value and appreciate my friends and family. I now look out for myself more than I ever have before. When I am sick, I look at it as a day that I get to eat more potato chips and drink more Gatorade! The most rewarding thing is that I get to educate people both personally and in the fitness industry about this rare condition called Addison's Disease. I want to be able to educate people so that they may be able to help someone who may be suffering from similar symptoms. I want to reach out to those suffering around me and help them find the support and resources they need. That's why I knew that this Editorial position was for me. I hope you enjoy reading my articles for 2002, this is my gift to you.

I look forward to hearing your experiences or stories.

Submitted by:

Heather Michelle Nicholson "Editor in Training"

your chest, mail it to the address below or send by e-mail. You may remain anonymous if you wish. No names will be published without your consent.

Heather Nicholson P.O. Box 1417 Bradford, Ontario L3Z 2B7 905-775-6923 Editor in training e-mail to: addisoneditor@yahoo.ca Or Helene Perry, 75 Wendover Dr. #218, Hamilton, Ontario L9C 2S7 hperry@interlynx.net

Let's Hear It For Life!

You will soon learn that I am not a cook! I like to make things that are quick and easy yet nutritious. Here is one for those who are always on the go!

Penne with Tomato, Black Olive and Feta

1 lb. of penne pasta

I tbsp. Olive oil

1 tsp. minced garlic

4 large tomatoes cut in wedges

1/3 cup black olives halved

1/2 cup crumbled feta cheese

1/2 chopped fresh parsley (optional-I don't like it cause it gets stuck in my teeth!)

2 tsp. dried basil

1/4 cup freshly grated Parmesan cheese

Cook pasta till tender but firm; drain; return to pot to keep warm. In skillet, heat oil over medium heat. Stir in garlic and tomatoes. Cook for 3 minutes. Add to drained pasta. Add olives, basil, feta and parsley. Toss gently. Sprinkle with parmesan.

Yield: 4 main course servings.

This dish is extremely easy to make. Be careful not to cook tomatoes too long or on high heat as they go soggy really quick!

This dish is a great source of sodium!

Do you have a favorite **healthy recipe or tip** that doesn't take too much of our stamina resources to create? If you would like to share your recipe or tip with other Addisonians, please send them to <u>addisoneditor@yahoo.com</u> or mail to P. O. Box 1417 Bradford, Ontario L3Z 2B7. Please let me know if you do not want your name used. Let's share with each other and we all win!