The Canadian Addison Society
La Société canadienne d'Addison

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President's Message:

I was most pleased to meet you all at the Ont. east meeting at Elaine and Graham Hall's on Sept 18th. A great meal as we compared notes about Addisons. After, Dr. Silverman spoke about Addison's and answered many questions.

The point came out that we should carry our "Medical History Letter" and our Canadian Addisons Society membership card where they can be easily found in an emergency. 12 people were present. The next meeting is planned for May. If someone from the Eastern area would like a meeting in their town, please help Elaine by getting a speaker and a meeting place.

Sybil was also very pleased at the amount of people who came to her place on the 19th, from the Montreal area. Twelve in all. They told of their problems, and expressed a wish for another meeting, hopefully in the New Year. If interested, please contact Sybil at (514) 486-9817.

I hope the many of us who are struggling with health problems this month continue to improve. I am looking forward to seeing many of you at our yearly meeting in Brantford, Nov.20th.

We are including the agenda in this letter and hoping that you will contact us with your ideas of how our group can improve. We also need 3 board members to replace those who have resigned. Any volunteers, please write or phone Joan or Greeta, email jsoutham@home.com or gfraser@greynet.net Phone: Joan (519) 753-1271 .Greeta (519) 538-4012.

Sincerely
Greeta Eraser.

BRITISH COLUMBIA

Vancouver Island Support Group

Eleven members held a highly informative meeting on September 11th, 1999 at Victoria General Hospital. We discussed the importance of finding one another for mutual support and for education, both of ourselves and of medical personnel [particularly ambulance and emergency staff] .One suggestion was that we try to establish a "buddy" system whereby

someone with Addison's would go to the Hospital to act as an advocate for another Addisonian, who under stress, might be losing the energy and mental acuity to explain their situation to professionals unfamiliar with this life-threatening disease.

It was noted we are gathering an increasing collection of reprints, tapes and videos. These are being lent out to members to continue our education.

It was agreed to jointly purchase the new Dutch report, "An Improved Medication of Addison's Disease " feasibility study, for reference. Several expressed appreciation for the networking offered by such groups as The Canadian Addisons Society and the N.A.D.F. plus email and the internet.

Jim reported on the latest efforts to have pre-filled emergency syringes of Dexamethasone made available to Canadians. There is still a problem because of the small [to a pharmaceutical firm] number of prescriptions that would be needed to make production viable.

During discussion of medications, it was noted that several people are testing [in cooperation with their doctors] lower dosages of their various forms of cortisone, generally with good results. Some reported a "leveling" effect from supplementation with DHEA. In discussion of other conditions that can accompany Addison's, some reported on use of "fosamax" and Calcium for osteoporosis prevention and potential use of plant estrogen in place of commercial hormone. Our next meeting will be at 1 pm. Sat November 20th, at Victoria General Hospital, Room 1814 A pharmacist will be speaking For more information, please call Jim Sadlish at 250-656-6270 or Email at wx699@victoria.tc.ca. or Florence Weeks at 250-598-0321 or Email at fmweekes@islandnet.com .

Lower Mainland Group
From Judyth Stanley Email bugbee@direct.ca

Our meeting was held on October 16 with 18 people attending. Guest Speaker was Zahida Esmali BScPharm. She gave a comprehensive talk on medications and their interactions, the meeting was taped and cost of the tape will be $5.00 plus shipping. The same applies to the talk by Dr. Kendler on Osteoporosis.

Our next meetings for the Lower Mainland Group will be February 26 and June 17,2000, Sherbrooke lounge, Sherbrooke Centre, 33 OE Columbia, New Westminster.

One interesting thing to come out of our introduction of ourselves was a couple of reactions experienced. Cushing's with Diabetes on Metformin had a severe reaction with revulsion to food and resulting anorexia. This is a rare reaction to the medication. The other was an Addison with a severe tremor from the Prednisone. The neurologist she had been seeing was going to subscribe medication for the tremor after Parkinson's had been ruled out. She had kept a record of medications and noticed that the tremor had started after starting the Prednisone so they switched to cortisone acetate and she is fine now. It shows how you

really should keep a record when you are trying a new drug.

[Note from Greeta: I had this problem in a milder way, I lost 40 lbs and blamed it on other things, until looking back to when I started on it, Am still taking it, and doctor upped dosage just to-day, I just realized it when reading fact sheet from new pharmacist.)

Our sympathy goes at this time to Gary Gelman and Family, at the passing of his wife Patti, the founder of the National Adrenal Diseases Foundation. We will also miss the long time director, Joyce Mullin who is leaving. We wish to thank them for their help over the years.

Our Membership fees to the Addison and Gushing International Federation have been paid for this year.

An article from New Zealand Addison's Network

Are you well labeled, in case you need an emergency trip to an unfamiliar Hospital?

As you'll have read in some of the stories in overseas newsletters (and on the e mail bulletin boards too), Addisonians sometimes get a tough time when admitted to hospitals as emergencies for Addisonian or other reasons, even in their own countries. They can face disbelief from the medical staff that they have Addisons and lack of knowledge about how to treat an Addisonian crisis.

It's also a scary prospect that our Addisons might be "missed" if we are part of an ordinary emergency. The challenge is to have with us the right amount of documentation and back-up medications for the situation.

Level 1- If you are around your usual patch:

At least wear a Medic-Alert bracelet or pendant. Emergency services are trained to look for these. Also, preferably carry in your wallet the Medic-Alert card that gives medication types and dosages and your doctor's contact number. And get in the habit of carrying the day's medications with you on your person.

Level 2: Traveling away from home - especially overseas.

Medic-Alert ID plus wallet card on your person; medications for at least 424 hours on your person. A more complete letter preferably on your doctor's letterhead and signed describing WHAT you suffer from, WHAT medications you are on, and any other conditions that could affect your treatment. Injectible steroid usually Solu-Cortef 100 mg.

Joan Southam from The Canadian Addison Society recently shared advice given to Canadian

support group members by a doctor from a hospital Emergency dept. We've adapted it, added other sources of comment to the checklist below, and run it past Dr, Braatvedt.

In times of emergency (an Addison emergency such as vomiting and dehydration, or a general emergency, such as a serious accident): Use the syringe BEFORE going to the hospital if possible. The important message is that using the injection can't do harm-but delay may make your situation worse.

Then pay attention to fluid balance - if possible - drinking plain water is better than nothing, if there has been a fluid loss through vomiting. Then ensure that follow through assessment by a doctor takes place as soon as possible, including possible IV therapy for fluid restabilisation.

In other words, just because improvement occurs after the injection (the vomiting stops) and you start to feel a bit human again, don't neglect the importance of getting fluid balance right, or the improvement won't continue.

When the Canadian audience said that sometimes being well labeled and trying to explain the needs of an Addisonian to the hospital staff does not work, the Canadian speaker encouraged that ALL complaints or concerns should be followed up with a letter to the head of emergency services, with a copy to the administrator of the hospital. This has to bring some sort of action or review.

Being believed is one hurdle-what about the possibility that the doctors might not know how to treat our emergency? There are standard emergency medical textbooks, which spell out clearly what to do for an Addisonian, the Canadian speaker reassured. Another option, especially for travelers to places away from main centers, is to have their doctor add to their letter, in specific detail, what to do in case of an emergency.

One of the opportunities through the ACIF (and through NADF) is obtaining explanatory and emergency treatment information for Addisonians in languages other than English.

MORE TIPS FOR TRAVELERS

The usual injectible in "emergency syringe kits" for Addisonians is 100 mg hydrocortisone. Another option to consider if you really want to "head bush" is 4mg dexamethasone, because it will sustain you longer than hydrocortisone - something to discuss with your doctor.

One member has always packed two complete sets of medications when traveling overseas - one in hand luggage one in suitcase. She wonders if that is "overkill" - but she has found out first hand when baggage went astray the importance of carrying at least 3 days supply in hand luggage. A bonus from having a signed doctor's letter describing her situation and medications and dosages, was that it could have been used to purchase replacement medications no hassle over the counter (at least in Germany) if the baggage had not turned up.

And what about the puzzle and paradox that constantly faces Addisonians-having extra cortisone (prednisone) when we need it, to deal with life's swings and roundabouts, but not subjecting ourselves to chronic over-dosage? The challenge is to get in first-before our body becomes cortisol deficient. How successful we are depends on our lifestyle, our nature, the extent of our support network, other medical conditions that we may have. Double or treble the dose when we are ill {or seriously stressed} is the consistent message - and when the illness passes, taper the dose over a few days.

When we are traveling, it makes sense to change our threshold for action. A members comments "I am passionate about trying to minimize 'downtime' and optimize quality of life. In my opinion increasing the hydrocortisone (or prednisone) dosage at the right time, rather than facing the disappointment of crashing and fatigue due to too-slow reaction is easier said than done! My rule of thumb when traveling in unfamiliar territory is to loosen the criteria for dosage increasing - when in doubt I do it, rather than delay and risk the added stress of dealing with the unfamiliar from a position of fatigue.

I have found my own early warning that it's time to cut back the dose; I usually take my morning hydrocortisone at about 6.30. If the dose turns out to be a bit higher than I needed, then between about 10 30 and noon, some poor person I interact with may 'get it in the jugular'. Someone testing my patience at that time is likely to find out that is very thin, and I don't hesitate to tell them, I am in over-react mode".

Calcium supplements — Calcium supplements are widely used available in several forms-Tablets, chewables and liquids. They may be available as part of a multi-complex compound. It is essential before you consider taking a supplement to discuss this with your physician and /or nutritionist. The amount of calcium supplement, if any, you require will be determined based on a number of factors including your age, diet and medical history. Also, calcium may interfere with absorption of certain medications, which is another reason to consult your physician.

When looking for a supplement, it is very important to read the label to determine if the supplement is right for you. Check the following carefully.

1 The amount of elemental calcium in the product, that is, the actual milligrams calcium you need.
2. Look for natural or refined calcium rather than dolomite or bone meal preparation.
3. Try to find a supplement with as few other nutrients included as possible. Higher priced 'designer' supplements are not necessarily better or better for you particularly. Look for the one that is best suited to your needs.

Above all, before taking any supplement, check first with your health care team. If your health changes or you make any significant changes in your diet, contact your physician and /or

nutritionist and discuss your supplement needs again.

Ask the Doctor? Questions asked Dr Killinger ,MD, PhD,FRCP

The question has been raised as to why some people with adrenal insufficiency have weight problems when they are treated with cortisone, while others seem not to have the same difficulty.

A. The cortisone replacement is designed to return your hormone levels to normal. It is very important that the amount of cortisone replacement is not excessive or it can lead to some weight difficulties. In the past, we have tended to use cortisone or prednisone doses which may be a little more than are actually needed. In general, patients can get along with either 25 or 37.5 mgs, of cortisone daily or 5 or 7.5 mgs. of prednisone. It's important to balance this with fludrocortisone. We tend to look at ACTH levels and renin levels as a guide to the dose of each of these medications.

Once the cortisone and florinef replacement has been appropriately balanced, then activities as well as food intake are both important in maintaining appropriate weight.

The second question also concerned about weight problems, and raises the question as to whether or not the thyroid is important in this area. This questioner also asks about the role of DDAVP.

A. Since the primary cause of adrenal insufficiency is autoimmune and the primary cause of hypothyroidism is also autoimmune a large proportion of patients with adrenal insufficiency are also on thyroid replacement. The amount of thyroid is titrated to obtain normal levels of TSH and once this has been achieved the patient is generally normal from a thyroid standpoint. In general, if their cortisone, fludrocortisone and thyroxine are at optimum levels, they should be able to maintain their weight as in a normal situation. DDAVP is a hormone that acts on the kidney to control water output and really does not play a role in weight gain or weight loss under normal circumstances.

This questioner also asks about over-the-counter medications that state on the box that they should not be taken if the patient has a thyroid problem.

A. This is because most of the drugs for allergies or cold remedies contain some type of adrenalin-like compound. If a patient has hyperthyroidism, the combination of excessive amounts of thyroxine plus the adrenalin-like compounds can cause stimulation of the heart. For this reason, the manufacturer is obliged to put this warning on the boxes. If a person is taking a normal amount of thyroid hormone, there should be no problem in using any of these medications.