The Canadian Addison Society
La Société canadienne d'Addison

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Season's Greetings'!

This month we have lots of exciting news, including Al McConnell's Report from Norway, the first International Addison Conference, coverage from Dr. Baxter's presentation at our first Brant ford meeting, and highlights from the Annual Meeting and Get-Together in Perth ON, Sept 7. Many of us receive news flashes from Greeta, who volunteers tirelessly in bringing us together. This, and the efforts of all our members is essentially what we are about - reaching out and sharing.

Summary from Annual Meeting;

- 11 Addisons and 6 family members present.
- Hostess Evelyn Paul graciously provided potluck lunch.
- Conclusions from Dutch Study emphasized individual tailoring of medications, as each case is different.
- Al mentioned a central registry in France where Addisons Disease (and others) are kept track of.
- Yearly fees of $20.00 agreed upon to maintain expenses.
- Approval granted for printing wallet cards for paid-up members; 500 ordered; Year runs from Sept. to Sept.
- $50.00 per year to C.O.R.D. was agreed upon to get us on-line; this will help with information and publicity. Al's daughter is preparing a presentation.
- $100.00 offered to Al towards Norway expenses; he kindly declined, so it was left for materials from the Conference.
- For people with diabetes and Addisons, the diabetes was treated before the Addisons. Several people had an allergy to sulfa. Muscle weakness, seizures etc. mentioned. The mom of Chad, a 19 yr. old Addison, told of problems when first diagnosed and locating a sympathetic endocrinologist. Chad is very sports oriented and finds Gatorade helps fluid loss; he increases his medication on heavy sports nights.
- Marc's illness has created work problems: dizzy, weak and ill.
- Gastrolite poor-tasting. Article in Thyro bulletin mentioned.
- Salt need agreed upon; educating families on this necessary.
- Address change for Greeta Fraser, who now lives in Trenton. Next Annual meeting in Trenton. This is adjacent to Hwy 401.
- Survey of those present - high number with thyroid disease; many had other complications; skin problems were common; some had relatives with related diseases. Quite a few found winter 95 difficult for their management. Some found surgery stressful Preparation was key in all these situations; having a doctor's letter explaining what to do, useful for emergency personnel. Wallet card will help in this regard.

Brantford Meeting

On Oct. 26th, 1996, at the meeting room of the Brantford City Police, the first area Addison Meeting was held. About 40 people attended; including Brantford, Point-au-Baril, Thorold, Paris, Kitchener-Walerloo, Bowmanville, and surrounding areas. Joan Southam and Isabel Rathbun organized the event. It was an excellent forum in which to meet, discuss and exchange information. The guest speaker was Dr . W. J. Baxter, Internal Medicine Gastroenterology, trained at McGill. Dr. Baxter give a thorough overview of Addition's Disease, starting with its discovery by Dr. Thomas Addison in 1856. Overhead diagrams with lists of symptoms, treatment, and other stats gave a well rounded presentation that was appreciated by all, judging by the comments and questions to follow.

Time ran over as we visited and tried to get to know each other .It was an unqualified success for those who helped run the event and a sure sign that the next meeting in Brantford, slated for Jan. 28. 1997 will be eagerly anticipated.

Some key points:
- Getting the proper diagnosis. Physicians need to be more aware of symptoms.
- Patients need to be advocates.
- Don't assume hospitals will recognize it.
- Addison ’s disease requires careful management. Some patients after diagnosis have little follow-up treatment. Don't ignore warning sign when sick.
- Quality of life issues. (Dr. Baxter diagnosed two of patients at the meeting)
- Dr. Baxter quoted article in New England Journal of Medicine Jan .4,1996 Clinical Problem-Solving Just in Time. It's about a 15 year old girl who underwent numerous tests and nearly died before correct diagnosis was made, despite the presence of key symptoms." Perhaps the only way to have made this diagnosis earlier would have been to appreciate that none of the diagnoses entertained by any of the physicians involved in the patient's care explained all the clinical findings. In fact, when a diagnosis is correct, it should explain all the abnormal findings. The task is to come up with one that does". This article is available in full in Greeta's files.

How to Prepare and Give a Hydrocortisone Injection

1. Assemble equipment: hydrocortisone for injection, alcohol pad, 3 cc syringe with needle (2.5 to 3.75 cm. (l to 1.5 in.) 22 gauge).
2. Wash your hands.
3. Prepare the medication. Remove the top from the vial and push the rubber stopper in until the liquid in the top chamber gets into the bottom chamber of the vial with the medication powder. Mix the vial contents by gently rolling the vial between your hands.
4. Wipe the top of the vial with alcohol. Insert the needle into the vial and inject a volume of air equal to the medication dose.
5. Turn the vial upside down and draw up the medication by pulling the plunger back to fill the syringe with the entire dose (100 mg. or 2 cc for adults).

6. Check for air bubbles. If air bubbles are present, tap the syringe to dislodge bubbles and push the air bubble out by pushing the plunger in. If no bubbles are present, push the plunger in to the 2 cc syringe marking.
7. Remove the needle from the vial; keep it sterile until the injection is completed.
8. Choose the injection site as instructed by the clinician & wipe it with an alcohol swab. Allow the alcohol to dry. Push the needle in at a 90-degree angle. Draw back on the plunger to check for blood. If blood is present, remove the needle from the skin, discard the used needle & syringe in a puncture-resistant container, & start over from step 1. If no blood is present, inject hydrocortisone. Remove the needle at the same angle.
9. Record the dose & injection site in your logbook or calendar. Tell the physician when you've given the injection.
10. Dispose of the used needle and syringe in a puncture-resistant container.

NEWSFLASH!! Memberships have grown from 8 founding members in Sept. 1994 to a 100 members in 1996! Welcome newcomers Ken Kelly and Elizabeth Corwin and all others who have recently joined.

Bone density and turnover In Addison's disease: effect of glucocorticoid treatment

Bone-Miner 1994 Jul, VOL: 26 (1), Pi 9-17, ISSN: 0169-6009. Osteoporosis is a well known side effect of chronic treatment with glucocorticoids. We have studied vertebral bone mineral density (HMD) and biochemical markers of bone metabolism in 30 patients diagnosed of Addison's disease (AD) to determine the effect of long-term replacement treatment with hydrocortisone (30 mg/day) or prednisone (7.5 mg/day). Lumbar bone mineral density was measured with dual energy X-ray absorptiometry in L-l-4 in two occasions, separated by 12 months. BMD in premenopausal women and men with AD was similar to healthy controls and postmenopausal women had slightly lower results. Rate of change of bone density followed up over a period of 12 months was -0.82%. Bone loss was not influenced by duration or type of steroid treatment. Biochemical parameters, serum calcium, alkaline phosphatase, osteocalcin, procollagen type I, PTH and 25 (OH) vitamin D were within normal limits. Our results show that in patients with AD, after replacement with low doses of glucocorticoids there is no significative trabecular bone loss neither modifications in bone formation markers. Author.

International Conference Report

This is a brief report on my attendance at the First International Conference for Addison's disease, Cushings Syndrome and Acromegly.

The conference, sponsored by Morbus Addisons Forening of Norway, was held on October 4, 5 & 6, 1996 in Oslo, Norway. Approximately 60 people attended representing 11 countries.

The meeting began with welcomes from our hosts, represented by Cetra Hastings and Ann-Christine Ball. This was followed by a representative from each country giving an overview of goals and activities of their respective groups.

Generally the **Goals** were:

1. Provide a caring network of support for people with Addison's Disease.
2. Work with the medical profession to create a higher degree of awareness of Addison's disease and its treatment
3. Supply up-to-date information to Addisonians to help improve knowledge of their circumstances and, thereby, improve their quality of life.

There were many other ideas and suggestions.

Other Items on Friday's **Agenda**:

- Discussion on how to finance a support group.
- Ideas on founding an International Organization. Discussion on children and youth with chronic illness.
- Introduction of Joan Hoffman's book, "Our Addison Kids" — support for parents and families. (Joan has been very generous with her time, sharing information and answering questions for many Canadian Addisonians.)

Workshops

- Sharing experiences
- What is being done in each country
- What can be done
- How can we help the parents

These Workshops consisted of 5 or 6 groups of 5 or 6 persons each, discussing an assigned topic. One person was appointed moderator and the group selected one of the participants to give a brief report of the results to the conference attendees at the conclusion of the Workshop.

On the second day, five Doctors from the Netherlands and Norway participated in the conference as well as Mat Knapen, who co-authored a book titled, "Addison Patients in the Netherlands. -Medical Report of the Survey." This book contains a wealth of information for Addisonians. It covers a survey of 91 Addisonians in the Netherlands who completed a comprehensive questionnaire, underwent a medical examination and participated in a discussion of the survey at the University Hospital Utrecht, the Netherlands. Mr. Knapen spoke to us on the Social Aspects of the survey.

John Beun and Laurens Mijnders from the Dutch group, both very involved in the Addison's Survey, also played a very active part in the entire conference.

Dr. Pierre Zelissen, who did much of medical work for the survey, presented the results of the survey on Medical Aspects of Addison's Disease. There were many questions.

Dr. Falch, Aker Hospital, Oslo, spoke to us on Osteoporosis - Bone Mineral Density (BMD). (The Dutch survey revealed that Addisonians, particularly males, taking a higher dosage of cortisone had reduced levels of BMD in 6.7% of women and 32.3% of males).

Dr. Eyvind Husebye discussed the Pathogenesis of autoimmune disease in Addison's.

Dr. Johan Halse Betania talked about the latest developments in treatment of Acromegaly. Acromegaly is characterized by advanced enlargement of facial features, hands and feet, resulting from overproduction of the growth-stimulating hormone, of the pituitary gland.

On Sunday, the last day of the conference, there were Workshops on " Experiences with Health Services" and "Educating health services."

Much of the rest of the day was dedicated to how to get financing and which groups were able to get government assistance.

There was also discussion on the need and practicality of forming an international organization, how to go about doing this and who would take the initiative.

It was generally agreed that since Addison's was a relatively rare disease, the only way we could acquire enough clout to accomplish anything, would be to form an International Organization. It seemed apparent that the Dutch and the Norwegians were best positioned to take a leadership role as they had access to financing and experience. The other countries would, of course, have to seek financial support and be able, eventually, to contribute their fair share.

In all, the conference was very well organized. The agenda covered the points that most people seemed to be interested in, the workshops were very interesting and productive and the participation of the Doctors was definitely a highlight. It was very good of them to travel and donate a Saturday to our conference. They answered many questions and generally were very informative and appreciated by all.

Cetra Hastings and Ann-Christine Ball and many others involved with Morbus Forening Addison worked constantly throughout the conference, as well as countless hours beforehand, organizing, planning and corresponding with people, literally all over the world. The result was a very successful conference, which I was proud to attend as the Canadian Addison Society representative.

The hospitality was great, the food delicious and I ate far too much. On the day after the conference Ann-Christine Ball spent the entire day showing two other attendees and myself around the Oslo area, including their cottage on the beautiful Oslo Fjord and finishing with a very nice dinner at a seaside restaurant.

Al McConnell
Treasurer