The Canadian Addison Society
La Société Canadienne d'Addison

193 Elgin Avenue West
Goderich, Ontario N7A 2E7
Phone: (519) 751-4472
Fax: (519) 751-4473
Email: jsoutham@rogers.com
Http:// members.rogers.com/jsoutham/index.htm

ISSUE NO.31 JANUARY 2003

In this issue:

PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. We advise readers to consult their own doctor before making changes to their Addison management program.

President's Message:

Dear Friends and fellow Addisonians:

At this time of the year, it is so important to take care of yourself with the colds and the flu that are so prevalent. Remember to get your flu shot! Make sure you have an emergency injection kit and know how to use it! If you have to go to the Emergency Department, make sure that you are "prepared" and take with you a listing of current medications and a note from your physician and/or endocrinologist with preferred treatment for your Addisonian crisis and dehydration. With the cut backs in emergency care causing delays, it is so important that we do all we can to facilitate our speedy treatment. I would like to take this time to wish everyone the very best of the New Year and hope all enjoyed the best of the blessed Christmas season. May we all enjoy happiness and good health in the year 2003!

Sincerely,
Joan Southam

Important Announcements:

- It's that time again – membership dues are payable. Please complete the membership form included at the back of the newsletter and mail your updated information and cheque Attention: John Gordon, Treasurer, Canadian Addison Society 193 Elgin Avenue West, Goderich, Ontario N7A 2E7
- The Canadian Addison Society Financial Statements are included at the end of the newsletter for your reference.
- Please let your endocrinologist know if you are willing to speak to medical students on Addison's Disease and it's symptoms. Feedback from one endocrinologist in Alberta feels that guest speakers are an important instructional tool as patients and their stories are remembered far greater than lectures in the long term. Francisca Swist of the CAS Alberta branch has been speaking to medical students the last five years – it's a great way to get the word out on Addison's. Way to make an impact Francisca!! It would be great if the individuals could make themselves available so that this information is relayed to all medical teaching facilities.
- Please note the following email change to contact Sharon Erickson, our newsletter editor – ericksons@shaw.ca - thank you.

New News:

- Check out this Corticosteroid Converter--- http://www.globalrph.com/corticocalc.htm

- Information presented on "The patient - consultant relationship" by Professor John Wass and Katherine White. Presented at Pituitary Foundation 4th Annual Conference, Hallam University, Sheffield - 23 November 2002

1. What makes a bad patient?
   - Don't turn up for appointments
   - Don't follow advice or instructions
   - Keep turning up like a bad penny
   - Are dishonest or misleading
   - Are moody, unpredictable, angry or upset
   - Can't be trusted

2. What makes a good patient?
   - Turn up on time
   - Follow medical advice
   - Take care of their health
   - Can be trusted
   - Give you clear, accurate information prepared beforehand
   - Polite and easy to deal with

3. It's hard to be a good patient when you are extremely ill
   - Exhaustion makes you: forgetful & cry easily
   - Continuing pain makes you: tired, irritable, and depressed
   - Not knowing what's wrong makes you: scared, angry

4. How a sick patient looks like a bad patient

- Forget appointments
- Get emotional
- Keep turning up like a bad penny
- Skip over symptoms
- Forget/misremember doctor's advice
- Appear untrustworthy

5. What can you do about it?

- Get organized in advance --- write down your symptoms & questions
- Find yourself 'somebody's Mum' --- take a friend with you to appointments
- Keep a record of your medical advice --- take notes during the appointment or consider taping it
- Address your emotions --- apologize or acknowledge when you are upset

6. What makes an endocrinologist a good communicator?

- Educate you about the condition --- the caregiver and the patient
- Train you in how to deal with emergencies --- the caregiver and the patient
- Ask the right questions
- Assess the patient's state of mind - as well as their physical condition
- Are accessible by phone or email

7. How can you help your endocrinologist to be a good communicator?

- Give them a list of your questions:
  - what you want to know about your medical condition & dealing with emergencies
  - further reading they would recommend
  - how to contact them with any queries between clinic appointments
- Tell them what you hope to gain from clinic appointments

8. How could most endocrinologists be better communicators?

- Write to their patient after each clinic (or copy the patient on their GP letter)
- Summarizing:
  - the symptoms/issues discussed & any test results
  - any therapeutic changes agreed (eg increase/decrease in medication)

9. Personal lessons learned

- Keep an appointments diary
- Keep a written record of all symptoms
- Use factual measurements ie: --- temperature, pulse, blood pressure, 1 - 10 scale for severity of symptoms over time
- Be prepared to cry

10. Tips from others

- If you have multiple conditions to manage --- Book a double appointment with your GP
- If you feel an appointment with your consultant went badly --- write to them expressing your concerns, or requesting further tests

11. Personal tips for health management

- Read as much up-to-date information on health topics as you can --- big strides in treatment and quality of life over past 10 years
- Ask your consultant's view of the material you have found
- Eat plenty of fruit and vegetables
- Drink plenty of water
- Walk everywhere you can

Highlights From Local Meetings:

Vancouver Island Support Group (Nanaimo)

Nanaimo meetings: Christy Lapi at clapi@shaw.ca, or 250-245-7554 or Barbara Hunn at bhunn@telus.net or 250-756-4385. Nanaimo meetings are held at Nanaimo Regional General Hospital, Room G245.

Vancouver Island Support Group (Victoria)

The Canadian Addison Society Vancouver Island Support group will meet on Sat, March 1, 2003 at Victoria General Hospital from 1:00 – 3:00 pm. The meeting will be held in Lecture Hall room S263 located directed across from the Information Desk near the front entrance. Endocrinologist Dr. Richard Phillips will be speaking at this meeting. 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.

BC Lower Mainland Support Group

Our next meeting will be Saturday, February 22, from 1:00 - 3:00 pm, in the Sherbrooke Lounge, 330 East Columbia, next to the Royal Columbian Hospital in New Westminster.

We are really excited about our guest speaker, who will be Dr. Michael Chung. Dr. Chung, Ph D. is a Pharmacist, as well as a practitioner of Chinese medicine--herbal and acupuncture, etc. Dr. Chung asked that those of us attending give him information about our conditions, the medications / supplements we are taking, as well as any other methods we have of dealing with our conditions prior to the meeting, so that he can be well-prepared to speak to us and help us. We are in the midst of compiling that information and sending it to him.

Those who attend and have not submitted information on their conditions will still learn so much, because, of course, most of our conditions are very similar. So we invite all members to make a special effort to attend this meeting.

Highlights from (BC Lower Mainland) October 2002 meeting -

- Review of changes to CAS recently.
- The latest issue of the CAS covered the AGM held in September, group updates and an excellent report on Dr. Killinger's talk to membership. The newsletter has grown to 14 pages from 4 pages in the original newsletter Fall of 1995. It is worth keeping for future references.

- Review of Judy's attendance at the CAS Victoria meeting with 14 members present. It was quite refreshing to see so many out. Jim now has the names of over 50 people on the Island that exceeds the ratio of 1 per 100,000 originally quoted to me when I was diagnosed in 1977. Several reported on using combinations of hydrocortisone or cortisone acetate along with Prednisone in order to take advantage of the differences in speed-of-effect and half-life; the idea being to even out their energy response. They are finding this helpful. Some people are also getting help from using 7-Keto DHEA instead of plain DHEA. Both these products are sold over-the-counter in the United States, though not in Canada. (Dosages in the States over the counter are not regulated and you can be receiving full dosage or a minimal amount - Judy)

- Judy's DHEA experience reviewed: She has been taking DHEA since January starting with 50 mg MWF. No side effects experienced until the end of June at which time she got acne in her hair. She switched to 25 mg MWF in August and the pharmacist at Kripps suggested she try 50 mg of Tin Oxide (stannic oxide) suggesting 3 or 4 a day if needed for acne. She has been using one pill 5 or 6 days a week and it seems to be working as she hasn't had any reaction since. She will be experimenting with less and see if it's just the cycle of the steroid or if I need that amount each week. Kripps Pharmacy is the only one in BC dispensing DHEA. Since taking DHEA, Judy reported she has lost 20 pounds and is no longer hungry all day.

- Reviewed letters in Addison News on long-term steroid use & update on prevalence of Addison's Disease.

- NADF included an update on the ENDO 2002 Conference in San Francisco. Also reminders to get yourself a Medic Alert; included an update on Fludrocort with the only difference to Florinef being listed as Fludrocort's inert ingredients.

- SHRA Bulletin received for Self Help groups - some reported that in emergency their Medic Alerts had not been noted or the information used.

- Penpals have been requested from: Myra Marnoch of Kamloops (a senior), from CAS a 25 year-old woman who had Cushing's disease, now has Addison's after surgery. Don McCaig (28) who lives in Vernon and has A Vascular Necrosis and wanted to know if anyone else has developed this from steroid use.

- Issue of flu shots? Hopefully you update yours as they are available now and one needs to be healthy to have the shot!

- E-mail received from the UK Addison's group who want to do a joint UK, Canada, Australia survey requested comments on survey information. Judy has responded with comments and expressed that meeting participants were interested in participating in the survey.

- Unable to secure a guest speaker for this meeting: Attempts to have paramedics attend were unsuccessful due to their shift schedules making it difficult to commit months in advance.

- Topics discussed by members were:

- The vitalness of taking medication in your flight baggage and carry on

- Questions were raised about carrying a syringe and injectable Solucortef. Jana went to demonstrate my Solucortef and discovered that the syringe I had did not contain a needle! The syringe was not sterile as it had seen much abuse in my purse from a trip out to Manitoba, through N. Dakota and down to Vancouver WA in the past year.
- Suggestion from Steve and Judy who have three children with Addisons: get one of the largest pill containers available, long enough to hold a syringe. Place a couple of syringes, needles, alcohol swabs and the solucortef. This way it can throw it in the glove compartment, a backpack, or whatever and everything stays nice and clean and dry. Also, everything is always together in one place so it can be grabbed on the go without worry whether or not we have everything.
- Interesting to note that the security guards at the airport didn't bat an eye at a handful of needles and vials of drugs, but they were quick to break the file off her nail clippers!

The next meeting is February 22, 2003 Sherbrooke Lounge, Sherbrooke Centre, 330 East Columbia St., New Westminster, BC from 1 - 3 p.m. There is on site parking for $2/hour.

The next meeting for CAS Lower Mainland after Feb 22 has also been confirmed for May 30, 2003 in the Sherbrooke Lounge, Sherbrooke Center, 330 E Columbia Street, New Westminster.

Saskatchewan Addison Support Group

If you wish information about this support group or upcoming meetings, contact Elizabeth Hill at Meadow Lake 306-236-5483 or Rob Zaleschuk at Caronport 306-756-2339

Southern Ontario Support Group

The Brantford Ontario meeting was opened at 1:30 by Lynda Daniels with a reminder that we all get our flu shots and to remember that our dues for 2003 memberships need to be paid.

Lynda then put forward the suggestion for future speakers from either the emergency department or from government to speak on applying for Canada Pension Plan Disability, (CPPD).

The subject for this meeting was osteoporosis, it's causes/prevention as well as how it relates to Addison's Disease. Our speaker was Terri L. Paul MD FRCPC, Endocrinology and Metabolism, University of Western Ontario, St Joseph's Health Care. Following are very important points from this presentation with her kind permission.

THE IMPACT OF OSTEOPOROSIS

- 1 in 4 women over the age of 50 have osteoporosis
- 1 in 8 men over the age of 50 have osteoporosis
- Osteoporosis costs $1.3 billion/year in Canada
- Over the next 25 years Canada will spend $32.5 billion treating osteoporotic fractures
- Of the 25,000 hip fractures per year in Canada, 70% are due to osteoporosis

RISK FACTORS FOR OSTEOPOROSIS

- female
- post menopause
- family history of osteoporosis
- limited exposure to sunlight or insufficient Vitamin D in your diet
- White or Eurasian
- alcohol (more than two drinks a day)
- age 50 or older
- prolonged sex hormone deficiencies i.e. ovaries removed or menopause before age 45
- not enough physical activity
- thin, "small-boned"
- smoker
- excess use of certain medications (cortisone, prednisone, anti-convulsants, thyroid hormone, aluminum containing antacids)*

FRACTURES AND QUALITY OF LIFE

Vertebral Fractures

- Pain
- Height loss
- Deformity (kyphosis, protruding abdomen)
- Low self-esteem
- Depression
- Fear of falling
- Decrease in survival rate

Hip Fractures

- Pain
- Increased number of hospitalizations/institutionalizations
- Decreased mobility and function
- Increased need for long term personal care
- Decrease in survival rate

TREATMENT OF OSTEOPOROSIS

Inhibitors of Bone Resorpton

(in alphabetical order)

- Bisphosphonates
  - Alendronate
  - Etidronate
  - Risedronate
- Calcitonin
  - Nasal
- Estrogen + progestin
- Selective estrogen receptor Modulators (SERMs)
  - Raioxifene

Stimulators of Bone Formation

- Cytokines and bone Peptides *
  - Fluoride *
  - Parathyroid hormone *
- Mixed mechanism of action
  - Vitamin D and metabolites
  - Anabolic steroids *
- Recommended for all women at risk for osteoporosis
  - Calcium (1200 – 1500mg) and Vitamin D (800 – 1000 IU)

*not approved osteo treatment in Canada

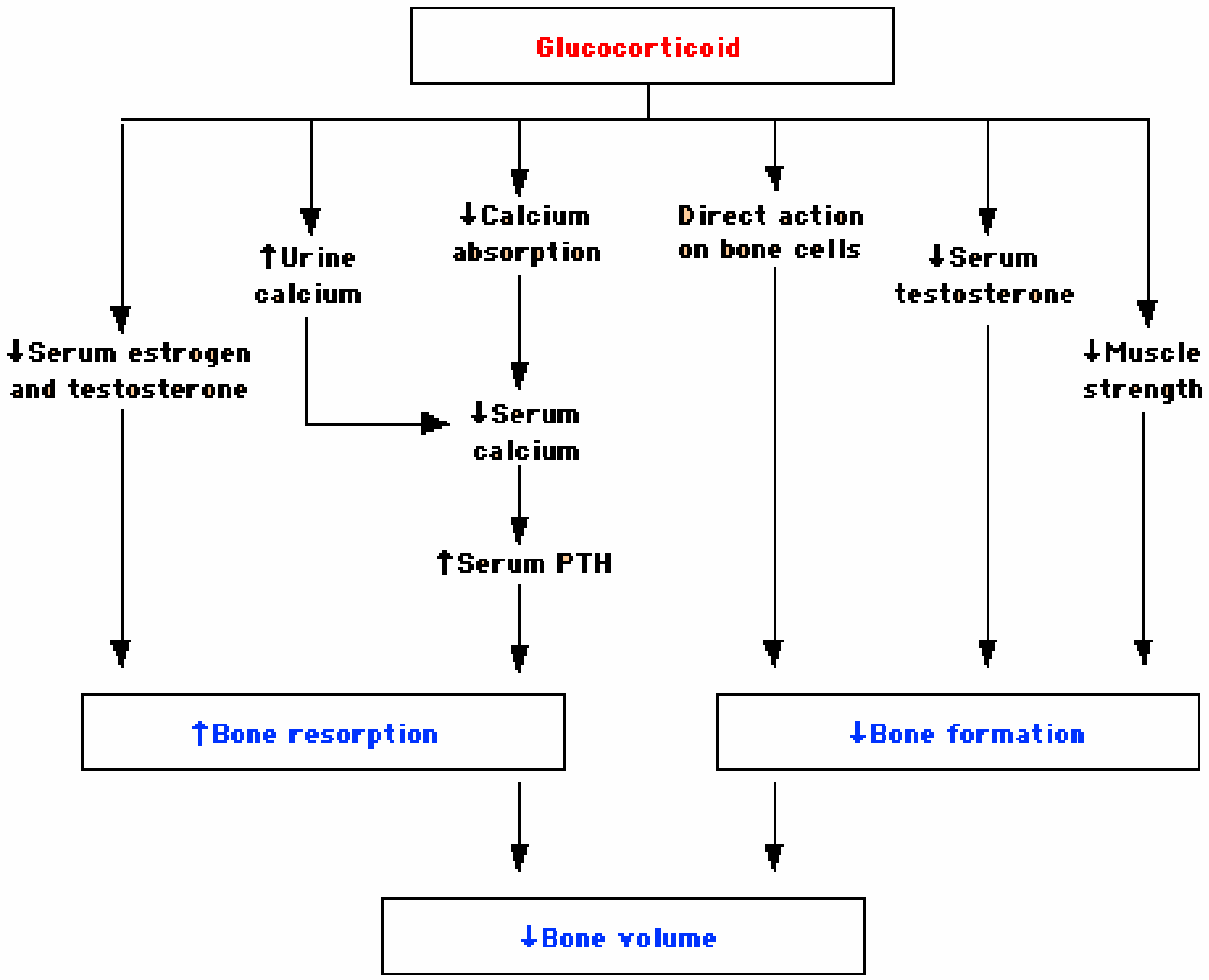
GLUCOCORTICOIDS

- Increase bone resorption and decrease bone formation, unlike other hormones that stimulate both but resorption > formation
- Leads to very rapid bone loss (within 6 months)
- One study showed that on a dose of 21 mg/day patients lost 27% of their lumbar spine bone mineral density in the first year

- Bone density gradually increases after therapy discontinued but reversal of osteoclast activity takes 6 months
- Decrease absorption of calcium from the gut
- Increase excretion of calcium from the kidneys
- Bone loss due to glucocorticoids is related to dose
- Low doses are safer than high doses

But is there any safe dose?

- Even replacement therapy in adrenal insufficiency can lead to decreased bone density
- Men receiving hydrocortisone at a dose of 16.4 mg/m^2 per day had a lower bone density. This is 1.6X the normal daily production rate suggesting they were slightly over treated.
- Studies show increased fracture risk in patients with Rheumatoid Arthritis who were treated with a mean dose of prednisone of 8 mg daily for 6 years
- Fracture risk ranging from 25 to 58%
- Saw an 8.2% decrease in lumbar spine density over 20 weeks in patients on low dose prednisone (<10 mg/day)
- Low doses of glucocorticoids (5 to 9 mg prednisone daily) may have an adverse effect on skeleton
- Very low doses (1 to 4 mg daily) probably have little effect?
- Alternate day therapy may not be protective of bone

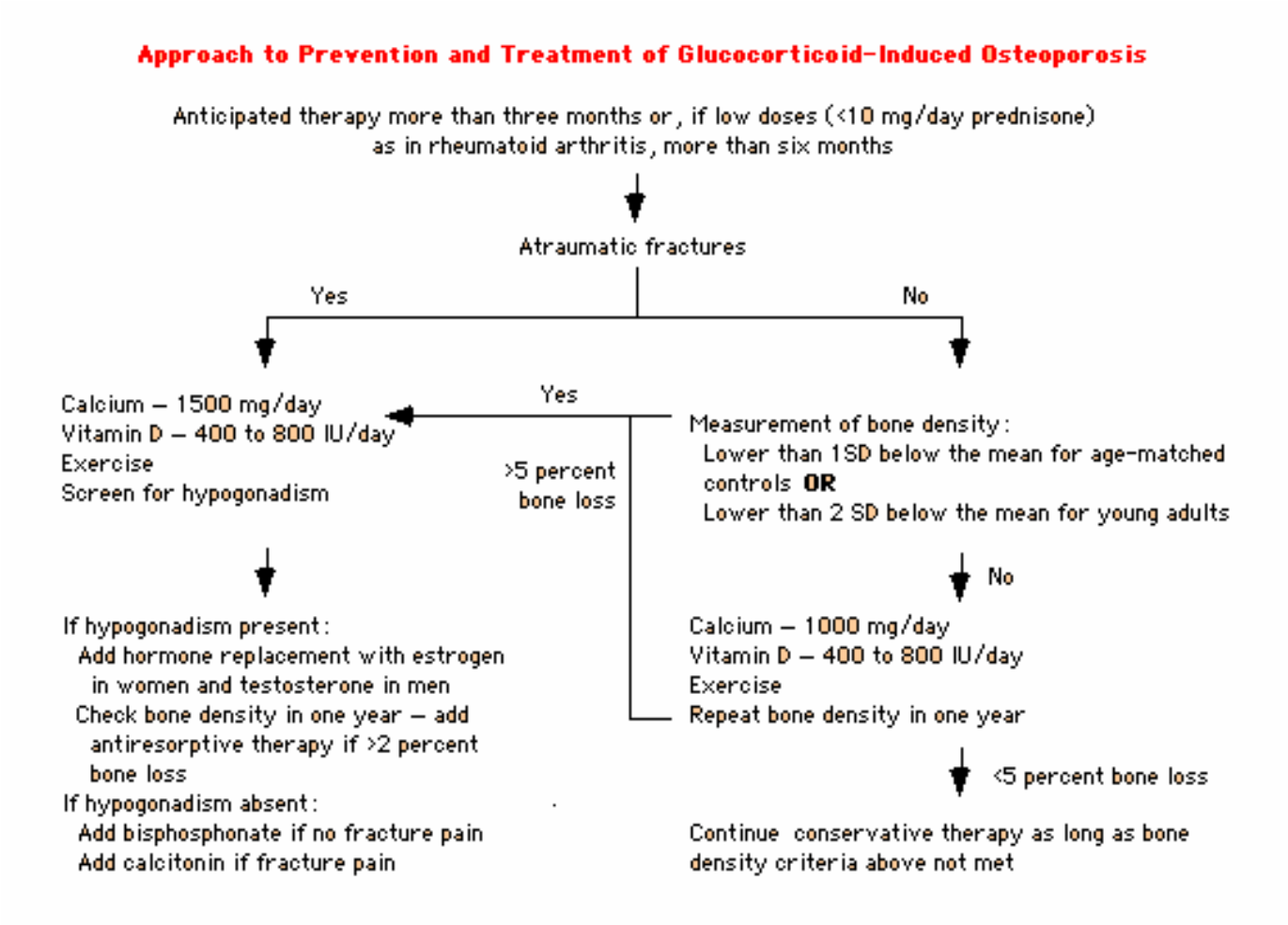


PREVENTION AND TREATMENT

- Calcium and vitamin D
- Exercise
- HRT if early menopause until the usual age of menopause age 51
- Anti-resorptive therapy: alendronate, risedronate, palmidronate, calcitonin
- Stimulation of bone formation: PTH

RECOMMENDATIONS

- Glucocorticoid dose should be as low as possible
- Do weight bearing exercises for at least 30 minutes every day
- Avoid smoking and excess alcohol
- Take measures to prevent falls
- Bone mineral density should be measured as baseline and followed especially at menopause
- Calcium and vitamin D supplements
- Bisphosphonate therapy if needed
- Calcitonin if bisphosphonates not tolerated
- Since glucocorticoids cause excretion of calcium in the urine, measuring 24 hr urine can indicate if treatment with a thiazide diuretic plus salt restriction may be of benefit



At the close of the meeting, we enjoyed coffee and a light snack, which was arranged by Lois Bleth and Ruth Ann Kruger. Thank you goes out to everyone who contributed to this treat.

Alberta Support Group

For information on this support group or for upcoming meetings, please contact Francisca Swist at francisca@shaw.ca or Ginny LaValley at 780-454-3866 – both are from Edmonton.

Eastern Ontario Support Group

The meeting of the Eastern Ontario Addison's group was held on Saturday October 19th at Robbies Restaurant in Ottawa. There were fourteen members and guests in attendance.

Dr Ooi was our guest speaker who is an endocrinologist at the Ottawa Hospital and a Professor at the University of Ottawa. He spoke to the group about emergency care, medication, emergency medicine and the consolidation of the endocrinology department to the Riverside Campus of the Ottawa Hospital. It was interesting to learn that the consolidation of the endocrinology department to the Riverside Campus will be made by 2004. Dr Ooi asked for input from the group on how to better serve patients of this department. Dr Ooi was quite concerned about emergency care of Addison patients and he suggested that we should all be very aware of our own needs. The Ottawa Hospital is hoping to put together a protocol for the care of Addison patients. In the meantime we should be sure to take our medical history and medication with us to all emergency visits as well as stressing to attending staff our immediate needs. The importance of wearing a Medic Alert bracelet was also highlighted. THEY DO SAVE LIVES.

The issue of diverse medication for Addison patients was discussed and Dr Ooi pointed out how very important it is to our own well-being to address the dosage and timing of the various drugs. We must know the signs and adjust to find the most appropriate times to take them. The length of time and when your medication peaks is very important for you as an individual. You must learn to listen to your body, if you feel unwell take extra medication and include lots of fluids. Do not allow yourself to become dehydrated.

The group enjoyed their time with Dr Ooi and were appreciative of the time he took from his busy schedule to be with us.

Beginning in January 2003 Susan Steadman (tel number 613-726-7414) will take over from Elaine Hall as the Eastern Ontario representative while Elaine devotes her time to her duties as the Canadian Addison Society liaison secretary.

Quebec Support Group

No date has been set for the next meeting.

If you would like information about upcoming Quebec meetings or more information, please contact Sophie Lapointe at 514-521-6538 or e-mail sophiel@sympatico.ca

Letter to the Editor:

This information was sent to Joan Southam, and we feel it will be of interest to all our members and their families. To set the stage for this information, you should be aware that pregnenolone is a steroid hormone produced by many organs in the body, one of these organs being the adrenal glands. It is also produced in the liver and the testicles or ovaries and the skin.

There is a movie made called Lorenzo's Oil, which you may find interesting to watch because it documents how Adrenomyeloneuropathy or AMN manifests itself in children. If the disease presents in adulthood, the outcome is quite different and it can mimic Addison's Disease.

The following letter is from: Michael Greenberg - December 22/02

A few things have happened over the past year that may be of assistance to the group. You had a gentleman email me to ask a few questions about pregnenolone. Well, he had recommended an endocrinologist to whom I eventually went. Nothing came of that visit except, when I mentioned my balance problem, he referred me to a neurologist. The neurologist put me through many neurological tests including a brain MRI. Nothing remarkable was apparent.

My wife, my sister and I put our collective heads together and we searched 'the web' and came up with an X-lined genetic condition which not only included adrenal insufficiency, but addressed my balance, impotence, fatigue, cataracts, and some mental confusion. We suggested to the doctor that he do a very long chain fatty acid test. It came back in the very high range, which confirmed the condition (in an affected male). (The females are carriers.) The condition is called Adrenoleukodystrophy or ALD and if it manifests itself in the third decade, it is the less severe Adrenomyeloneuropathy or AMN.

One website devoted to all leukodystrophies is the United Leukodystrophy Foundation www.ulf.org. The condition occurs with the inability to metabolize these very long chain fatty acids, which are synthesized by the body (normally metabolized in the peoxisomes). These fatty acids build up in the adrenal glands, the testes and the myelin sheath of the spine and the cortex of the brain, causing dysfunction and in many cases, death. It is fatal up to the teenage years. Lorenzo's oil was an attempt by parents of and ALD boy to save his life.

The reason that I pass this along to you is that, because it is a genetic condition, those male addisonians may wish to be tested to see if they have this gene and may therefore make decisions as to having children. Female carriers generally do not suffer from adrenal insufficiency but the way the disease presents itself is extremely variable in both the affected males and the female carriers. There is genetic testing that can be done. The blood test for very long chain fatty acids is less reliable for the female carriers. This test may be done on the male fetus to determine if he has the condition. The earlier it is detected and 'treated' (it cannot really be treated) the less damage to the spinal cord and brain.

Your friend, always...in health

Michael Greenberg, Jntmchl@aol.com

"We all know that water is important, 75% of Americans are chronically dehydrated. (Likely applies to half the world population). In 37% of Americans, the thirst mechanism is so weak that it is often mistaken for hunger. Even mild dehydration will slow down one's metabolism as much as 3%. One glass of water shut down midnight hunger pangs for almost 100% of dieters studied in a University of Washington study. Lack of water is the #1 trigger of daytime fatigue. Preliminary research indicates that 8-10 glasses of water a day could significantly ease back and joint pain for up to 80% of sufferers. A mere 2% drop in body water can trigger fuzzy short-term memory, trouble with basic math and difficulty focusing on the computer screen or on a printed page. Drinking 5 glasses of water daily decreases the risk of colon cancer by 45% plus it can slash the risk of breast cancer by 79% and one is 50% less likely to develop bladder cancer. Are you drinking the amount of water you should every day?"

We would like to hear from you re:

Florinef – Have you noticed any changes since this prescription changed last spring? (from previous pink to the current white pill formulation.) We're interested in any comments you may have, as well as if you are having any problems. If you are experiencing problems, you may wish to contact Shire Biochem Inc., 275 Armand-Frappier Blvd., Laval Quebec H7V 4A7 or call toll free 1-800-397-4473. For medical information call toll free 1-800-268-2772.

Reminders:

- Medical Questions and Answers - Dr. Donald Killinger, MD, Phd, FRCPC, 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/e-mail or fax through The Canadian Addison Society and they will be forwarded on to Dr. Killinger.
- We would like to remind you that The Canadian Addison Society will gratefully accept donations of Canadian Tire Money. If you can spare this form of donation to help alleviate the various cost of running the organization it would be most appreciated by all.
- Please – 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.
- 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.

This is your newsletter! We need your contributions. Please send your stories, tips, ideas c/o our editor Sharon Erickson via email: ericksons@shaw.ca

The Canadian Addison Society
La Société Canadienne d'Addison

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Website: http://members.rogers.com/jsoutham

New Membership Renewed Membership

*Name:*_____

*Address:*_____

_____

Postal Code: _____ *Telephone:*_____

*E-mail Address:*_____*Fax:*_____

*If you DO NOT want your name to be made available to other Addisonians in your area please sign here*_____

The yearly fee for the Canadian Addison Society is $25.00 due January 1

You also have the choice of directing $5.00 of the annual fee to an approved local support group of your choice. Please check box of your choice.

( ) $25.00 to go to the Canadian Addison Society

OR

( ) $5.00 to Montreal Support Group – Quebec +$20.00 to Society

( ) $5.00 to Ottawa Valley Support Group –Ontario + $20.00 to Society

( ) $5.00 to Brantford and District Support Group – Ontario + $20.00 to Society

( ) $5.00 to the Edmonton Support Group – Alberta + $20.00 to Society

( ) $5.00 to New Westminster Vancouver Group – British Columbia +$20.00 to Society

( ) $5.00 to Vancouver Island Support Group – British Columbia + $20.00 to Society

Please make cheque or money order payable to the Canadian Addison Society and send: c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7