



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

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PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison management program.

Annual General Meeting:

The 2012 Annual General Meeting will be held Saturday, October 13, 2012 in Victoria B.C., at the Victoria General Hospital in Room 1814 near the Cafeteria, one floor down from the main entrance. Registration will start at 12:30 and the meeting will run from 1:00 to 4:30

Dr. Priya Manjoo, a Victoria endocrinologist, has agreed to speak to the AGM.

Agenda:

- 1) Registration
- 2) President's Report
- 3) Minutes of the 2011 AGM
- 4) Election of New Board Members (if required)
- 5) Financial Report
- 6) Membership Update
- 7) Director's Reports
- 8) New Business
- 9) Speaker - Dr. Priya Manjoo, Endocrinologist

If you expect to attend the meeting from out of town and need billeting, please contact Jim Sadlish who will try to arrange it. As well, Derek and Lisa are once again kindly inviting visiting members to their home for dinner an evening before or after the AGM. If you are planning to come to Victoria for the meeting, please let Jim Sadlish know which evening would better suit you.

We're Now on CanadaHelps.org:

Making on-line Donations to The Canadian Addison Society

The Canadian Addison Society is now registered with the [Canada Helps Organization](http://CanadaHelps.org) to allow for on-line **donations or memorial donations ONLY**. [CanadaHelps](http://CanadaHelps.org) provides a central donation site for a large number of charities. Some of you may well be familiar with it already.

- Tax receipts will be sent in .pdf format, directly to the donor from [CanadaHelps](http://CanadaHelps.org). They will not be sent by The Canadian Addison Society, although they do clearly indicate on them that the donation was to The Canadian Addison Society.
- Only credit cards can be used to make donations, cheques are not accepted. If one wishes to send cheques, they will be processed as they have been for years. Cheques must be mailed directly to The Canadian Addison Society at which point, we will issue the tax receipt and the receipt will be sent to the donor by regular mail.
- The donor's credit card will be charged by CanadaHelps for the donation.
- The funds received from donations made through CanadaHelps will be forwarded to The Canadian Addison Society, once a week, by CanadaHelps, at a cost to the organization of 3.9% per donation.
- When the funds are received by The Canadian Addison Society, they will be recorded as non-tax receipted income because tax receipts would already have been provided to the donor by CanadaHelps.

IMPORTANT: Membership Fees or membership renewals cannot be processed through CanadaHelps, as they are not tax deductible. However, we are looking at other options to allow for on-line membership and renewals. More on this in the future.

The following Q and A will give you additional information about the process:

Donating

How do I make a donation?

Click on the "Donate Now through CanadaHelps.org" button at the right of our home page and you will be taken to The Canadian Addison Society Charity Profile page. To complete your donation, enter your donation details, add it to your "Giving Basket" and then pay for the gift.

What payment methods does [CanadaHelps](#) accept?

CanadaHelps accepts donations by credit card, including Visa, Mastercard and Amex, and by Interac Online.

I don't want to donate online, can I send a cheque to CanadaHelps?

No. CanadaHelps accepts donations made online through their secure website only. To donate by cheque, please send the donation directly to Canadian Addison Society, 193 Elgin Avenue West, Goderich ON N7A 2E7.

Can I request that my donation be used in a particular way?

Yes, include a message or instruction with your donation that will be received by the Canadian Addison Society.

Can I designate my donation in honour or in memory of someone?

Yes. You can designate all donations in honour or in memory of someone.

Can I have CanadaHelps send a card to my honouree or to the family of the person who has passed away?

CanadaHelps offers free ecards for any donation you make in honour or in memory of someone. Ecards are available for any occasion, including birthdays, weddings, sympathy, Christmas, Hanukah and more. You can request that The Canadian Addison Society send a hard-copy postal card or note to your designated honouree or memorial contact, and CanadaHelps will pass this request on to them. The onus is on the Society to fulfill your request for a postal card.

How much money gets sent to my charity?

CanadaHelps assesses a 3.9% transaction fee on donations before EFT disbursement.

When does the charity get my donation? How?

CanadaHelps sends a weekly disbursement to charities that have registered to receive donations by direct deposit. Donations made from Sunday to Saturday are disbursed the following Friday.

Can I cancel my donation?

No. Donations are non-refundable according to the [Canada Revenue Agency](#). Charitable tax receipts are issued in real time, and because they are in digital format, we cannot ask that the file be returned. You cannot change your mind once you've made a charitable donation.

Receipting**How do I get my receipt?**

Tax receipts can be downloaded once a donation is completed and are sent by email immediately following the payment of your donation(s). Please check your email following the donation and be sure to check your junk/spam folder in case the message has been diverted

by your email client. If you have a MyCanadaHelps account, all donations and all receipts are stored online for you to be downloaded and printed at any time.

Is my receipt valid for tax credits?

Yes. CanadaHelps uses secure PDFs for tax receipting. Electronic receipts are valid for tax filing by the CRA.

I live in Quebec and am required to have three copies of my tax receipt. What do I do?

Please print your PDF receipt three times.

I've lost my charitable receipt(s). How can I be reissued my tax receipts?

Please contact CanadaHelps at: www.canadahelps.org/info/4/30/ss, with your name, and approximate date of donation. We'll resend you your tax receipt by email.

What information must be on a tax receipt?

Tax receipts must contain the name and address of the payee of the gift as well as details about CanadaHelps, including our address, charitable business number and official signature. Official tax receipts also need to have the Canada Revenue Agency website on them.

Why can't I have tax receipts issued in someone else's name?

Receipts can only be issued to the payee of a donation. The donor/payee of a donation makes the cash donation to charity and therefore qualifies for the tax credit. For more information about how Canadian charities must issue tax receipts, please visit www.cra-arc.gc.ca/tx/chrts/plcy/cpc/cpc-010-eng.html.

If you would like to dedicate your gift, you can make a donation in honour of someone, or give them a [Charity Gift Card](#) – but only the donor or payee can receive the tax receipt.

Privacy

Why does CanadaHelps collect my email address?

Your email address is used as a login for future donations and is how CanadaHelps issues your tax receipt and will communicate with you about donation details. As an online entity, CanadaHelps does not mail donors newsletters or receipts.

What information is collected and what information is passed onto the Canadian Addison Society?

CanadaHelps collects your email address, name, and address and payment details. CanadaHelps passes only the information you want to pass on to the charities you give to; you can give the charities your name only, name and email, all contact information, or make your donation anonymously to the charities you donate to.

Do CanadaHelps sell/trade donor information?

No. CanadaHelps does not share donor information with any third parties. Please read the [privacy and security policy](#) for more information.

News and Announcements:

- We regret to advise you that former member Lynda Daniels has passed away from heart failure due to sepsis. Our thoughts go out to her husband, Skip, and her family.

Personal Experiences:

As I type this, I cannot help but find myself tearing up reading all of the articles. I always hear how strange this disease is, and at times find myself having to explain to the nurse what Addison's disease is, or how to spell Florinef, because they haven't heard of that, but I get sad at the thought of so many others suffering from this disease. My story started when I was 14. It was a very hot summer and I spent most of the time outside riding my bike or playing with my friends, - well, until I would get tired and go inside to rest. I got a terrible tan that year, or so my mom thought. I was extremely dark but still fairly healthy. I soon started with an insatiable appetite yet I was losing weight, nausea, dizzy, weak and just getting more and more dark. My mom is Hispanic and my dad Anglo so I thought it was just my colour. I quickly became very ill and ended up in the hospital for 4 weeks. They had no idea what was wrong with me. When they finally figured it out, the doctor's came to my room to share the "great" news with me: I had Addison's disease and would start feeling better soon, that is after taking the 14 pills I had to take a day. To help me feel better, the doctor's told me that John F. Kennedy had this disease, to which I responded "and he's dead!". I was being difficult and feeling confused. Seeing my parents agonize day in and day out without being able to help me was difficult to watch. Well, that is how my story began. I learned, however, that a "normal" life is possible with Addison's disease, you just need to listen to your body. If you are tired, rest. Sleepy, then take a nap. I try to take my Florinef and hydrocortisone at the same time each day. I am a mom of a 15-year-old healthy daughter and healthy twin boys who are now 10. I had to see a fertility specialist to help me get pregnant. My biggest issue is completely cosmetic: I hide from the sun so I won't get darker, I have some spots on my lips that I cover with a lip tint (works great) and my dentist is the only one who looks inside my mouth closely enough to notice the dark spots. I am constantly getting compliments on my great skin color. If they only knew! For now, I'll keep that little secret all to myself! I have been a successful businesswoman for 25 years now, rarely miss work due to being ill and enjoy a full and complete life. Addison's disease is a disease I have but certainly not what defines me. Don't let it define YOU! Good luck and stay healthy!

Submitted Anne in San Antonio

Highlights from Local Meetings:

Vancouver Island Support Group - Victoria

The Victoria support group met at the Victoria General Hospital on Saturday, June 2. Twelve attended including 4 spouses, one driving from Qualicum. Discussion was lively, touching on a wide range of medical issues.

A new member went undiagnosed for years, even though her symptoms were classic for Addison's. Her family doctor at the time was very reluctant to refer her to an endocrinologist or any specialist. She had unexplained darkened skin, was weak with low blood pressure and low blood glucose and previously had thyroiditis. Experiencing long-term stress was another factor, but the most notable was that her sister has Addison's. She has now changed doctors. Balancing thyroid replacement has been tricky, as too much results in a racing heart rate and too little affects her memory.

Does strenuous exercise require extra cortisol replacement? Several members have experienced exhaustion during a rigorous workout. Some references suggest taking a small amount of extra cortisol replacement beforehand, if you know you will be really pushing yourself. See item 16 at - <http://www.nadf.us/diseases/addisonsqa.htm> and Exercise/Sports at - <http://www.addisonsociety.ca/related/FAQApril2011.pdf>

Rehydration is important for us during exercise or in hot weather. Some members purchase electrolytes formulated to add to water for a rehydration drink. Others make up their own drink using recipes on the web and at <http://www.addisonsociety.ca/tips.html>. Several people will drink club soda in hot weather, as some brands have sodium (note - some are sodium free) with a very small amount of potassium. One woman, visiting Mexico, became dehydrated when she caught an intestinal bug. Not able to keep down her medication or get up, her husband got her to a hospital Emergency. The doctor there put her on intravenous saline, which helped. He gave her husband a prescription for Solu-Cortef which he purchased at a pharmacy. The doctor gave his wife this injection after she's had been administered 2 bags of saline. It's always a good idea to take our emergency medication and syringes when travelling.

DHEA was made up by a compounding pharmacy from a prescription for one person and ordered in by a PharmaSave store for another member with a prescription. It has greatly improved the quality of life for some individuals although there can be side effects, such as greasy hair, scalp pimples and unwanted hair growth. Reducing or spacing doses may lessen these unwanted effects and still give the benefits.

Medical replacement is tailored for each of us. Medications, dosages, and schedules seem to be different in every case. Endocrinologists are continually adjusting and fine-tuning these variables to improve treatment for members. A woman has slightly increased her dexamethasone dose, eliminated a previous, small prednisone top-up, and reduced her thyroid replacement. She monitors her blood sugar and keeps her carb consumption down. Another, who takes 2 kinds of insulin (long and short acting), has increased her Cortef a bit, to temporarily deal with the stress of a family medical problem. One member is prescribed additional Vitamin D3 for low bone density and now is given B12 shots each month. Another woman takes Cortef three times during the day and Florinef at noon. Swelling ankles and puffy eyes in the morning for a woman improved when her endocrinologist halved her Florinef dose. Another's blood pressure was so low her doctor increased her Florinef by half.

Several people find dental work stressful, with one remaining unwell for a week afterwards possibly due to cold symptoms, and another always taking extra Cortef beforehand. One member requests freezing without epinephrine, used by dentists to slow absorption, prolonging the action of the anaesthetic. She manages the dental work much better without the epinephrine.

Weather seems to affect one woman's energy level. On dark, gloomy days she has little energy, but feels more vigorous on sunny days. Another wakes up not knowing how dark or light her skin will be on rising. Her skin colour has been different for every support group meeting she attends. It varies from day to day, possibly depending on ACTH levels and the cortisol replacement levels in her body. One member has developed a large dark patch of a different texture on her abdomen which a dermatologist classified as hyperpigmentation. It does not diminish with extra replacement. She also suffers from a burning feet sensation, especially at night.

The Canadian Addison Society AGM will be held at Victoria General Hospital on Saturday, October 13, in Room 1814 next to the Cafeteria. The meeting will run from 1:00 until 4:00 PM. Refreshments will be available about 2:30 including beverages, buns, veggies, meats and cheeses, etc. Cookies, squares or loaves would be gratefully appreciated. The search for a speaker is ongoing, with several avenues yet to explore. The speaker's address is scheduled for 3:00.

Submitted by Jim Sadlish

For further information on the Vancouver Island Support Group, contact Jim Sadlish at vanisleaddisons@gmail.com or (250) 656-6270.

Vancouver Island Support Group - Nanaimo

The Nanaimo support group met Saturday, May 26 at the Chase River Boys and Girls Club. Eight people attended, 4 with Addisons, 2 driving from Port Alberni and 2 from Sidney. The clubhouse was kindly made available for our support group by the Area Co-ordinator the Boys and Girls Club of Central Vancouver Island, who is the aunt of a young Nanaimo member with Addison's. This is the first Nanaimo meeting in a long while and a sincere attempt to establish a regular schedule for future meetings.

Each member introduced themselves and related their medical histories leading up to diagnosis and how their treatment has evolved since diagnosis. Several people have multiple disorders to contend with, some cases are quite extraordinary.

A woman with many present health concerns was first aware of being severely ill when feeling nauseous in the heat of an Arizona vacation. She immediately returned with her husband to Canada where she was ultimately diagnosed with Addison's. She does not take Florinef because it causes her arms and feet to swell. Her Cortef dose is 10mg with breakfast and 15mg in the evening. Other health concerns for her are low blood sugar, low potassium,

stress, hypopituitary function, osteoporosis, possible celiac disease and night sweats. She has also contended with many major surgeries. Over the last year, her health situation has improved because she has learned which symptoms to watch for and when to take extra medication to avoid a crisis. She has found the U.K. Addison's Disease Self Help Owner's Manual quite useful (<http://www.addisonsociety.ca/linksresources.html>). Her doctors want to reduce her Cortef dose, but she has found for her well-being she needs to maintain her current level plus take extra with stress. In multi-generation family events, she uses a muscle relaxant to help with stress. For potassium, she was advised by an acquaintance to try a sports drink called eLoad, however, another member cautioned that some sports drinks have high sugar and caffeine content. A re-hydration drink recipe can be found at <http://www.addisonsociety.ca/tips.html>.

Another woman who has lived with Addison's for many years has now been diagnosed with hypothyroidism and is taking Synthroid. She takes Prednisone just once a day with breakfast. Now, hypertension is also a concern. Interestingly, her son has Addison's, which was diagnosed following the stress of multiple surgeries when he was a young man.

After a holiday from a very stressful job in Vancouver, a founding member of the support group noticed that she was getting rather dark and losing weight. Her family doctor agreed that something was not right. Her internist concurred and luckily he had recently diagnosed another patient with Addison's. Tests confirmed that diagnosis and with a new regime of replacement medications, she started back to work almost immediately. The stress of work set her back very quickly. She decided to move to Vancouver Island to a job near her new residence, so she could take a reprieve from her work when necessary. Her last crisis was from overwork in the garden, getting heat stroke. She now takes care to drink lots of water in hot weather. Her medications are cortisone acetate taken in the morning and sometimes, when needed, in the afternoon, plus Florinef and thyroid replacement. She will consider getting a prescription for the Solu-Cortef injection for emergencies and arranging an appointment with the new Nanaimo endocrinologist, Dr. Guzder.

A man was eventually diagnosed with adrenal insufficiency when his kidneys failed and his blood pressure was very low. The nephrologist recalled the darkened skin and salt craving symptoms from his medical training. Various specialists had previously declared him in normal health. Energy returned after his first dose of replacement medication.

A mother who arranged the Nanaimo meeting place has a teenage daughter with the very rare condition, Schmidt's syndrome, autoimmune polyglandular Type 2. Unfortunately, at the time of the meeting, her daughter was in the hospital with stomach pains and text messages were being received with reports of her condition and test results while we met. At age 9, she was diagnosed with Type 1 diabetes; at age 12, hypothyroidism; and then Addison's at 13. Prior to her Addison's diagnosis, she was nauseous for 30 days and required an insulin pump to keep her blood sugar under control. They made 22 visits to the ER in one month. She could not keep food down, bringing up dark bile with the nausea. Doctors could not determine the cause and eventually suggested she see a psychiatrist. Her mother rejected that idea, knowing her daughter was severely medically ill. In crisis, she again went to Emergency with

very low blood pressure, so low that it took 4 attempts to insert an intravenous needle. By a lucky chance, the pediatrician who had diagnosed her diabetes requested blood tests for her adrenals and she was diagnosed with Schmidt's syndrome. Once on adrenal replacement meds, she was given spoonfuls of PediaSure (like Ensure for kids) for nourishment before eating solid food was possible.

This young Addisonian has a daily replacement of 15mg of Cortef, 5mg every 8 hours, 0.1mg of Florinef in the morning and .05mg at bedtime. Since her blood sugar readings are quite variable, she has been prescribed birth control pills which give her the necessary hormones to keep her blood sugar readings in a consistently acceptable range. She checks her long-term average blood sugar levels with an A1C Test every 3 months (<http://www.healthlinkbc.ca/kb/content/medicaltest/hw8432.html>). Her Vancouver endocrinologist, Dr. Sue Stock, has been exceptionally helpful keeping in touch throughout hospital emergencies and determining safe combinations for her various replacement medications.

The next meeting in Nanaimo will be held at the Chase River Boys and Girls Club on October 20, 2012. For information on Central Island activities, contact Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

Eleven members were present at our May 26, 2012 meeting. Members introduced themselves and welcomed new members, a spouse and a parent. Everyone gave a short recap of their diagnosis.

- Thanks to everyone for providing such a wonderful variety of appetizers and finger food. We all enjoyed getting together to chat, listen to recent travel experiences and updates on rehydration and documents to carry when travelling. Rehydration: 1 L water, add ¼ tsp. salt and 1 T sugar, you can add a bit of lemon or other juice to flavour.
- I had several queries about finding a new GP or endocrinologist; I replied with information on endocrinologists in our immediate vicinity. One member was able to find a new doctor after hers retired but was accepted by special request. I have sent an email enquiring if this is a national problem or particular to BC. For those looking for a physician in BC go to <https://www.cpsbc.ca/> College of Physicians and Surgeons and look under 'Find a Family Physician'.
- Members are still experiencing delays in being diagnosed. We did send brochures to all endocrinologists in BC in 2006 but will follow up with information sheets to Internal Medicine as well. There are 977 in BC. I have contacted the College and will research an update for endocrinologists and Doctors of internal medicine to mail information to.
- A mail out for brochure holders and information was done by Central/Southern Ontario Group and will be reported on at the AGM.

- Moh's husband was travelling in Europe and went into hospital cutting short his trip. INTERESTING NOTE: she had the number for the hospital, but when she tried to phone, the receptionists did not speak English and there was no one around who did. Her daughter suggested she use the Google translator to help her. It worked fabulously!!! She simply typed in her script and had it translated to Hungarian. Then she called the hospital in Budapest. When the receptionist answered she held the phone to the computer speaker, clicked on the audio button, and the computer spoke her message for her!!! Without saying a word, the receptionist connected her to the nurse's station. When she gave his name, the nurse walked the phone down to him, and voila! Easy as anything—"Gotta love technology". Other members mentioned Smart Phone can be used with a translator app.
- For those looking for a way to have a dose of medication where you or spouse can always find it in a hurry, one member has it in a small pill container that is on her key chain. She purchased hers at Shoppers.
- One member had her first Addisonian crisis in 30 years with no advance warning other than throwing up a couple of times which she attributed to food poisoning. She has just got home from a very scary 2-week stay in hospital with apparently severe Addisonian crisis. Her brain just turned off, BP bottomed out, etc. She gave everybody in her family an awful scare. It came on very suddenly. She had worked that day, came home and her husband took her to hospital around 8 pm. After that, there are many blanks but she mentioned hallucinations and paranoia. Another member had her first crisis in 27 years with almost identical onset with the throwing up, hospital stay, etc. Both experienced kidneys failing. As well, another member reported that she has follow up for her kidneys as well.
- Check with your doctor about getting the shingles vaccine. Anyone who previously had chickenpox, which lies dormant in your body, is more susceptible to getting it. You will have to order in advance as it took three months for a member to receive the prescription.
- A query about Florinef from a member - it was noted that Costco was not putting 'Keep in Refrigerator' when filling their prescription. I had noticed this as well. I called Costco who called the distributor: Florinef does need to be refrigerated and it will be noted on their computer screen. If you notice any discrepancy with any of your refills, please ask the pharmacist. You can also enquire at Medical & Scientific Information 1-888-550-6060 who will return your call and answer any of your questions regarding medications.
- Available at the meeting were membership forms, also on line at <http://www.addisonsociety.ca/>, Society information pamphlets for doctors' offices, *Safe Food Handling for People with Weakened Immune Systems*; the *Advance Care Planning Guide* explained by our last guest speaker; and Moh was able to obtain the plastic Green

Sleeve for your fridge to keep your current medical information in. Any extra booklets etc will be taken to the AGM in October or available at our next meeting.

- The AGM is October 13, 2012 in Victoria. Moh and I will be attending and staying in a B&B in downtown Victoria. Anyone interested in going please let us know. B&B/hotel booklets are available from BCAA - free for members.

Our guest speaker was Shelley Abercromby, Prohealth Clinic Research. Shelley has a B.Sc., majoring in cell and molecular biology. She has conducted molecular research on biological pathways in western red cedar trees, worked as a research technician performing microbial testing on pharmaceutical products and as a clinical trials assistant at the BC Cancer Research Centre. Currently, she is a study coordinator for Osteoporosis Research at the Prohealth Clinical Research Centre. She became interested in Addison's after a friend was diagnosed with Addison's.

A short informative video gave us an insight on osteoblasts (digger cells) which create holes in bone and remove old bone prior to rebuilding; and osteoclasts which increase bone density, some inside and some outside bone. As you age, 'diggers' remove bone faster than 'builders' can replace it and glucocorticoids can increase signalling which activates the 'digger' cells. This leads to increased bone weakening, which is difficult to reverse. This was quite fascinating and can be seen at <http://www.youtube.com/watch?v=IDrHHXzSN6U>. Long term use of steroids deplete bone density and can also the result in secondary adrenal insufficiency and osteoporosis

What is glucocorticoid therapy?

- anti-inflammatory and autoimmunesuppressive properties
- commonly used to treat a variety of chronic inflammatory conditions such as:
 - o giant cell arteritis
 - o polymyalgia rheumatica
 - o rheumatoid arthritis
 - o asthma
 - o chronic obstructive pulmonary disease (COPD)
 - o dermatological conditions

Common glucocorticoids

- prednisone
- hydrocortisone
- cortisone
- dexamethasone
- methylprednisolone
- triamcinolone
- betamethasone
- prednisolone

Glucocorticoid therapy risks

- decreased intestinal calcium absorption
- increased calcium secretion in urine
- secondary hyperparathyroidism
- decreased gender hormone levels
- increased resorption and impairment of bone formation
- increased RANKL
- increased osteoprotegerin expression

What is glucocorticoid-induced osteoporosis?

- significant side effect of the therapy
- decreased bone formation due to osteoblast inhibition
- increased osteoclast-mediated bone resorption
- rapid bone loss occurs during the first 6 to 12 months of glucocorticoid treatment
- fracture risk is increased in a dose/duration dependent fashion with oral glucocorticoid use

WHO FRAX risk factors estimate 10-year risk of fracture

<http://www.shef.ac.uk/FRAX/tool.jsp?country=19>

Age (50-90), sex and clinical risk factors

- BMI/DXA
- Prior fragility fracture
- Parental history of hip fracture
- Current tobacco smoking
- Ever long-term use of glucocorticoids
- Rheumatoid arthritis or other secondary causes
- Alcohol intake 3 or more units daily

Basic therapy

Calcium

- 1200mg elemental from combination of diet and supplement
- calcium carbonate (60% elemental calcium)
 - o TUMS, Caltrate, OsCal, etc
 - o Take with a meal
 - o If constipation, use bulk, fluids, magnesium
- Calcium citrate (20% elemental calcium)
 - o more expensive, more tablets, take on full stomach

Vitamin D3

- 2000IU daily
- weekly or monthly dosing
- non-toxic if less than 10,000IU daily (FDA)
- skeletal benefits: increased absorption of calcium
- extra-skeletal benefits: cancer, infection, falls,

Exercise

- walking-type 20 minutes per day
- balance, gait, strength and other benefits

Treatment of glucocorticoid-induced osteoporosis

- several medication have been approved to treat glucocorticoid osteoporosis, including
 - o risedronate (Actonel®)
 - currently approved for treatment and prevention of postmenopausal osteoporosis
 - treatment to increase bone mass in men with osteoporosis
 - treatment and prevention of GIOP in the US
- medications in clinical trials
 - o denosumab (Prolia®): approved for treatment of osteoporosis in postmenopausal women at high risk of fracture (Canada and US)

A randomized, double-blind, active-controlled study to evaluate the efficacy and safety of denosumab compared with risedronate in glucocorticoid-treated individuals is available at Prohealth Clinic Research headed by Dr. David Kendler. (Dr. Kendler spoke to our group July 10, 1999, minutes from the meeting can be found at <http://www.addisonsociety.ca/newsletters/Newsletter1999July.pdf>). If you are on glucocorticoid therapy, you can be a part of this trial.

You will receive either risedronate (Actonel) or Denosumab as study medication as well as reasonable travel reimbursements, study investigations and study-required supplements free of charge. There are no placebos for the 2-year study. Participating in a clinical trial may help other with similar conditions benefit in the future. Applications to the study will be accepted for the next year. Some travel expenses will be covered.

Who is eligible to participate?

- men and women over 50 who are taking prednisone more than 7.5mg daily and are expected to be treated with oral glucocorticoids for a total of at least 6 months
- men and women between 18 and 50 must have a history of osteoporotic fracture
- not an osteoporosis therapy
- a thorough review of medical history by the research staff is required prior to entry

If you are already undergoing treatment for osteoporosis, you may apply, as there are different rules for each medication. People interested in the study may be contacted for future studies, if they would like. As there is no indication of which dose you will be on, the results will be very informative for the medical profession to see which shows the most improvement for bone density.

If you are interested in learning more about this Study, please contact Shelley at 604-263-3661 ext.31.

Submitted by Judy Stanley

Our next meeting will be October 27, 2012, in the Neil Russell Room; reminder with more information will be sent out closer to the date. For further information on this support group or any upcoming meetings, contact Judy Stanley, (604) 936-6694 or bugbee@shaw.ca.

Alberta Support Group

I continue to get phone calls quite regularly from newly diagnosed Addisonians who get my name from the Canadian Addison website. I hope to attend the annual meeting in Victoria this fall!

Submitted by Ginny Snaychuk

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton, or Peter Little at bettypeter66@gmail.com or (780) 918-2342 in Edmonton.

Saskatchewan Support Group

There are now 5 Addisonians living in and around the Meadow Lake, Sk area.

For information on this support group, contact Elizabeth Hill at (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.

South/Central Ontario Support Group

The May 12th, 2012 meeting began with Harold Smith promoting a round table discussion about the variance in doses and importance of accuracy, timing of medication. Some Addisonians are on Prednisone, some on Cortef. Most are taking Florinef. Some have multiple auto-immune disorders. Some have challenges with fatigue, others have limited to no issues with energy levels.

The guest speaker was Ken Yetman, Canada Revenue Agency on the topic *Disability Tax Credit – What is it? Could you qualify?*

- Harold shared his personal story of the application process and his recent approval for the Disability Tax Credit. Harold included a personal letter with his application, which he feels made a positive difference. Once approved, he also wrote a second letter for the government to go back and review his tax returns from the date of his diagnosis. It is retroactive up to 10 years.
- Be sure to include all the information requested, including name, address, social insurance number, date of birth, contact phone number (daytime). The phone number is important if they need to call to verify something, rather than go through a possible lengthy process of a letter.
- Addisonians *may* be eligible for the credit based on the category labelled “Life-Sustaining Therapy”. If you have a secondary condition, related to Addison’s or not, you should consider including it on the same application, providing it fits into one of the eligible

categories. Harold did this. The application needs to be completed by your physician and then submitted by you. This does not guarantee approval, but you can re-apply if turned down on your initial application. You may submit the application at any time of the year.

- Do NOT send it in with your income tax return at tax time, as it is too busy, and consequently it may get missed.
- Keep a copy of your application!
- Key words regarding your condition are – SEVERE and PRO-LONGED.
- Definition of Prolonged = An impairment that has lasted, or is expected to last, for a continuous period of at least 12 months. Open to interpretation.
- If there are any questions, the government will contact your doctor and also send you a copy of the letter for follow-up.
- Non-refundable tax credit – it reduces your taxes that would otherwise be payable. Potentially reduces both federal and provincial taxes.
- May be transferable to a lower income spouse.
- Guidelines are set-up by Parliament – the only person who can work to change it is your Member of Parliament.
- Ken went on to briefly discuss a new topic: claiming Medical Expenses on your tax return. Line 330 – for ex, a prescription. Claim what you pay out of pocket (i.e. percentage eligible). Must take into account 3% of Net Income. If this amount is higher, you will get zero back.
- The group had a brief Q&A with Ken.

Emergency Injection Training Clinic

- The Group is fortunate to have member Denise Burpee, RN, BScN, ready, willing and able to take charge of our Emergency Injection Training Clinics.
- Don't leave home without your emergency injection kit. Expiry date on the Solu-Cortef Act-O-Vials is about 2yrs. Every Addisonian should have a kit available at all times. The kit will include the syringes, Solu-Cortef vials, alcohol swaps, cotton balls, a copy of the prescription from their doctor and the injection instructions which may be found at www.addisonsociety.ca (follow the link for Healthy Living and Injection Kit.)
- Be prepared. You may never need it, but it is good to know how to use, JUST IN CASE. Also carry a small hard container to safely dispose of the syringe afterwards. If you have not yet been able to attend an Emergency Injection Training Clinic, you are encouraged to study the instructions on the website.
- It is estimated that you may have an extra 6 hours to get to the hospital after the injection. You may wish to verify this with your doctor. Take the kit on the plane when travelling by air but be certain to carry documentation such as your doctor's Rx for the kit and his/her explanation of your potential need for stress dosing should you suffer an Addisonian crisis. Keep the emergency instructions **with** the kit. Always wear your MedicAlert bracelet or necklace.
- We have been advised that EMS Personnel are NOT allowed to inject the Solu-Cortef stress dose.

Miscellaneous Topics – Harold Smith

- Discussion and feedback was held on the brochure holder kits as part of our Community Awareness Campaign. The balance of 50 test kits is finally in the hands of members who have volunteered to help. They will be delivered to their endos and/or GPs and the members will report the doctor's information to Harold via email. This will allow us to track the repeat requests for replacement brochures to refill the holders. This in turn will give us evidence as to whether the program is effective in brochure distribution and will help us determine if this is the way to go nationally.
- Harold mentioned the radio spot that is on the website. Please check it out as it is very interesting and worth a listen!
- Reminder of the importance of Medic-Alert was raised and a reminder of how important it is to keep the information on file with MedicAlert up-to-date. Things may change over the years. Is your bracelet or necklace carrying accurate and up-to-date info?
- Question about Emergency Rooms – File being "flagged" - Francine gave the example where she has her file flagged at her local hospital and the ambulance was able to call ahead so the ER was ready for her arrival. WOW! Wouldn't that be a refreshing experience? Contact your ER and have them flag your file. Her first experience proved that the ER staff was not knowledgeable about Addison's which is a common experience for many of us. After the fact, Francine advocated for herself and the hospital now knows her situation.

Suggestions for future meetings

- Nutritionist – foods to avoid, recommended vitamins, overall nutrition
- Exercise – increasing and maintaining muscle, recovering after exercise
- Hormonal – concerns about bone density after long-term steroid usage

The next meeting will be Sat. September 29, 2012, from 1 pm to 4:30 pm (registration from 12:30 pm) in the Community Room, Brantford Police Services Building, 344 Elgin Street, Brantford, Ontario, agenda to be determined (watch the website www.addisonsociety.ca and follow the link "upcoming meetings" for details).

Submitted by Harold Smith

For further information on Southern Ontario Support Group activities or meetings, contact Harold Smith in Kitchener at hsmith9995@rogers.com or (519) 742-9995.

Eastern Ontario Support Group

The Eastern Ontario support group met 19 May 2012 with 11 people attending. There was a round table of introductions as we had new attendees. As people introduced themselves (when they were diagnosed, other medical issues), this initiated lively discussion on a number of topics.

- The Society was asked to do a radio interview for a Windsor/Detroit FM station. You can hear it by going to the [Society website](#) and clicking on the YouTube icon at the top of the home page.
- The Vancouver group heard from a guest speaker who reminded members of the importance of advanced planning directives (known in Ontario as *Power of Attorney for Health Care*). This is something that everyone, with or without a chronic condition, should talk about with their families.
- Membership renewals for 2012 were due in January. If you have not yet renewed, please do so immediately (forms were available for attendees and can be found on the website).
- As part of our outreach education, newsletters are being sent once a year to all ends in Canada (different regions each quarter).
- The first place paramedics look for information is on the patient's fridge. So, remember to have a sheet with your medical conditions, medications and allergies, emergency contact numbers, and perhaps a short medical history, on the fridge (fold it in half with your name on it so it isn't on public display). One member has a special magnetic container for on the fridge, received from her local paramedics, which contains her pertinent emergency information.
- Members who have to drive long distances or stay overnight to attend medical appointment are reminded to check CRA rules for allowable income tax expenses.
- Addison's disease was mentioned in the March 2012 issue of *O, The Oprah Magazine* in an article entitled: "From Neuroscientist to Fashion Designer." The story concerns a woman who successfully changed careers after being diagnosed with Addison's.
- The April 2012 newsletter for the Canadian Addison Society is available online. Go to the community tab: Newsletters.
- Several members are having trouble obtaining a single or a couple of Solu-cortef vials, as the pharmacy must order it in boxes of 10. Patricia commented that she has never had a problem at the Shoppers at Bank and Walkley. Two members near Peterborough will coordinate to buy their Solu-cortef together, making it easy for their pharmacy.
- Steve has offered to arrange a meeting in Kingston or Cornwall if enough members expressed an interest. It seems there were no expressions of interest.

All in all, it was a good meeting with enthusiastic participation. Our next meeting will be Saturday 13 October 2012 at noon at Robbie's Restaurant on St. Laurent Blvd in Ottawa. There was a request for us to repeat our 'how to do emergency injections' clinic, so this will be the focus of the next meeting. With this in mind, please bring any outdated Solu-cortef vials to the next meeting. See you then.

Submitted by Steve McKenna

For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at steveandpat@rogers.com or 613-523-7648.

Québec Support Group

We are fortunate to have new representatives in Québec, Georgia Kapralios and Dr. George Kamranis, whose son has Addison's Disease. They can be contacted at centresantedentaire@bellnet.ca. They can communicate in English, French and Greek.

Atlantic Support Group

The Atlantic Canada Support Group is looking for a volunteer to act as contact point. If you can do this, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Medical Q & A

There is now a very large and wide-ranging set of questions on both daily living and very situation-specific issues that have been answered by our medical advisor. To review these questions, please go to the Canadian Addison Society website under Education (<http://www.addisonsociety.ca/related/FAQNovemberb2011.pdf>), or see previous issues of the newsletter.

Before submitting a question to our medical advisor, please consult the wealth of Q&As on our website. Many questions have already been answered.

Q: If I get food poisoning and/or really bad stomach flu and am unable to keep anything down, how do I deal with my oral hydrocortisone dose? Do I need to get an injection if it lasts more than a day or two? I'm going on vacation to Mexico and am a little worried about possible food poisoning.

A: Emergency kits containing Solu-cortef are designed for people who are travelling. If you can't keep your cortisol down for 24 hrs you should go to an emergency department, if this is convenient or possible; if not, use the kit. Be sure that your travelling companion is familiar with how to use it **before** you go. You should take at least two kits with you so if you use one kit early on in your trip, you will not be anxious that something might come up late on.

If you are not familiar with the emergency kit, there is a description on the web site. Your family doctor or endocrinologist can give you a prescription for this.

(Ed. Note: Emergency procedures can be found at <http://www.addisonsociety.ca/emergencyproc.html>, injection procedures at <http://www.addisonsociety.ca/injection.html>, and a description of the kit in the FAQ Addisonian Crisis – Emergency at <http://www.addisonsociety.ca/related/FAQNovemberb2011.pdf>. Emergency letters and

procedures in various languages, including Spanish can be found at <http://www.addisonsociety.ca/emergencylett.html>.)

Q: I have had Addison's disease for 6 years. I am on Cortef and Florinef. Recently, I have noted hyperpigmentation and low energy. My blood cortisol level is 21. Should I increase my Cortef or wait for my family doctor to contact my endocrinologist?

A: If you have been doing well on the current dose of Cortef and Florinef for the past 6 years and you now notice new pigmentation and feel unwell, it suggests that there has been some change either in the content of cortisol in the pills or the absorption of cortisol from your intestinal tract. You should see your endocrinologist to see what is going on.

It is not unusual to have a low cortisol level in individuals with Addison's disease depending on when it was taken relative to your last dose of cortisol. In the morning, cortisol levels are always low. You should see your endocrinologist to help sort this out.

Q: My question is about the biological equivalents of dexamethasone, prednisone, Cortef (hydrocortisone) and cortisone.

A: The equivalent of the different glucocorticoids is: 0.25 mg dex = 5 mg Pred = 20 mg cortisol = 25 mg cortisone. Dexamethasone is not usually used as replacement glucocorticoid in Addison's disease because of its long duration of action. Cortisol is normally secreted episodically with more pulses in the early morning hours than during the day. This gives it a diurnal variation of cortisol with highest levels in the AM and lower levels in the evening

There are a lot of questions and answers about cortisol replacement on the website of the CAS and other Addison's websites. (*Ed. note: see FAQ - cortisol medication* <http://www.addisonsociety.ca/related/FAQNovember2011.pdf>.)

Q: Can the drug cortisone acetate cause anxiety/depression?

A: Cortisone acetate is a hormone that is similar but not identical to hydrocortisone, the hormone secreted by the adrenal gland. Either cortisone acetate or cortisol (hydrocortisone) is given to individuals whose adrenals do not secrete hydrocortisone (adrenal insufficiency, Addison's disease). When it is given to replace the hydrocortisone that is not being produced in an individual with Addison's disease, it does not cause side effects as long as it is given in appropriate doses.

Individuals with Addison's disease can feel depressed before they are diagnosed because they often feel unwell for a long period before they are diagnosed. This depression improves after they have been on replacement, but the improvement can occur gradually because they have felt unwell for a long time.

There are disorders that occur when the production of hydrocortisone is excessive (Cushing's syndrome). This disorder can be associated with significant emotional problems. In this case, the secretion of hydrocortisone is many times normal.

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Send your question to Dr. Killinger directly from the webpage <http://www.addisonsociety.ca/faq.html#>, by emailing liaisonsecretary@addisonsociety.ca or c/o The Addison Society (see address on front of this newsletter). Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.