



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

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In this issue:

- News and Announcements
- President's Comments
- Newsletter Editor Comments
- Highlights from Local Meetings
- Medical Qs & As

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. Please note that the Society does not endorse the information provided by guest speakers.

News and Announcements:

Please remember to renew your membership in the Society - \$25. due in January.

Your membership fees are important to the ongoing operation of the Society and our ability to continue making resources available to members. You will find the necessary membership renewal form at the end of this newsletter, or online at <http://www.addisonsociety.ca/membership.html>.

We thank you for your continued support.

President's Comments

Welcome to a New Year at The Canadian Addison Society. I was pleased to take on the role of President as of the Annual General Meeting on September 28, 2013. We are looking forward to an exciting future for the Society with a number of new initiatives either planned or in motion.

As a beginning, this fall the Society became an Affiliate Member of CORD (Canadian Organization for Rare Disorders). You may wish to visit their website www.raredisorders.ca to learn of the significant work done by this very special organization on behalf of many with rare disorders. They speak with a loud voice when lobbying for improvements in the care of those with rare disorders of which Addison's Disease is one.

Another activity is the truly global event of **Rare Disease Day**. The banner shown below is available through our website under the link EDUCATION, then to Links & Resources. One suggestion is to ask each member currently using email to add this banner to each email they send between now and February 28, 2014. It may seem like a small thing but many small things will have an impact. Maybe next year we can organize something more significant in order to have the Society participate more fully.



As a lead-in to the next section of the Newsletter, I wish to express a most sincere thank you on behalf of all members to Pat Hehner who has just retired after 10 years of dedication, as Volunteer Newsletter Editor for the Society. Thank You Patricia!!

Newsletter Editor:

That's my cue...My first Newsletter as Editor!

Thank Goodness it is a light one. Also a little late I know.

Thanks to Pat Hehner for her assistance and guidance during the transition. Pat's copious notes have been invaluable. I promise to improve as I become more familiar with the process. While the first of anything is often challenging, I am looking forward to the experience and to have a real connection to members across Canada. You can reach me at newsletter@addisonsociety.ca. Thanks, Carrie

Highlights from Local Meetings:

Vancouver Island Support Group - Victoria

The next Victoria meeting of the Vancouver Island support group is scheduled for March 1, 2014, at Serious Coffee in Esquimalt.

For further information on the Vancouver Island Support Group, contact Jim Sadlish at vanisleaddisons@gmail.com or (250) 656-6270. For information on Central Island activities, please contact Sharon Erickson at ericksons@shaw.ca.

Submitted by Jim Sadlish

BC Lower Mainland Support Group

The BC Lower Mainland Group Met October 19, 2013. Guest speaker, Trevor Leismeister, **M.Ed., RCC** from **Progressive Rehab – OrionHealth** came highly recommended by a member who was referred to OrionHealth. Trevor is a Vocational Rehabilitation (VR) Consultant and Registered Clinical Counselor.

Trevor spoke of his role as a Vocational Rehabilitation Consultant working with referral agencies such as Insurance Companies, ICBC, Non-Profit employment programs, Private Agencies etc. or individuals seeking assistance.

He works on a one to one basis in a four phase program for job assistance.

1. Same job - same employer: most successful, may need modifications at work
2. Same employer - different position: able to work in an alternative position
3. Different employer - same job: i.e. your position filled after a long time of absence
4. Unable to return to work – different job – different employer: does client need more clinical assessment, what are options, possibility for best fit or leave option up to individual for job that is rewarding.

Vocational Rehabilitation – What is it and how can it help? It requires a supportive employer and resources to support a person returning to work. Looks at what to do when a person can no longer work (e.g., applying for disability benefits, volunteering, etc). If a person does not have a physical disability, how much does the employer need to know? If a person is displaced from the workforce, works on getting them back to work. If they have to go to court he may testify as vocational expert. It suggests reasonable options, insurance companies also want to see a client placed in the most suited position. If displaced from the workforce, works on getting a client back to work.

Question: if hurt on job an employer has a duty to accommodate, if not feasible.

Answer: an employer wants to know if a person is going to be able to do the required job on returning to work. i.e. Administrator who works at home has 90% recovered from an injury, but the company needs to know if the worker is 100% okay, after reassurance still will not accept. i.e. welder had heart attack at 61, needed a pace maker, because a welding arc would interfere with the pace maker the welder could not go back to work. In this case a

different work option was found and he went to work for Home Depot increasing self esteem by working in the community.

Question: Wage discrepancy - Reimbursement definition depends on insurance i.e. Work BC would cover 80% of previous wage.

The BC Coalition of People with Disabilities (BCCPD) is a provincial, cross-disability voice in British Columbia which has an Advocacy Access Program. This free service helps people with all disabilities secure provincial and federal disability benefits. The program also facilitates *pro bono* legal clinics on an appointment basis and a *pro bono* social worker visits our office every week. We assist hundreds of clients one-on-one to: 1. Apply and appeal the denial of provincial and federal disability benefits 2. Obtain the health goods and services attached to provincial benefits 3. Apply for subsidized housing 4. Understand income assistance rights and responsibilities

New members introduced themselves – attending were 6 with Addison's and 2 family members. I have had several calls and emails recently, one from Golden, and have updated everyone on our meetings. 9 regrets were sent.

One member recently experienced her first crisis in 14 years brought on by septic infection and spent several days in ICU. Had she not returned to Canada immediately, gone directly hospital she would not have been at the meeting. Update: 23/10/13 - she had her gall bladder out and is now home and recovering. Reminder, always take someone to advocate for you in an emergency.

A discussion followed on signs of an impending crisis or what to do if one hits with no warning, the need to carry an emergency kit at all times and getting to ER after injecting Solu-Cortef as you will probably be dehydrated. Don't assume because you are not going on a long trip that you don't need to carry it.

A member emailed from Bermuda for the rehydration mix which can be found on our website under 'Tips', mix is available at any café using their salt and sugar packets or carry Gastrolyte packets (Oral Rehydration Salts) available in Canada from a local pharmacy. For those travelling to hot and/or humid locations this winter for vacations a timely reminder. Also Emergency letters are available on line in several languages (see previous newsletters or UK site for access to ER letters in 8 languages); also a translation App is available if you have a smart phone.

Moh is no longer Education Coordinator so we will be asking at each meeting to see if anyone has a guest speaker to come to the next meeting. The Security person who let me in has a dog with Addison's. I have the information on her Vet to contact. It was interesting to hear what they go through for a pet.

Someone is required to assist taking notes at each meeting, send them to Judy to combine with her notes for distribution to attendees and to the newsletter editor.

We discussed only having two meetings a year, eliminating the February meeting due to the variable weather. We decided to have the fall meeting (October) and continue with our end of May meeting. These were the dates most members expressed they would be available for.

Thanks to our newly elected President Harold Smith, we received a year's supply of Act-o-Vials which are 'Not For Use' and contain no active ingredients. We will be able to practise injecting an orange at each meeting. This makes it easier for us to actually use our emergency kits in a crisis enabling us to get to ER for further care. Needles, swabs, oranges and copies of the emergency letters from our website were available. You can bring your significant other or advocate to a meeting as they will probably be doing the injecting.

Flu shots are available. If you have yearly updates please watch your local papers for times and venues. They are also available at pharmacies and your doctor's office. The shots are free with a chronic condition and your spouse as caregiver is also included. We had ours and the doctor recommended a pneumonia shot as well. They do need a booster every 5 or 10 years.

We are reprinting the following information piece from UBC for the benefit of members in the region, regarding their Home Interview program for first year med students. This is a wonderful way for us to educate a new crop of soon-to-be Doctors about Addison's.

Other Support Groups across Canada may find it useful to try and duplicate this program in partnership with the nearest University offering a Medical Program.

Course: DPAS410 (Doctor, Patient & Society) (1st Yr. course)

Description: The students participate in an At Home Interview project where they interview a patient with a chronic illness. This is part of the medical students' studies to help them gain a stronger understanding of the patient perspective.

Needed: We are looking for individuals, and family members of individuals, with disabilities and chronic conditions who are willing to be interviewed in their home or community by medical students. The interview would cover basic biographies, experience of conditions, how it's affected their family and social life, experience with health professionals, medical institutions and service agencies.

The interviews would only take 30 minutes to an hour in either **January, February or March of 2014**. We like to work around the schedules of the individuals being interviewed which is why there is such flexibility in terms of interview dates.

Where: The interviews usually take place in the individuals' homes but some people have arranged to meet elsewhere such as the UBC campus or a coffee shop.

Students find it very valuable and previous patients have found it interesting and enjoyable and see it as a positive way of participating in the training of future doctors.

If you know anyone who is interested or if you have any questions at all, please contact Emily Turner:

Emily Turner
604-827-5958
dpas.support@ubc.ca

Next meeting for the BC Lower Mainland Support Group is **Saturday, May 10, 2014** at the Royal Columbian Hospital Twr., 330 E. Columbia St. Neil Russell Room, 3rd Floor, New Westminster. For further information on this support group contact Judy Stanley, (604) 936-6694 or bugbee@shaw.ca.

Alberta Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton

Saskatchewan Support Group

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 next meeting of the South/Central Ontario Group will be **Saturday May 10, 2014** at the Erin Mills United Church, Lower Hall Meeting Room, 3010 The Collegeway, Mississauga ON L5L 4X9 from 1:00 to 4:30 pm (registration at 12:30 pm). This location is accessible by Public Transit. Please watch the "Upcoming Meetings" page on the website www.addisonsociety.ca for details on the agenda and speaker.

For further information on South/Central Ontario Support Group activities or meetings, contact Harold Smith in Kitchener at hsmith81@hotmail.ca or (519) 742-8170.

Submitted by Harold Smith

Eastern Ontario Support Group

The group met at Robbie's Restaurant in Ottawa at noon on October 19th with 11 people in attendance. We were glad to welcome a new member to the group who had recently been diagnosed. The following items were discussed:

- Provided summary of CAS AGM held Saturday Sept 28, 2013 in Brantford, ON, including new president and vice-president
- Reminded all present that their dues for the next calendar year are due by January 1st, 2014
- Advised that our newsletter editor, Patricia Hehner, is retiring from this big job; it is being taken over by Carrie Smith. We all thanked Patricia very much for her excellent work on the newsletter for the last 10 years - GOOD WORK PATRICIA!
- Told everyone the October 2013 newsletter is now on the web
- Advised that the Ottawa Hospital now has an official form for Addisonians to use as a generic emergency response letter and is available to all doctors and patients. Told everyone it can be found on our website in the emergency letter section of the CAS web site (click on Ottawa Emergency Letter in the box on the right side of the screen)
- In regard to the official form from the Ottawa Hospital, reminded those in attendance that the paramedics will first look on your refrigerator for medical information. They cannot, and will not, look in your wallet or anywhere else in your house for medical information for privacy and safety reasons. They recommend it be put on the fridge and, if you don't want everyone to see this information, fold the paper and label it properly with your name and what it is (ex: Medical Information for: *John Smith*)
- Spoke about various places on the internet that information of interest can be found, such as YouTube, Facebook, etc. Also discussed the links on the CAS web site to such places as the UK site that lists many other organizations like ours that disseminate information and discuss living with this condition
<http://www.addisons.org.uk/comms/world/page1.html>
- Told everyone about the Pfizer training version Act-O-Vials received from Harold Smith. Everyone was supplied with a vial, needle and swab to practice giving an emergency injection. We got some oranges in the sale rack to use for the injections. Even though we've done this before, everyone in attendance was happy to try it again, even if they had already done this at a previous meeting. We have more vials on hand to try this again.
- Discussed having a **meeting in Kingston** again and a member from there, Kelly Cole, has offered to host such a meeting and suggested **January 2014**. Will organize this with Kelly and those who wish to attend a meeting in the Kingston area. Thank you, Kelly, for volunteering to make this happen
- The next meeting will be on **SATURDAY, MAY 10, 2014** in Ottawa at the same location

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

Our representatives in Québec can be contacted at centresantedentaire@bellnet.ca.

Atlantic Support Group

Holly Mclean is the regional representative and leader. She lives in northern New Brunswick. You can reach Holly at hquilter@nb.sympatico.ca or 506-546-1687

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/FAQNovember2011.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: Is it common for people with Addison's to get foot and calf cramps at night and if so, what might cause that?

A: Leg cramps and foot cramps at night are quite common and tend to be more common as we get older. There are situations such as low calcium which can cause cramps in hands and feet but individuals with Addison's do not have an increased tendency for either low calcium or leg cramps. Leg cramps can come on after strenuous activity such as jogging. Your family doctor would be the person to ask since she/he would know your age, activity and any medication that you are on.

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.



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193 Elgin Avenue West
Goderich ON N7A 2E7

Website: www.addisonsociety.ca

Membership in The Canadian Addison Society is \$25.00 per year, due January 1st.

New Membership Renewed 1yr 2yrs 5yrs ** Plus a Contribution

Name: _____

Address _____

Postal Code: _____ Telephone: _____

E-mail Address: _____

How do you wish to receive the Newsletter?

I will read it on the website at www.addisonsociety.ca or by mail

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

You may also direct \$5.00 of your annual fee to one of the local support groups below. Please check a box of your choice.

- \$25.00 to go to The Canadian Addison Society OR
 \$5.00 to Eastern Ontario Support Group – ON + \$20.00 to Society
 \$5.00 to South/Central Ontario Support Group – ON + \$20.00 to Society
 \$5.00 to Saskatchewan Support Group – SK + \$20.00 to Society
 \$5.00 to Alberta Support Group – AB + \$20.00 to Society
 \$5.00 to BC Lower Mainland Support Group – BC + \$20.00 to Society
 \$5.00 to Vancouver Island Support Group – BC + \$20.00 to Society
 \$5.00 to Quebec Support Group + \$20.00 to Society

** Tax receipts are issued for donations over \$15.00.

Please mail your payment to The Canadian Addison Society c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7

Optional (for newsletter mailing purposes if you are comfortable providing this information)

Your Endocrinologist & Hospital _____

ER Director of the Hospital _____

Revised: December, 2013