The Canadian Addison Society
La Société canadienne d’Addison

193 Elgin Avenue West
Goderich, Ontario N7A 2E7
Toll free number: 1-888-550-5582
Email: liaisonsecretary@addisonsociety.ca
www.addisonsociety.ca

ISSUE NO. 70 **APRIL 2013**

In this issue:

- Vice-President Needed
- President’s Message
- Invitation to Apply for an Awesome (Free) Camp for Adrenal Insufficiency Children
- Personal Experiences
- UBC Faculty of Medicine: *Doctor, Patient and Society* & the *At Home Interview*
- 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.

Vice-President Needed:

As noted at our 2012 Annual General Meeting, the Canadian Addison Society needs to find a replacement for Jim Sadlish whose term as Vice President is ending. (Jim will stay on as Local Support Group Leader.) We are urgently looking for a member to fill this role. It doesn't really demand any more time than the Directors already put in. For more information, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or 1-888-550-5582.

President’s Message:

Globally a lot has been happening in the past few months.

As a result of an inquiry through the Australian Addison’s Disease Association regarding preloaded syringes for hydrocortisone injection, we have reconfirmed with manufacturer Pfizer, US and Canada divisions, that no such syringes are available. The Solu-Cortef vials, with which we are all familiar, remain our best option and are available in Australia, UK, USA and Canada.

Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor for The Canadian Addison Society again advised that dexamethasone is not our best choice for use in an Addisonian crisis, as it has very little salt retaining activity and thus does not support blood pressure. However, a preloaded syringe with 4 mg dexamethasone is a reasonable emergency kit for use when travelling (http://www.addisonsociety.ca/related/FAQNovemberb2011.pdf under Addisonian Crisis / Emergency).

We provided Canadian data for a comparison of drug costs which is being prepared by the UK group (ADSHG) for one of its upcoming newsletters (only available to UK members). We will look at their results with interest and include any helpful information in our own newsletter in due course. We note that the experimental once-a-day medication, Plenadren, is available in the EU but costs in the UK are very expensive.

NADF is trying to initiate a Global Addison's Awareness Campaign. This year, due to short notice, we are unable to participate. However, any future participation would probably be on a local level, organized by regional support groups. So, start thinking creatively and talking about this in your local groups.

Submitted by Judy Stanley

Invitation to Apply for an Awesome (Free) Camp for Adrenal Insufficiency (AI) Children:

We received this message from NADF in the U.S. Feel free to check it out.

> NADF has been in contact with the amazing Double H Ranch located in the Adirondacks of New York State.
>
> This wonderful camp was created by philanthropist Charles R. Woods, with the support of renowned actor Paul Newman, specifically for children, ages 6 - 16, who live with life-threatening health conditions.
>
> Upon receiving NADF's request for inclusion for our adrenal insufficient children (Addison's disease, CAH, adrenoleukodystrophy, congenital adrenal hypoplasia, familial glucocorticoid deficiency, et al) the medical team at the Double H Ranch were consulted.
>
> We just received word that the Double H Ranch would gladly accept applications for inclusion in the amazing Double H/Hole in the Wall camp experience, from the parents/guardians of adrenal insufficient children. (All applications are medically reviewed for approval to insure that each child is the right fit for their program.)

This camp experience is completely free for the kids who are accepted for attendance.

For more information about Double H Ranch, please visit their website at: http://www.doublehranch.org/.

Double H Ranch camper applications can be downloaded at http://www.doublehranch.org/summer-camp/criteria/.

Personal Experiences:

This is a story about inflammation in the pituitary, a problem which occurs in both males and females, but it is not uncommon for it to occur in late pregnancy. It commonly results in some degree of pituitary hormone deficiency.

My story seems to be quite different from everything I have read online so far. In 2007, I was diagnosed with a disease called Lymphocytic Hypophycytis. But my problems started a couple of years before this. Lymphocytic Hypophycytis (LH) manifests during the third trimester of pregnancy. In December of 2005, I had my second son. I noticed I was not recovering as well as I did with my first, but I just figured I was tired and lethargic because I had 2 babies very close together, and my second son was a very difficult baby. These issues continued to the point that I found it difficult even to move. My muscles were very weak and I could have slept all day every day if someone would have let me. I was getting very down and had very little interest in what was going on around me, and at that point, if I'm honest, I didn't care. I felt so awful.

Everybody around me had a different opinion of what was wrong with me. Some thought I was just being lazy and more or less wrote me off; my husband and parents decided I had post partum psychosis. So in February of 2007, they had me admitted to the psych ward of the hospital. I spent 4 1/2 weeks there. And if they thought I was out of it before I went in the hospital, you should have seen me when I got out. They had me on so many meds, I could have started my own pharmacy. Unfortunately, not one of those meds was addressing the actual problem I was having. The hospital actually didn't do any bloodwork other than to check to see if I was on drugs. Finally, at a follow up appointment with my OB (which I barely remember due to all the meds I was taking), he sent me for the right bloodwork and when he got the results, called me and got me right in to see an endocrinologist who worked in the same hospital.

The way LH is supposed to work is, during the third trimester of pregnancy, the pituitary gland stops producing, or stops stimulating the production of certain hormones. At this point, one would be put on replacement for the remainder of the pregnancy, if it were discovered. After birth, the hormones slowly start returning to normal. That's how "normal" LH works. It turns out I have a "variant" form of LH. All my hormones returned to normal except my cortisol, TSH & free T4, and estrogen. In my situation, I don't produce any ACTH at all. So I have been taking Cortef since 2007 and Synthroid as well. I have tried every birth control on the market for the estrogen situation and have ended up with a whole other set of gynecological problems, but that's a whole other story!

I wanted to note that as I was reading the newsletter, I noted the letter to Dr. Killinger about the person who had been diagnosed only 1week prior. After I started taking Cortef and Synthroid, in the initial year or so, I felt better - not normal, but better enough that I could have a quality of life. Since then, things have been very difficult. My lab work has shown my levels are normal (for the most part), but I can honestly say, I feel crummy a lot of the time. I still get tired regularly and have to plan my days accordingly. I'm only 37 years old (I was diagnosed at 31) and I feel like I'm 90. It's very frustrating. I really appreciate reading other personal experiences and especially the symptoms others experience. It validates my feelings/symptoms and reminds me that I'm not crazy. It's very hard for the outside world to understand what you're going through when there is nothing visible. You end up being the lazy one because you're tired all the time. So - thank you to everyone for being so open and honest. I have finally felt like I am not alone.

Submitted by Erin

* * * * * * * * * *

I was diagnosed with Addison's May 2012 after two years of suffering, seeing specialists, tests, etc. Like so many others, I had no answers and was relieved to have a diagnosis. I am a teacher and took May and June off to recover and started back to work full-time in September. Since returning to work I have had good days and bad, and have been back in the ER twice. I am a mother of three young boys, (9, 6 and 4 years old) and think, despite my diagnosis, treatment and positive attitude that ‘Addison's is not who I am’, maybe, right now it is winning. I am taking another leave from work. Is this common? How long till I can manage life again? Will I ever work full-time, manage my family, etc? I know many think that it is just physical stress but I cannot ignore the emotional stress and how it too is taking its toll on me! Can anyone else relate??

I also believed that now that I have a diagnosis, my arrival to the ER would result in immediate help and treatment. How naive was I!!! Both visits, I have had to FIGHT for steroids, been told I do not need them, I have a migraine like many others, etc. I am being told this while my BP is 78/36!!! I have contacted my local hospital and will be writing a letter of concern and hopefully will have a course of action on my file for next time I present!

Submitted by Karen

Ed. Note: We strongly encourage anyone in this situation to check the Canadian Addison Society website under Healthy Living for general and hospital-specific protocols which can be used on arrival in an ER (http://www.addisonsociety.ca/ohp.html). As well, Emergency Procedures (http://www.addisonsociety.ca/emergencyproc.html) written by our medical advisor could be helpful.

UBC Faculty of Medicine: *Doctor, Patient and Society* & the *At Home Interview (AHI)*:

Presentation to the BC Lower Mainland Support Group of the Canadian Addison's Society
27 October 2012 (Original slides have been edited for length)

OBJECTIVE OF PRESENTATION

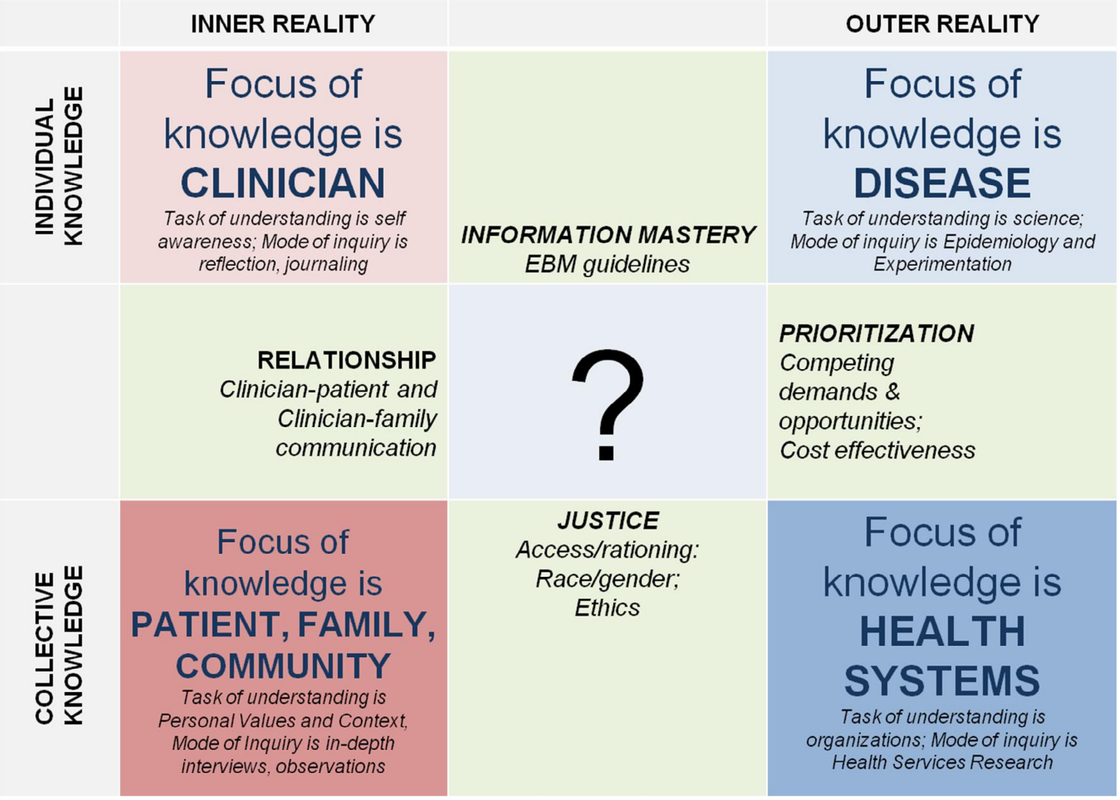
- To describe the *Doctor, Patient and Society* course and the *At Home Interview (AHI)* assignment;
- To convey the influence of the *At Home Interview* through feedback from some students

OVERVIEW OF 1st YEAR MEDICAL SCHOOL

- We have 288 1st year medical studentsIn term 1, we cover: Principles /Fundamentals of Medicine; Clinical Skills; Family Medicine; Doctor, Patient and Society
- In term 2, students go to various sites

The overall goal for *Doctor, Patient and Society*:

- to develop knowledge base of medical practice to question, to integrate, to reflect and to critically think



	INNER REALITY		OUTER REALITY
INDIVIDUAL KNOWLEDGE	Focus of knowledge is **CLINICIAN** *Task of understanding is self awareness; Mode of inquiry is reflection, journaling*	***INFORMATION MASTERY*** *EBM guidelines*	Focus of knowledge is **DISEASE** *Task of understanding is science; Mode of inquiry is Epidemiology and Experimentation*
	RELATIONSHIP *Clinician-patient and Clinician-family communication*	?	***PRIORITIZATION*** *Competing demands & opportunities;* *Cost effectiveness*
COLLECTIVE KNOWLEDGE	Focus of knowledge is **PATIENT, FAMILY, COMMUNITY** *Task of understanding is Personal Values and Context, Mode of Inquiry is in-depth interviews, observations*	***JUSTICE*** *Access/rationing:* *Race/gender;* *Ethics*	Focus of knowledge is **HEALTH SYSTEMS** *Task of understanding is organizations; Mode of inquiry is Health Services Research*

DATE	BLOCK	DELIVERABLES & ASSIGNMENTS	ASSESSMENTS
Sep-Oct	Culture, Compassion & Communication	Group Collaborative Agreement Signed Professionalism Document	Advisor assessment (P/P-/F)
Oct	Study Design	‘How to read a paper’ – student group presentations	Advisor assessment (P/P-/F)
Nov-Dec	Ethics & Law	Student group presentations	
Dec	Term-1 Exam		*EBM MCQ Exam*

DATE	BLOCK	DELIVERABLES & ASSIGNMENTS	ASSESSMENTS
Jan-Mar	Determinants of Health	At Home Interview, group presentation & written report OR, The Health Mentor Program School visit: ‘Do Bugs Need Drugs?’ Documentation of self reflection	Advisor assessment (P/P-/F)
April	Addiction Medicine		Advisor assessment (P/P-/F)
May	Sexual Medicine		
May	Term-2 Exam		EBM MCQ Exam (P/F)

AT HOME INTERVIEW (AHI)

LEARNING OBJECTIVES:

- Identify the social issues that need to be addressed in providing health care for an individual with a chronic condition.
- Identify the social and psychological impacts of chronic conditions in the lives of individuals.
- Identify, if possible and as necessary, the impact of a chronic condition on an individual's family.
- Identify the similarities and differences between treating acute conditions and providing care for a person with chronic conditions.

ORAL PRESENTATION (IN GROUP DISCUSSION) - WRITTEN REPORT

PREPARE FOR THE INTERVIEW

- Assigned reading materials
- Locate additional article(s) relating to the familial, social, and/impacts of the condition of your interview participant. Develop questions for AHI that are relevant to your participant's condition and that will enable him/her to tell the illness narrative.
- Audio-recording is allowed only with the explicit consent of the interview participant prior to the beginning of interview. Video-recording not permitted.

ETHICAL IMPLICATIONS FOR AT HOME INTERVIEW ASSIGNMENT

- Assure interview participant that all information will be kept confidential.
- At any point, interviewee may decide not to participate or may refuse to answer questions. This is their prerogative.
- Do not use identifying details in your presentation.
- Do not discuss details of patient/interview with friends, family or colleagues .
- All information recorded (electronic or paper) must be destroyed when your written report has been submitted and assessed.

UBC BEHAVOURAL RESEARCH ETHICS BOARD CERTIFICATE

INTERVIEW QUESTIONS SHOULD COVER THE FOLLOWING TOPICS

- Basic biographical and demographic information that may be relevant to the family, social and economic impact of condition.
- The individual's description and knowledge about the medical aspects of the condition.
- Onset or cause of the condition.
- Knowledge of the condition prior to onset.
- Impact on everyday activities.
- Impact on relationships with families and friends.
- Impact on education, occupation, other social relationships, etc.
- Experiences with health care providers (including alternative therapies). Knowledge that would be useful for health care providers.

ANALYSE YOUR INTERVIEW

- Focus on the familial, social and psychological issues. Are there central organizing issues or themes in the account?
- What is the relationship among the progress of the disease, the social career of care, and the individual's personal experience or biography?
- How did the issues that arose in the interview compare or contrast to the information presented in the social and psychological literature you reviewed?
- How is the kind of information obtained in the AHI different from that obtained in a clinical interview?
- What family or social issues are important for appropriate care for a person with this condition?
- If the condition has a genetic component, how does that affect relations within the nuclear and extended family?
- What insight has this interview given you into this disability or chronic condition, and the lives of others with disabilities or chronic health problems? How might these findings affect your approach to patients and your practice in the future?

WHAT WAS THE PURPOSE, FROM YOUR PERSPECTIVE OF THE *AT HOME INTERVIEW*?

- *This was a fantastic project to learn from. I took a lot of time to get suggestions and feedback from my interviewee on how I personally could improve my listening and interviewing skills*
- *This was the best project of the year. I learned that there is so much more to treating someone with a chronic illness than just their illness. I think it is easy to lose sight of that and speaking to this patient really made an impact on me that I hope I never forget!*
- *It allowed us to interact with a patient with a chronic disease and gave us a glimpse of the way that it had changed their lives. To gain an understanding of chronic illness and how it affects a person as a whole, in all areas of life, not just the medical side.*
- *To gain insight about what life living with a disability is like and what obstacles they face day to day. Having a better understanding of disabilities will help you better serve disabled people and treat them with respect.*
- *Understand the impact of chronic disease on patients and their daily function. Realize the perspective that patients have on our health care system and understand the challenges and shortcomings that they have encountered.It opened my eyes into the reality that chronic illnesses are experienced differently by different individuals depending on their situations. Listening to my peers' experiences was another source of learning; it is as if I did 8 interviews total.*

HOW DID THE *AT HOME INTERVIEW* CONTRIBUTE TO YOUR OVERALL LEARNING

- *This was by far the most valuable assignment of the year - I got a LOT out of it. Fantastic opportunity to experience an individual's perspective on chronic disease. Complemented the medical side of things we learn in FMED.*
- *Very helpful for encouraging us to understand a person in more depth than we are able to do in clinics and to understand how they interact with the health care system. This was the*

most meaningful part of the DPAS410 curriculum for me as was not just a story but someone's personal life that was shared with me, and it brought practical relevance to the curriculum.
- *This project was one of my favorites. I had such a positive experience at my patient's house and gained a lot of insight into disabilities. I found it was intimidating to make contact and go to someone's house for an interview, but it was great once I got there.*
- *I found it very interesting and rewarding to be able to speak to a patient so intimately about their experiences. This was a very insightful and meaningful assignment and helped to develop compassion and a greater understanding of what patients and their family and friends must endure to cope with their chronic illness. I also really enjoyed our group presentations to share our interview findings.*
- *This assignment was valuable because it gave me exposure to a chronic illness I had previously not known about; it helped me to understand first hand how a chronic illness can affect someone's life; and it gave me some good experience 'history-taking' in a context other than what we are usually exposed to.I think this was a good learning opportunity - many of us don't know someone with a chronic illness. One of the BEST experiences I had in medical school= very, very valuable. I was touched by the person I interviewed and they have inspired me.*

ADDITIONAL EDUCATIONAL OPPORTUNITIES FOR ADDISON'S SOCIETY AND UBC MEDICAL SCHOOL

- **Health Mentor Program (pilot began 2012)**
  - Person with chronic condition volunteers as 'health mentor' to a group of students of several disciplines (e.g. medicine, nursing, rehab, etc).
  - Meet 2-3 hrs, 6 times/18months, with your group.
  - Each meeting focuses on one aspect of living with a chronic condition; students ask questions relevant to the specified focus.Students write self-reflection journals (supervised by their advisor) and give a presentation to their group.**Community Advisory Board**
- **UBC Annual Health Fair – 'allies in health'**
- ***Doctor, Patient and Society 420* -** all 2nd year students select one of three options:
  - Community Service Learning Option (CSLO)
  - Self-Directed Project Option (SDPO)
  - Discussion Group Option, in which they also visit one Community Health Organizations, to learn about services offered to client

Highlights from Local Meetings:

Vancouver Island Support Group - Victoria

The Vancouver Island support group met at the Esquimalt Serious Coffee in Victoria, on February 16 with fourteen attending.

A pharmacy bulletin was presented on Vitamin K2 and its role in calcium metabolism and heart health. Vitamin K2 has been found to direct calcium to areas of the body where it is needed, such as improving bone density, and preventing calcium building up in other areas where it is not needed. Vitamin K2 seems to have the ability to break down deposits in the arteries. It can be taken as a supplement or in cheeses, egg yolks, butter, chicken and ground beef. http://en.wikipedia.org/wiki/Vitamin_K

Some members take few or no calcium supplements. One found that her bone density improved from training with 5 to 7 pound weights and regular walking, without taking calcium supplements. Doctors advise us to take daily calcium supplements with Vitamin D, but recent news stories caution against high calcium intake. Our doctors can advise us of what is the current recommended calcium supplement dose. A woman with very good bone density has been told she has osteoarthritis in her hips, spine and neck causing the fusing of some joints and the creation of bone spurs. She will consult her endocrinologist to ask about appropriate calcium supplements.

Taking extra medication prior to clinical operations was discussed. One woman had local anaesthetic for five eye operations without increasing meds. Another routinely takes extra for dental procedures. For abdominal surgery, she doubled her cortisol replacement beforehand. A nurse, and member of our group, said it was standard for her hospital to consult with an endocrinologist before surgery. A patient may be given a Solu-Cortef IV before the procedure, she said. Check the Society website under Surgery: http://www.addisonsociety.ca/related/FAQApril2011.pdf

A woman increased her dose to improve energy while helping a family member through a lengthy recovery from an accident. A couple of people take replacement only once each day, in the morning. One takes .75mg of Dexamethasone while the other takes 20mg of Cortef. While discussing medications, one member was informed by an Earthquake Preparedness coordinator that she should keep 3 months' supply of medication stowed in an earthquake kit. Realistically, if a large quake strikes, we cannot count on purchasing meds right away if they are needed. Having 3 months' supply in an earthquake kit will require rotating your stock of pills to keep them fresh.

One member asks her doctor to write "as needed" on her prescription to allow refills without renewing prescriptions. Once, picking up her prescription, she was given pills in the manufacturer's bottle which showed the expiry date. Knowing expiry dates is very helpful. Another woman always asks for her meds to have the expiry date printed on the label. You may ask your doctor to prescribe medications for longer than 3 months in B.C. Evidently, even non-members can purchase medications at Costco, taking advantage of their reduced costs and prescription filling fees. When you request Solu-Cortef from your pharmacist, ask for a long expiry date. It is possible to get a product with an expiry date for up to 2 years.

A woman was taken to hospital in crisis caused by a bladder infection, after weeks of feeling very low in energy. She was given a regime of antibiotics and increased cortisol replacement to fight the infection, and felt better after 48 hours. Unfortunately, she spent Christmas in hospital instead of hosting a large dinner party, as planned. She wondered how long it should take to reduce her Prednisone back to normal after this crisis. Each time she reduced, every two weeks, she felt tired. It was suggested that she try reducing by smaller amounts each time, so her body can more easily adjust to the change.

Employees of the University of Victoria are eligible, through UVic's Health Services, to take part in a program called Functional Medicine. This concept uses an overall view of each patient, for example, medical history, family health history, genetics, environment and lifestyle choices, to address the underlying causes of disease. This knowledge equips healthcare practitioners to better help patients manage. Functional Medicine addresses the whole person, not a set of isolated symptoms, and is an approach being used in many medical schools throughout the world. http://www.functionalmedicine.org/

DHEA seems impossible to acquire in Canada, other than at compounding pharmacies with a prescription. Sources in the US are reluctant to ship to Canada. A woman was able to find 'pure' DHEA from Amazon.com but it had to be picked up in the USA.

Two members have had past emergency eye operations because of fluid blockages in their eyes, a type of glaucoma (i.e. secondary acute angle-closure glaucoma). Taking corticosteroids is a risk factor. Both have been advised to have their eyes checked each year to avoid complications. We all should take note.
http://www.mayoclinic.com/health/glaucoma/DS00283/METHOD=print&DSECTION=all

Several people have had colds or flu. Even after having a flu shot, a woman had flu-like symptoms and increased meds by one half to cope. Another doubled up for a cold. A member recommends taking probiotics from the health food store to fight colds. Check the Society website for medical advice under Common Cold/Flu
http://www.addisonsociety.ca/related/FAQApril2011.pdf

Submitted by Jim Sadlish

Our next meeting will be April 27 and feature a speaker, Marilyn Walker. As part of her teaching and research as a university professor, Marilyn has done a lot of work on stress and stress management. She is also a member of our support group. The meeting will be at Serious Coffee, Esquimalt Plaza, 1153 Esquimalt Road in Victoria.

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

For information on Central Island activities, contact Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

The guest speaker at the October 2012 meeting was from the UBC Faculty of Medicine, describing how their yearly interviews with volunteer Addisonians from the Vancouver support group fit into their course *Doctor, Patient and Society* & the *At Home Interview*. A summary of the Powerpoint presentation is included elsewhere in this newsletter.

This group also met March 9, 2013 with 6 Addisonians and 2 husbands attending. Gerry Ott talked briefly about the provincial magazine called "My Voice" about planning living wills and handling legal documents for end of life. The magazine is available through the BC government at their website www.seniorsbc.ca or www.healthlink-bc.ca.

Next meeting to be confirmed is May 25th in Neil Russell Room. This is our social and finger food meeting where we get to know each other better. If the room isn't available for this date, the meeting will be cancelled unless someone is willing to set up and take down. Please contact Judy 604-036-6694

Gerry mentioned that membership forms are available and on line for those who hadn't paid, $25 membership fee apply. Reminder: the $5.00 for our or any group goes towards gifts for guest speaker, expenses for the meetings and any cost incurred for the room.

We introduced ourselves while waiting for the speaker to arrive.

Our guest was Gayle Ryon, EHSC:EX representing the BC Ambulance Service. Due to the small group, discussion was informal.

He explained the levels of medical care available from paramedics in BC. Their medical education ranges from:

1. Having an occupational first aid certificate plus one week of ambulance equipment training (usually the driver has these qualifications)
2. Primary Care Paramedic has an additional 6-months training course; this is the bulk of paramedics in the province (about 3,400). These paramedics can administer an IV saline or glucose drip.
3. Advanced Care Paramedic (Gayle is one): These paramedics have extensive training on administering IV's through difficult access points like the jugular, cardiac episodes and diabetes treatments, etc. They can administer drugs if an emergency physician directs them to via phone while on route to hospital. These specialists can be found only in urban areas at present.

Wording on our Medic Alert Bracelets

Gerry Ott asked Gayle to assess him as if he had just been found unconscious in an auto accident. Gayle did his usual routine of inspecting the body for visible signs of trauma. He checked Gerry's pulse, noted his breathing rate and that his airways were clear. Soon he noted the necklace and read it. Gayle kind of glossed over the word Addison's and verbally mentioned the allergies listed on the necklace.

This misdirection got us talking about the actual words on our health tags and how best to word our disease to trigger the best response from health providers. Carla has *"Acute Adrenal Insufficiency – takes cortisone"* written on her bracelet and Gayle thought that was a clearer message. *(Please see end of these minutes for more on this topic.)*

Gayle also talked about preparing our homes, cars and purses for a visit from paramedics.

Here are a few of his suggestions:
- Displaying a red cross on our refrigerators indicating where we keep our drugs.
- Keep an up-to-date list of drugs we take and make sure it **is dated.**
- Eliminate unnecessary drugs from our urgent drug collection so as not to confuse medics
- Date all our emergency papers so medics know they are current
- Keep up-to-date list of medications in glove compartment of our cars along with IV kit if we have one
- Advocacy is important, keep phone number of our advocate with our drugs

911 Calls

We also discussed what we can say when on the phone with 911 to get the service we require. BC 911 operators use a card system to filter calls. First we are asked if this is a health, fire or police issue. Once a health issue is identified they have to follow the questions on the cards so it may seem to us that we are wasting time answering unnecessary questions. This process must be followed for legal and accountability reasons. If the operator suspects a cardiac arrest, it is likely two ambulances and a fire truck may show up at your house. He was going to explain why, but we didn't get back to it before the end of the meeting.

Gayle mentioned that we can use the words "*Advanced Directive*" to the operator and that will trigger a different response from the medics. My understanding is that an "*Advanced Directive*" is a letter from our doctors detailing the treatment we need. *(I am having this wording clarified as most of us rely on the Ottawa Protocol letter found on the Addison's website when we go to emergency).*

Additional note received from Gayle after the meeting: *There was some good content in the meeting that I would like to review with BC Ambulance Service; I am meeting again with Gerry on Tuesday to work on a formal proposal and will be able to give a more qualified answer to some of your questions once I've had a chance to talk with our medical director.*

So stay tuned, there may be more useful information for all of us.

Submitted by Patti Chabot

The next meeting of the BC Lower Mainland Group will be Sat. May 25, 2013, 1:00 pm to 3:00 pm in the Neil Russell Room, Royal Columbian Hospital, 330 E. Columbia St., New Westminster BC.

For further information on this support group or any upcoming meetings, 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, or Peter Little at bettypeter66@gmail.comor (780) 918-2342 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 Support Group is scheduled for Sat May 11, 2013 from 1 pm to 4:30 pm (registration from12:30 pm) at the Erin Mills United Church (Lower Hall Meeting Room), 3010 The Collegeway, Mississauga, Ontario L5L 4X9 (accessible by public transit).

Our guest speaker, Dr. Scott Clack, ND, of Touchstone Naturopathic Centre, Oakville, will speak on nutrition, energy, hormones, and other related topics, including a Q&A session.

As well, we will once again have an Emergency Injection Training Clinic, with member Denise Burpee, RN, BScN. This exercise takes only a short time yet may be a life-saving for one of us.

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 next meeting will be noon Saturday, May 11, 2013, the weekend before the long May weekend, at the usual location (Robbie's Restaurant on St. Laurent Blvd in Ottawa).

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 are Georgia Kapralios and Dr. George Kambranis, 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: Most of the Saskatchewan members are on Cortef. I have been prescribed Dexamethasone from an internist. I haven't seen an endocrinologist yet. Do you have any thoughts on Dexamethasone as treatment for Addisons? Should I request Cortef instead?

> **A: Dexamethasone is a long acting hydrocortisone derivative. The fact that it is long acting makes it an unsatisfactory replacement for hydrocortisone because hydrocortisone is secreted by the body in bursts every 60 to 90 minutes. The interval between bursts is important to give the cells time between each stimulation. Dexamethasone gives continuous stimulation and results in over treatment.**
>
> **Most individuals are on hydrocortisone (cortisol Cortef) or cortisone. The cortisone is converted to hydrocortisone in the liver. These medications are usually taken 2 or 3 times a day. Prednisone is also used by some people but we tend to discourage this because it is also long acting.**

Q: I have Addison's and take cortisone, Florinef, Synthroid and B12 shots. Is it safe to take coenzyme Q10?

A: The coenzyme Q10 should not cause any problems with your other medications.

Q: I have just been diagnosed with Addison's and it will be some time before I can get in to see an endocrinologist. Is it safe to continue playing sports that involve contact (floor hockey) or should I get exercise in another way?

A: If you have just been diagnosed with Addison's disease, it was probably your family doctor who made the diagnosis. Did your family doctor start you on replacement medication? If not, I would be surprised that you feel energetic enough to play floor hockey. If you are on medication, the endocrinologist will make some adjustments, but probably not change things too much.

I don't think the contact in the floor hockey is the issue, it is how you feel and what your stamina is like that matters. Since I do not know very much about your situation, I do not want to give you specific advice. Your family doctor will know where you stand in your hydrocortisone replacement and should be able to help you out.

Q: I was diagnosed with H pylori, and given antibiotics. Unfortunately, I had a very rough time with the meds and ended up in hospital because of dehydration. I am now experiencing anxiety. I am also experiencing ear issues - blocked ears and a tingling sensation in my face, most often after I eat. Could this be related to my Addison's Disease? Will the anxiety go away when the Addison's eventually gets in order? What do the electrolytes do and could they be out of whack because of my ill health for the past several months? I am feeling much better as far as my gastrointestinal situation goes although I do have the occasional discomfort.

A: You can sort out some of these concerns by getting your Family Doctor to give you a lab slip to check your electrolytes and perhaps recheck the H pylori test to see if it is clear. Some of the tingling sensations could be related to stress. None of these symptoms are likely to lead to serious problems as long as you are taking your hydrocortisone and Florinef.

Q: I am 37 yrs old and was diagnosed with Addison’s in March of 2011. I am 5'4", 122 pounds and take 35 mg of cortef (15 mg at 8am, 10mg at noon and 5pm) and .1mg of Florinef daily.

I am very active and recently (Oct 2012) competed in a physique competition, which required training 6 days/week. I managed my Addison’s well during the training and am looking to compete again. My biggest challenge is getting out of bed in the morning. I want to train early and find getting out of bed so difficult. Is there a way to improve this?

I get 8-10 hours a sleep a night and it isn't enough. Falling asleep and sleeping isn’t a problem. I am usually in bed by 9-930 and sleep until 7 am. I used to take 5 mg of cortisol at 5pm and then I really could not get out of bed in the morning. I felt like a ton of bricks was on my forehead and I was told it is low cortisol. We increased the 5pm dose to 10 mg and things are better. I feel my cortisol is low in the mornings causing the extreme fatigue until I take more morning medications.

> **A: The problem of being tired in the AM is not restricted to individuals with Addison's disease. The first thing I would generally ask is whether you are sleeping properly. You should also try to get to bed early--by 10 PM. I may sound like your mother but this may be an important factor in overcoming morning fatigue.**
>
> **Sometimes, if you take hydrocortisone too late in the day you will have trouble sleeping. You could try cutting the 10mg you take at 5 PM to 5 mg and taking it at 4 PM if this is possible.**
>
> **As well, you can try having your hydrocortisone and a glass of water at your bedside and take the 15 mg before you get out of bed.**
>
> *(Ed. Note: Some UK Addisonians have commented that, unless they take their meds before getting out of bed, they do not feel well all day.)*

Q: I am newly diagnosed with Addison's disease and gained about 30 pounds of water weight before I was diagnosed. Even after being on hydrocortisone for six months, I am still carrying the retained water. It is my understanding that the retained water is intracellular water and that this kind of retained water is almost impossible to get rid of. Will the retained water go away over time? Is there anything I can do to speed up the loss of water?

> **A: Your problem is unusual and I am not sure I have all the answers. It is unusual to retain a lot of fluid before you are diagnosed with Addison’s disease because you are missing aldosterone, the adrenal hormone that causes salt retention. The cortisol will help to improve blood flow in your kidneys, so it could help to mobilize the fluid, but I would not want to promise that this would take place. I think you should talk to your endocrinologist about why this fluid retention occurred and what caused it. It may be a different problem.**

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.

The Canadian Addison Society
La Société canadienne d'Addison

193 Elgin Avenue West
Goderich, Ontario N7A 2E7
Toll free number: 1-888-550-5582
Email: liaisonsecretary@addisonsociety.ca
http://www.addisonsociety.ca

Membership in The Canadian Addison Society is $25.00 due January 1st of each year.

New Membership ☐ *Renewed Membership* ☐ **+** *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*

☐ *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 Québec Support Group – QC+ $20.00 to Society*
☐ *$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*

+ *Contributions are also gratefully accepted. A tax receipt will be issued for contributions over $10.00.*

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

Revised: October 2010