



# The Canadian Addison Society La Société canadienne d'Addison

2 Palace Arch Drive, Etobicoke, Ontario M9A 2S1  
1-888-550-5582

[info@addisonsociety.ca](mailto:info@addisonsociety.ca)  
[www.addisonsociety.ca](http://www.addisonsociety.ca)

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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/Adrenal Insufficiency management program. Please note that the Society does not endorse the information provided by guest speakers.*

## News and Announcements



### John Gordon

It is with sadness that we must report to you that John Gordon passed away January 17, 2017, at 82 years of age. Sincere sympathy has been shared with Irene and family on behalf of all Society members.

Many of you will have known John for years. John was the Treasurer for the Society for 15 years and Irene was Secretary Extraordinaire for 10 years. Both Irene and John made huge contributions of their time and talent to our Society over many years for which we will be eternally grateful.

You may follow this link to view John's full Obituary.

<http://mccallumpalla.sharingmemories.ca/site/JohnDonaldGordon.html?s=40>

### A few member recollections:

*"So sorry to hear of John's passing. He was a truly great member volunteering for Treasurer for so many years. We appreciated he and Irene's input and coming out to BC to present and explain the reports to members. He will be missed but left behind many memories for those who knew him."*

*"I am truly saddened to hear that John has died. He did so much for our Addison's group. He will be missed deeply."*

*"I am very sorry to hear of John's passing. I did meet John (and Irene) on two separate occasions at the Annual General Meeting's in B.C. A very nice, friendly man and he was very good at his job of Treasurer for the Society."*

*"Sad news! Very grateful for all John (and Irene) have done for our society. I learned that he was very involved in all his communities after reading his obituary. You will be missed!"*

*"Members have shared how John had a gentle presence and consistently shared his successes and challenges over his many years as a vital director of the Society. Many felt that Irene and John reflected a sense of familiarity and safety at meetings. They were only a phone call away when there were any member-related inquiries. John reminded us that we must continue to share our message of hope and seek the highest quality of life."*

## **News and Announcements *continued***

### **Membership Renewal**

Members, have you renewed your Membership for 2017?

This is the last time you will be required to renew.

Your 2017 Membership dues will convert your membership to a **Lifetime Membership**.

Renewal can be done on-line from our website using the PayPal link.

### **Editor's Comments**

Have you had an experience with Adrenal Insufficiency either as the patient, caregiver, family, friend, nurse, doctor or any other role? Please consider sharing your story for our **Personal Experiences** section, for the benefit of others. You may do so anonymously. Please forward to [newsletter@addisonsociety.ca](mailto:newsletter@addisonsociety.ca)

Please see "*Becci's Story*" (attached)



### **President's Comments**

[president@addisonsociety.ca](mailto:president@addisonsociety.ca)

**Rare Disease Day will be here very soon.**



Please visit <http://www.rarediseaseday.org/> to learn more about this worldwide event.

### **Seeking Regional Representative Volunteers**

The Society is seeking members interested in becoming our volunteer Regional Representative in several regions in Canada. We are seeking Representatives in the following regions, some of which are replacements for retiring members and others are new assignments.

#### **Edmonton, Calgary, Quebec City**

The duties of the Representative may be viewed on our website or by following this link  
<http://www.addisonsociety.ca/pdfs/duties-of-the-regional-representative-nov-2016.pdf>

The Canadian Addison Society is a 100% volunteer organization.

If you have interest in taking on one of these important volunteer positions, please contact the writer at [president@addisonsociety.ca](mailto:president@addisonsociety.ca)

### **Welcome to a new Regional Representative**

We offer a big welcome to the Regional Representative role to member Geoff Metcalfe for stepping forward to take on the Regional Representative's role for the B.C. Lower Mainland Support Group. The Society's National Past President, Judy Stanley had also been the long time Regional Representative for this group and has stepped aside for personal reasons. The Society is indebted to Judy for her many years of volunteer service to the Society.

## **Support Group Contact Information & Meeting Reports**

### **B.C. - Vancouver Island Support Group**

The next meeting of this support group is scheduled for **February 25, 2017** from 1 to 3 pm. Location is 749 Wesley Court, Saanich.

For further information on the Vancouver Island Support Group, please contact Derek Clarke at [vancouverislandaddisons@gmail.com](mailto:vancouverislandaddisons@gmail.com) or (250) 857-4320.

For information on Central Island activities, please contact Sharon Erickson at [ericksons@shaw.ca](mailto:ericksons@shaw.ca)

### **BC - Lower Mainland Support Group**

The next scheduled meeting for this group is for Saturday, **April 22, 2017** at 1 pm. Location is the Neil Russell room at Royal Columbian Hospital New Westminster.

For further information on this Support Group please contact Geoff Metcalfe at [calfe579@telus.net](mailto:calfe579@telus.net) or 604-533-0579.

### **Alberta - Edmonton Region Support Group**

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

We are searching for a volunteer to take on the Regional Representative role in the **Edmonton** Region. If you are interested, please contact either Ginny Snaychuk at [gjinray@shaw.ca](mailto:gjinray@shaw.ca) or Harold Smith at [president@addisonsociety.ca](mailto:president@addisonsociety.ca).

### **Alberta - Calgary Region Support Group**

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

We are searching for a volunteer to take on the Regional Representative role in the **Calgary** Region. If you are interested, please contact either Ginny Snaychuk at [gjinray@shaw.ca](mailto:gjinray@shaw.ca) or Harold Smith at [president@addisonsociety.ca](mailto:president@addisonsociety.ca)

### **Saskatchewan Support Group**

The Saskatchewan Addison Support Group met October 2016 at a members' home. There were 9 Addison's (8 female and 1 man) and 4 spouses.

I was fortunate enough to connect via computer to the 2016 AGM (Saskatoon, SK to Woodstock, ON) before the group met- it was really great to connect faces to names!! I would highly encourage other Provincial Reps to try and connect next year.

After listening to CAS AGM 2016, I highly encouraged non-CAS Addison's to become members. CAS wishes the Federal / Provincial government to listen to us and to make to Provincial Paramedic legislation regarding giving an Addison in crisis an emergency injection of Solu-Cortef injections –we need to increase our membership base. We had 6 non-CAS members at this meeting so it would help a lot with the cause. CAS Lifetime membership is coming in January 2017 instead of yearly memberships.

At our meeting our members shared their own experiences living with Addison's. Some are experiencing real difficulties obtaining a diagnosis with possibly other autoimmune disorders and seeking out Endos, Internists or GP's that will listen to them and their real symptoms'. Some ladies are on DHEA and have found compounding pharmacies to make it. Amounts vary on the amount of DHEA taken just like very different amounts of Cortef / Florinef taken on a daily basis.

Whether it is a glucocorticoid or mineral steroid a standard dose of a steroid—IS NOT THE NORM for this group- the daily dose taken is based on an individual symptoms', activities of daily living and blood work.

Our meeting concluded with learning how to mix and draw up Solu-Cortef into a syringe for injecting into a muscle for Emergency use. CAS sent us training vials supplied by Pfizer – and it is greatly appreciated. This group recommends a family member practice in the drawing up of the medication so it is not wasted. Some took extra vials and syringes home so they could show their spouse...

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## **Support Group Contact Information & Meeting Reports *continued***

### **Saskatchewan Support Group *continued***

It appears there is a Saskatoon / Regina and surrounding area Addison's sub-group. A few Addisonian's meet between meetings in Saskatoon to support each other.

Hello from Saskatoon Sask.

We have formed an Addison sub Group of 7 to 8 Addisonian ladies .We meet periodically for coffee at a restaurant of our choice.

Our group is very supportive and we enjoy our time together with laughter, tears & frustrations. We discuss all aspects of baffling this disease.

We encourage everyone to form a sub group or join one as we receive unconditional love from our group. Anyone who wishes to join our group please email me at [jgweb2004k@yahoo.ca](mailto:jgweb2004k@yahoo.ca)

*Jeannette Weber*

We are trying to arrange the next main support group Saskatchewan meeting in Regina sometime in November. It will be posted on the CAS website.

For information on the Saskatchewan Support Group, contact Elizabeth Hill (306) 236-5483 [elizabethhill10@hotmail.com](mailto:elizabethhill10@hotmail.com)

### **Ontario - South/Central Support Group**

The next meeting of this support group is tentatively scheduled for May 2017. Watch the Society's website for developing plans for this meeting.

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

### **Ontario - Eastern Support Group**

We will be looking to have a special guest at our next meeting in May 2017 and we hope that you will be able to attend. Watch the Society's website for developing plans for this meeting.

For more information on Eastern Ontario Support Group activities or meetings, please contact Ghislain Hardy, email [ghislain2406@live.ca](mailto:ghislain2406@live.ca) or telephone (613) 601-3671. *Those located in Quebec, near Ottawa, would be most welcome at our meetings.*

### **Quebec - Montreal Region Support Group**

The Montreal Region Addison's support group met for the third time in December at PF Chang's on Decarie. We had a great turnout, seven adults and two new babies! As always it was a great opportunity to meet, share and learn from each other. Not only did we have the opportunity to share our individual stories but we also had the chance to see how living with Addison's and other autoimmune diseases affects our daily lives.

Some topics discussed were DHEA, Renin levels, osteoporosis just to name a few. Articles regarding these topics were sent via email. We discussed the possibility of getting the Montreal and Ottawa chapters together and finding an endocrinologist who would be willing to answer questions. All in all a great afternoon. Our next meeting will be scheduled sometime during the summer.

*Shelley Saklatvala*

For information on Montreal Region Support Group activities or meetings, please contact Shelley Saklatvala, email [shell326@hotmail.com](mailto:shell326@hotmail.com) or telephone (514) 991-0294.

### **Quebec - Québec City Region Support Group**

We are searching for a volunteer to become our Regional Representative for a Quebec City Region Support Group. If you can assist in this volunteer role please contact Harold Smith, [president@addisonsociety.ca](mailto:president@addisonsociety.ca). In the interim, if you are trying to connect with the Society for support please call our Montreal Area Regional Representative, Shelley Saklatvala at (514)-991-0294 or you may also call the Society via our Toll Free number 1-888-550-5582 or email [info@addisonsociety.ca](mailto:info@addisonsociety.ca) or [president@addisonsociety.ca](mailto:president@addisonsociety.ca).

### **Atlantic Canada Support Group**

For information on the Atlantic Canada Support Group activities or meetings, please contact, Holly Mclean email [hquilter@nb.sympatico.ca](mailto:hquilter@nb.sympatico.ca) or telephone 506-546-1687. Holly lives in northern New Brunswick

## Medical Q & A's

*There is a very large and wide-ranging set of questions on both daily living and situation-specific issues that have been answered by our medical advisor over the years. Before submitting a question to our medical advisor, please consult the wealth of Q&A's on our website. To review these questions and answers, please go to the Canadian Addison Society website under Education or refer to previous issues of the newsletter available on the website.*

### Question 1

I am wondering at what times I should be taking my meds - Cortef, Florinef. I have been taking my night pill around 5:30-6:00 pm and the morning pill around 8:30 am in the morning. I am so very lethargic, no energy and do not feel well at all. I am also somewhat shaky. I take 20 mg of the Cortef in the morning and 10 mg in the late afternoon. I take 0.1 mg of the Florinef in the morning. Should I be taking this Med with food. The morning pill should have food with it, I assume.

### Response 1

The timing of your medication can vary and you can try different options to see what seems best for you. The usual approach is to try to take the morning dose as early as possible. You can have it at your bedside table and take it when you wake up so it will be in your system as you start your day. It is a good idea to take a second dose at noon or earlier depending of when you take the first dose. This can be 5 or 10 mg. You can then take a third dose in the late afternoon e.g. at 4 or 5 PM, possibly 5 mg. You can take the morning pill without food. The point is to take it as early as possible even before you get up.

Some individuals do well on 2 doses a day and others do well using 3 or 4 doses a day. The total daily dose has to be watched and you should check with your endocrinologist to monitor your situation.

You can experiment with the number and timing of your doses to see what is best for you. Be sure to check with your endocrinologist about your changes. You can take your other pills during the day with food.

### Question 2

You answered a question for me a couple of years ago, about secondary adrenal insufficiency as a result of taking Flonase spray. I was on Cortef for about 3 years as a result, and this year I was able to successfully taper off from the Cortef with my adrenal function returning in large part. I have now been off it for about 6 months. My question is that recently sometimes in the evening I get the same sensations that I used to have when my cortisol level was low before my next Cortef dose. Sometimes I also feel nausea, which I used to get, and I need to lie down for a couple of hours before it passes. A few times it has been bad enough that I resorted to taking 2.5 mg of Cortef, and that resolves both the low cortisol feeling and the nausea within about 20 minutes. Is it safe to do this a couple of times per week? And does this indicate that my adrenal function may relapse? My doctor suggests testing my cortisol level again with a morning blood test, but I think my level in the morning is okay, but it is in the evening that this low cortisol symptom is happening. Thanks ever so much for your help, it is much appreciated.

### Response 2

After coming off cortisol it is difficult to be sure when your pituitary/ adrenal function is completely normal. We usually suggest that individuals should be given extra cortisol before stressful situations such as surgery for 6 to 12 months after coming off cortisol. In your case, if your pituitary and adrenal function was normal before using the steroid puffer, the function should return to normal with time.

In your case, you seem to have difficulty in the afternoon and this seems to be resolved by cortisol. Normally I would encourage you to carry on without added cortisol with the idea that your pituitary/adrenal function would progressively improve. Since this does not seem to be improving, it would be worthwhile discussing this with your endocrinologist and do some checks of your hormone levels. If you checked your cortisol and ACTH levels throughout the day, e.g. AM, noon and 4PM you would get an idea what your levels are like. Be sure not to take cortisol before doing this. Check this out with your endocrinologist to see if she/he agrees. They may have other ways to get the information you need.

## **Medical Questions and Answers**

**Dr. Donald Killinger, MD, PhD, FRCPC**

Medical Advisor to The Canadian Addison Society

Dr. Killinger will answer your questions about Addison's/Adrenal Insufficiency. Send your question to Dr. Killinger directly from the webpage or this link <http://www.addisonsociety.ca/ask-a-question.html>

By emailing [info@addisonsociety.ca](mailto:info@addisonsociety.ca) or by Canada Post to The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, ON M9A 2S1  
*Questions and answers that may be of interest to everyone may be published in the Newsletter and on the website.*



At the early age of 25, I was admitted to the hospital with an insanely high heart rate and a dangerously low blood pressure reading. I was kept under close surveillance in the palliative care unit while doctors and specialists began tests to try and figure out what was wrong.

About three months prior I had noticed myself slipping at work, making silly mistakes and losing track of what I was doing. It was uncharacteristic of me, and a big problem because at the time I was training on a Garde manger position in a high-end restaurant in Toronto. It's not the sort of place where small mistakes are forgiven: seared scallops go from delicious and buttery to tough and burnt in seconds.

A little while after my focus and memory went I started to experience gastrointestinal issues that a series of drop-in clinic doctors called a stomach bug and sent me home to rest with a prescription for codeine. Eventually the stomach bug' gave way to fatigue. The kind of fatigue where I could start my day, have a shower, lift my arm to brush my hair and 10 seconds in, drop to the ground in exhaustion just to crawl to the couch and fall into a deep sleep for a good few hours. Thing was, in between the weird bouts of fatigue I would still feel normal. And not being one to complain I would do what I could with the energetic hours and rest during the tired ones.

Slowly all good hours turned to tired ones and I went home to my parents in Waterloo to rest up and ride out the 'stomach bug' doctors were sure I was suffering from. While there, despite my best efforts to eat I started losing weight, and lots of it. Which wasn't helping my energy levels and my activity dwindled from that of an active, university graduate, career building, passionate 25-year-old, sister, daughter, and friend, to making as many loops around the kitchen table a day as I could muster. This carried on, amidst the busy lives of my folks, inwardly scared by what was happening to their youngest daughter and outwardly keeping busy with work and the running of the house and continued doctor visits.

Late one Saturday night I dragged myself to the washroom and slumped over the toilet where I began to throw up over and over again continuing into Sunday morning. Already so depleted, I felt like a ragdoll, shaking with each convulsion, not knowing how I could possibly lose more nourishment or survive the ongoing assault on the body. When my Dad woke around 5 am Sunday morning and found me in the bathroom, flattened, I waved the white flag of surrender and said to him, "I can't do it anymore... please take me to the hospital".

So, there I was, seconds after the triage nurse checked my vitals, people were running and hooking up machines and IV and racing me down the corridors. My vitals now stabilized but the journey was only just beginning. In the two weeks that followed, various specialists were brought in, blood tests taken, CAT scans and MRIs performed. I'd like to say I was feeling appreciative and grateful for life, family, and technology, but truth is I felt nothing. That's what stood out, I was so tired, I just felt empty. Happy to finally shut off while someone else took over.

I did enjoy the company of my roommate, a cranky rough around the edges woman in her 60s just wrought with health issues from a life hard won. My interactions with Roberta showed me I still had a bit of fight left, with our hardy banter, complaints about shifty hospital food and the always active justice piece in me that lectured her doctors about how to best deliver bad news and still be mindful of the heart and spirit of the patient receiving it. Pretty sure that colourful woman received a new death sentence everyday while in hospital care.

I also cherished my early morning visits with my Dad on his way to work. He didn't always know what to say so we would each pick a goddess card for the day and read it to each other. Do our best to enjoy the present moment, together. No one ever talked about an ending where I didn't get better but it was hard to deny the possibility given the growing interest in the 'young thing' in ward C, sharing space with all the 90 years old in palliative care to pass over.

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The internist would sit with me every day, intrigued and frustrated by the lack of direction with my treatment plan. Until the day of the breakthrough! The final piece of the puzzle in place, Doc was excited to see me that morning to share the good news, I was diagnosed with Addison's Disease. Then we went on to talk treatment options, and life options. In the Doctor's opinion, I could read everything I could find on my newly discovered chronic illness and probably be overwhelmed and depressed or I could know what I needed to maintain optimal health and just go about life the same. Reality has landed me somewhere in the middle. It hasn't been enough to just maintain and go about life the same, because it isn't. My normal is not what it was and not like the average person's. I've had to really dial back on what ideas and dreams I had for myself.

It pushes a person to get really crystal clear on what matters to them the most. I only have so much energy and so much good health to pore into the people and things I love. There is no acting now and thinking later. If I neglect the needs of my health, the effects are almost immediate. Training for any kind of physical accomplishment, work schedule, trip agenda, must be slow and steady, and often one at a time. Life is simple. But life is good. I have had help from many people along the way and I am so indebted to the constant support and understanding of close friends and family. Somehow, I have had the good fortune of amassing the most beautiful, genuine, life-loving group of people and it makes all the difference.

Living with a chronic illness is just that, on-going. It has constant ups and downs and takes a lot of community, healthcare workers, diets, sleep, exercise, tricks, mindfulness practices, mantras, pages of journals, screaming in cars, laughter, and love- especially self-love, to live with it. So, if anything I share here can make that same struggle or one like it easier for someone else, that makes me so happy. Welcome to my journal of health. I vow to be as honest and real as I can with my shared experience and I hope the same from you. If you have any questions for me, or content you want, or story you must share then please write. Really looking forward to connecting with you as I continue along this life of mine.