



# The Canadian Addison Society La Société Canadienne d'Addison

*Offering support for those with Addison's  
disease and other forms of Adrenal Insufficiency*

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## Distribute to:


## PLEASE NOTE:

*The content of this newsletter is intended for basic information only and not as personal medical advice. Please note that the Society does not endorse the information provided by guest speakers. Meeting minutes/notes are prepared by non-medical volunteers. Readers are advised to consult their own doctors before making changes to their Addison/Adrenal Insufficiency management program.*

## **News and Announcements**

### 2022 Annual General Meeting

The 2022 Annual General Meeting will be held in virtual format on **October 15**. Attendance is not restricted but voting privileges are with members only. If you plan to attend, please register with the Secretary-Treasurer: [admin@addisonsociety.ca](mailto:admin@addisonsociety.ca)

This is a very important meeting as several Directors will be re-elected for another three-year term, plus one new Director will become our new President. This new President is of course succeeding Harold Smith, who is retiring at the time of the AGM.

Attending is as simple as providing your email address and on **October 15**, clicking on the link that will be sent to you via email. Please mark this date (**October 15**) on your calendar and register to attend.

### National EMS Status

To learn the current status of Paramedic approvals to inject hydrocortisone (HC), Solu-Cortef, in your province /territory in case of adrenal crisis, please see the **National EMS Status Chart** attached to this newsletter. We continue on members' behalf, to work with all provinces and territories still not providing this service in some form.

In most cases, the onus is also on you, the patient, to always have your emergency kit with you and your MedicAlert bracelet or similar, easily accessible in case you are unable to explain your steroid needs. Remember, not all crises occur close to a medical facility.



**President's Comments**

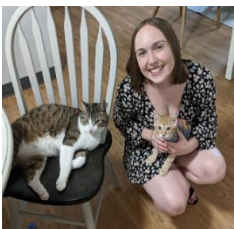
This is it! My final submission for the Newsletter 'President's Message'. Bittersweet is the most appropriate description of my feelings. Most readers will be aware that this is my second attempt at retirement, however this one is going to have to be the final one.

I have great memories of our many accomplishments as a Society over these many years, and of course none of it would have been possible without the selfless participation of so many members as volunteers. I have stated many times over the years, and it still applies that nothing happens in this Society without the effort and time of a volunteer. Nothing! We have grown from 125 to now approaching 450 members in just a few short recent years with the introduction of our Lifetime Membership. I am pleased that once you join, we can stay in touch and yet hope we are not pests but are here if you seek information or some other form of support. That is the Society's primary mission, support.

The pandemic has certainly challenged us yet here we are, still operating and in a few areas meeting regularly, albeit virtually. The in-person meetings that were the norm in some regions naturally had to be suspended and are missed by many regular attendees, yet the increased frequency possible with virtual meetings can be a bonus. Many who could never get to a meeting are finding the support they sought through the 'new' virtual meetings.

Going forward I would encourage Regional Reps to do both where practical and safe. In addition, I would suggest Directors could be immensely helpful by helping to promote member participation in the meetings, virtual or in-person when it is time to start holding them again. So many medical challenges with members it is wise to wait it out before rushing back to in-person meetings. Be wise, be safe.

Thanks to all  
Harold



**Editor's Comments**

Hi everyone! My name is Carly Charron, and I am happy to be taking on the role of Newsletter Editor. I am 25 years old and live in London, Ontario with my fiancé and two cats. In October 2019 I started experiencing fatigue, nausea, and light-headedness (symptoms we are all too familiar with) but just brushed it off as being due to the stress of university. By the end of December, I was so weak I could barely stand. I was admitted to the hospital on New Year's Eve and rang in 2020 with a diagnosis of Addison's Disease.

I remember my fiancé saying to me "The year can only get better from here", little did we know that COVID-19 was lurking just around the corner. Despite my illness, and a global pandemic, I completed my BSc in Genetics, and am now a PhD candidate at Western University, where I am working on developing an edible Salmonella vaccine for chickens. If I'm successful, maybe one day we will all be able to enjoy raw cookie dough without fear. Although I am very busy with school, in my spare time I enjoy hiking, cooking, reading, and playing piano.



### **Youth Ambassador**

Hello! My name is Kyle Yeates and I am honoured to be your youth ambassador! I am a recent BSc graduate in Physics from Saint Mary's university and have been living with Addison's Disease (more specifically, Schmidt's Syndrome) for the past 5 years since I was diagnosed at 18 years of age.

Life can be tough living with adrenal insufficiency when you're young. That's why I'm here to support you if you have questions or are just looking for someone to talk to that understands what you're going through! Feel free to send me an email at [youthadvisorycouncil@addisonsociety.ca](mailto:youthadvisorycouncil@addisonsociety.ca) if you'd like to connect!

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### **Managing Addison's and School – By Kyle Yeates**

School can be a really challenging time, even without the kerfuffle that comes with adrenal insufficiency. That's why I thought it might be helpful to provide a brief blurb about my experience as a university student so that you might have someone to compare to, and maybe help you prepare for your wonderfully hectic time at a post secondary institution!

My experience began back in 2018 after finishing my first year as an undergraduate Physics student at Laurentian University. At the time, I was still undiagnosed with Addison's and things were tough. I'd managed to flunk 4 out of my 10 classes due to constant exhaustion and brain fog, which made studying a near hopeless endeavor. At the time, I had thought that these symptoms were the result of being "out of shape", a poor university diet, or that I was simply "too dumb" to get a degree in physics. In a bizarre way, I was almost "lucky" to come home for the summer only to suffer from my first adrenal crisis. It was almost magical the difference hydrocortisone would have. Now I could walk or simply study without being fatigued. In my case, the brain fog wouldn't disappear for a few more years, but I now felt like I could face the impossible odds and pursue my passion for physics.

Going to university after getting diagnosed with Addison's can seem an incredibly daunting experience, but it isn't the end of the world! Enjoying this exciting time really comes down to building some positive work, study, and lifestyle habits. The most important habit for someone with adrenal insufficiency was just to learn to take advantage of every good day like it's your last. What I mean by this is that with Addison's you need to make sure you have time to recover from something stressful such as nasty cold, exams, etc. If you leave your projects to sit, you run the risk of running out of time. With Addison's, you can't just push through tight deadlines by staying up late and missing out on sleep since your body will give out on you if you don't respect it. That's why it's crucial to take advantage of a rigorous work schedule to guarantee you have plenty of time to rest and recharge between assignments or tests.

Another useful tip is to register at your school's disability and accessibility department as they can and will provide you invaluable tools to help manage adrenal insufficiency at school. Some examples of assistance offered can be the extension or even rescheduling of exams or midterms, should you come down with the flu or any other illness that might put you out of commission. The accessibility department can also contact your professors to inform them of your condition and to know what to do should you suffer from an adrenal crisis. This one is especially important as it could save your life! An accidental benefit of this form of contact is that it can help your professors remember who you are, which itself may lead to some exciting research (or employment) opportunities.

Frankly, those two would be the biggest bits of advice I can give to someone with adrenal insufficiency going into university. I must stress that university is tough, but it's an excellent opportunity to prove to yourself that you have what it takes to tackle your personal challenges and make a positive impact on the world. Finally, I need to stress that going to school with adrenal insufficiency doesn't need to feel impossible or scary. So long as you make a plan and stick to it, you'll soon find yourself deep in the rhythm of writing assignments, studying for tests, and taking your exciting first few steps towards the brightest years of your life!

### **Auto-Injectors and Pediatric Hydrocortisone Product**

Many of you will be aware or have heard some news regarding Auto-Injectors being developed to possibly replace our current emergency injection method, which would eliminate the cumbersome and sometimes near impossible task of preparing the shot in the current very challenging manner.

Attached to this newsletter is a status sheet outlining the situation, as we know it, of the candidates currently in the works as of August 2022. Please understand these candidates are still far from being approved and available in Canada. All three Auto-Injector companies involved have applied to the FDA in the USA, as one would expect. While only an assumption, we anticipate they will first achieve FDA approval and roll out their product stateside first, and only then can we expect them to apply to Health Canada for approval to sell in Canada. We are likely speaking of a few years yet.

One opportunity that may exist once they are FDA-approved and present in the USA market will be through Health Canada's Special Access Program. Speak with your doctor once you are aware the product is being sold in the USA.

On the other hand, the pediatric hydrocortisone product, Alkindi Sprinkle was very recently approved and available in the USA marketplace. We have yet to hear of an application to Health Canada. We will keep you posted as these products move through the processes involved in seeking approvals.

## Support Group Reports

*With the lack of in-person meetings, there are no Support Group Meeting Reports*

<p><b>Support Group Contacts</b> <i>Please contact one of the following members for information on the support group in your area</i></p>	<p><b><u>B.C. - Vancouver Island (Victoria)</u></b> Derek Clarke 250-857-4320. <a href="mailto:vancouverislandaddisons@gmail.com">vancouverislandaddisons@gmail.com</a></p>	<p><b><u>Quebec - Montreal</u></b> Shelley Saklatvala 514-991-0294 <a href="mailto:shell326@hotmail.com">shell326@hotmail.com</a></p>
<p><b><u>Alberta</u></b> Rosemary Brown 403-391-1507 <a href="mailto:hdbrown52@outlook.com">hdbrown52@outlook.com</a></p>	<p><b><u>B.C. - Vancouver Island (Nanaimo)</u></b> Sharon Erickson 250-729-1446</p>	<p><b><u>Quebec - Québec City</u></b> 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 Shelley Saklatvala 514-991-0294 <a href="mailto:shell326@hotmail.com">shell326@hotmail.com</a></p>
<p><b><u>Atlantic Canada</u></b> Annmarie West 506-333-1034 <a href="mailto:AtlanticProvinces@addisonsociety.ca">AtlanticProvinces@addisonsociety.ca</a></p>	<p><b><u>Manitoba</u></b> Pam Hilton 204-451-6763 or <a href="mailto:pamhilton41@gmail.com">pamhilton41@gmail.com</a></p>	<p><b><u>Saskatchewan</u></b> Nicki (Barr) Clarke 306-531-4567 <a href="mailto:nclarke@hotmail.com">nclarke@hotmail.com</a></p>
<p><b><u>BC - Lower Mainland</u></b> Geoff Metcalfe 604-533-0579 <a href="mailto:calfe579@telus.net">calfe579@telus.net</a></p>	<p><b><u>Ontario - Eastern</u></b> David Sparks <a href="mailto:davidsparks04@gmail.com">davidsparks04@gmail.com</a></p>	<p><b><u>The Territories</u></b> We are searching for a volunteer to become our Regional Representative for a Territories Support Group. If you can assist in this volunteer role, please contact Harold Smith <a href="mailto:hsmith.addisonsociety@outlook.com">hsmith.addisonsociety@outlook.com</a></p>
<p><b><u>BC- Northern BC</u></b> Tyanna Trottier 250-845-9446 <a href="mailto:tyannatrottier@gmail.com">tyannatrottier@gmail.com</a></p>	<p><b><u>Ontario - South/Central</u></b> Sheri Thiffault 647-406-7780 <a href="mailto:thiffaultsheri@gmail.com">thiffaultsheri@gmail.com</a></p>	<p><b>Volunteer Today</b></p>

## Medical Q & As

### Question 1

*For the past ~6 years (Jan 2016-present), I have been suffering from an unexplained dizzy/woozy/floating sensation which has eluded diagnosis. This sensation is accompanied by a constellation of symptoms including chronic fatigue (not sleepy, little energy, easily winded), weakness, and cold intolerance.*

*I am a stable Crohn's patient who was on Entocort (budesonide) for 12 years from 2007-2019 and was able taper to complete cessation after confirmatory testing from an ACTH stimulation test (peak cortisol 586 nmol/L) in June 2019. Interestingly enough, during the ACTH stimulation test, I had never felt better; I felt alive again! Unfortunately, this euphoria only lasted 55 minutes, but based on how good I felt, I can't help but think my symptoms might somehow be related to HPA-axis dysfunction and/or secondary adrenal insufficiency due to chronic exogenous glucocorticoid administration. Despite reporting this euphoria to my endocrinologist and based on routine blood work and monitoring (morning cortisol ~350 nmol/L), they are reluctant to try some form of short-term glucocorticoid replacement therapy.*

*Could I be on to something here? If so, could you recommend an endocrinologist in the Toronto, Ontario area that specializes in adrenal insufficiency for a second opinion and additional testing?*

### Response 1

*Budesonide, used for the treatment of inflammatory bowel disease, can suppress both ACTH and cortisol production. This can result in adrenal insufficiency symptoms. The ACTH stimulation test showed a good peak, indicating that the adrenal glands can respond well to ACTH stimulation. However, this does not necessarily mean you are producing sufficient ACTH and cortisol on a daily basis. I would like to know if a baseline ACTH and cortisol were done at the time of the ACTH stimulation test. If they were both low, you may still have adrenal insufficiency. If this was not done, I would suggest arranging a fasting ACTH and cortisol. If in doubt a trial of hydrocortisone (10 or 15 mg in the morning) under careful observation may need to be considered – this in close connection with your endocrinologist. However, the cortisol level of 350 actually makes adrenal insufficiency unlikely.*

### Question 2

*My mother (passed) had Addison's disease. My 15yr old daughter has recently had similar symptoms as my mother did right before she was diagnosed. She hasn't been tested yet as we're waiting for a referral, but while waiting, some of her symptoms have improved (mostly her extreme fatigue has become mild fatigue). I'm wondering what are the chances of it being inherited & if her symptoms have begun to improve is it still a possibility? Do the symptoms come & go? Thank u so much in advance!*

### Response 2

*The symptoms you describe are not very specific. They can result from adrenal insufficiency, but also from many other causes. Some forms of adrenal insufficiency can be inherited. The risk for inheritable adrenal insufficiency depends on the cause of adrenal insufficiency in your mother, and on the specific mutation. This requires first to make the diagnosis, and then consider genetic testing. Symptoms may come and go depending on variation in overall health and with that the demands on the pituitary-adrenal system.*

**Question 3**

*I'm highly suspected of having Addison's Disease at 46 years of age. This began 1 1/2 years ago when I started getting blood tests for chronic exhaustion and muscle cramping/clawing all over. They at first thought I had Cushing's Disease, but it seems I probably have the opposite of that. My 8am Cortisol has been tested 4 times over the past year, and each time it's lower than the last. Oct 2020 it was at 100/200-260 and one month ago it was at under 24/135-537. I've been referred to a hormone specialist, and the doctor who did so told me he couldn't make a diagnosis as I was seeing him for something else but said to Google "Low Cortisol" and "constant fatigue" together and read what came up. The ONLY thing was Addison's. Because of lockdowns in Ontario, I can't see the endocrinologist for almost a month. I am so tired all the time that I cannot function normally. Until I can see the hormone doctor to get replacements, what foods should I be eating for energy and concentration, and what should I be avoiding? I couldn't figure out conflicting diet suggestions online. I know white sugar is bad and makes me crash and sleep. Am I allowed brown sugar or unpasteurized natural honey? Everything says avoid tea and coffee, even green tea. Is it the caffeine or something else? Are caffeinated herbal teas okay, or will I crash shortly afterwards? Please, I am getting nothing done and haven't for over a year now. I can't drive or do housework or stay awake more than an hour or two at a time. Thank you.*

**Response 3**

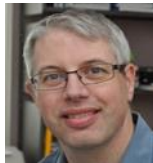
*Making the correct diagnosis of adrenal insufficiency is not always straightforward, and "Dr. Google" cannot always provide the right answers. I would recommend that your family doctor arranges a fasting blood sample for ACTH, cortisol, creatinine, sodium, and potassium. This should be taken between 8 and 10 AM, unless you are a shift worker. If you have a blood pressure cuff, I suggest that you measure your blood pressure after lying down and then after standing for 2 minutes. If the blood pressure drops significantly (more than 20 mm Hg), you may be at more severe risk and should go to an emergency.*

*A low cortisol (less than 100 nmol/L) together with a high ACTH make adrenal insufficiency more likely and would be reason to refer to an endocrinologist. Low levels of both cortisol and ACTH would require further assessment. Because you mention that Cushing syndrome has been considered, it would be really important to check all medications and products that you are using. Any of these products (tablets, injections, skin creams, eye drops, inhalations, etc.) can be absorbed, make you look like having Cushing syndrome, while at the same time suppressing your own ACTH and cortisol production, resulting in low levels.*

*There are no specific food recommendations, but I would ensure that you have sufficient salt and water intake (unless you have high blood pressure or heart or liver failure).*

**Medical Questions and Answers**

Dr. Stan Van Uum, MD, PhD, FRCPC, Medical Advisor to The Canadian Addison Society will answer your questions about Addison's/Adrenal Insufficiency



Send your question to Dr. Van Uum directly from the Society webpage or use this link:

<http://www.addisonsociety.ca/ask-a-question.html>

By emailing [info@addisonsociety.ca](mailto:info@addisonsociety.ca) or by regular Canada Post mail to:

The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, ON M9A 2S1

*Questions and answers of interest to others may be published (anonymously) in the Newsletter and/or on the website*



## NATIONAL EMS STATUS by Province & Territory

Regarding Paramedic authority to inject hydrocortisone in cases of suspected Adrenal Crisis in identifiable Adrenal Insufficient patients

Province/ Territory / Jurisdiction	Protocol Endorsement and/or Approval (Patient Supply of Injectable HC)	Protocol (Ambulance Supply of Injectable HC)	Comments
British Columbia	YES	UNDER REVIEW	Adrenal Crisis guideline has been endorsed and/or approved. Only Advanced Care Paramedics (ACPs) may administer (under Schedule 2 provision). Check with your local paramedic service for education and implementation timelines in your area.
Alberta	YES		Specialized treatment protocols are in place in some regions. Only Advanced Care Paramedics (ACPs) may administer. Check with your local paramedic service for education and implementation timelines in your area. Patients must be registered. AHS and the Alberta College of Paramedics are in discussions.
Saskatchewan	YES		Available in some regions. Check with your local paramedic service.
Manitoba	YES	YES (in some regions)	Adrenal Crisis guideline has been endorsed and/or approved. Check with your local paramedic service for education and implementation timelines in your area.
Ontario	YES	SUBMISSION IN PROGRESS	A submission is currently being prepared (Ministry of Health) for Ontario ambulances to stock injectable hydrocortisone.
Québec			Review of said submission for pre-hospital administration of injectable hydrocortisone has been acknowledged by the medical committee for emergency health services.
New Brunswick	REGIONAL		Available in some regions. ACPs are now available in some regions. Check with your local Paramedic service.
Prince Edward Island	REGIONAL		Available in some regions. Check with your local paramedic service.
Nova Scotia	REGISTRATION REQUIRED		Patients must be registered (Special Patient Program). A provincial submission is currently under revision
Newfoundland and Labrador	YES	YES	Confirm with your local Paramedic service.
Yukon	YES		Advanced, Critical Care Paramedics, and Flight Nurses are authorized to inject. Confirm with your local EMS.
Northwest Territories	YES		Approved for Injection by Community Nurses in Health Centers. Patients are advised to register medical information in advance.
Nunavut	REGIONAL		Refer to each Health Centre and Nursing Station in jurisdiction for EMS services available.
Indigenous Communities			Local Indigenous EMS training programs may exist. Contact community leaders.

August 2022



## **MEDICATION UPDATES**

### **Adrenal Crisis Auto-Injector Candidates**

All activity is currently in USA only. No applications have yet to be received by Health Canada

#### **CrossJect:**

A needle-free technology candidate seeking orphan drug status for its novel room-temperature liquid-stable formulation of hydrocortisone.

<https://www.crossject.com/en/therapeutic-areas/acute-adrenal-crisis>

Eton Pharmaceuticals has acquired the North American rights for this product:

<https://www.globenewswire.com/news-release/2021/06/15/2247745/0/en/Eton-Pharmaceuticals-Acquires-U-S-and-Canadian-Rights-to-ZENEO-Hydrocortisone-Autoinjector.html>

#### **Antares ATRS-1902:**

A rescue pen needle design making use of a novel liquid-stable hydrocortisone formulation with comparable drug profile to Solu-Cortef™.

<https://www.antareshpharma.com/application/files/5616/4250/9306/Antares-Pharma-Receives-FDA-Fast-Track-Designation-for-ATRS-1902-for-Adrenal-Crisis-Rescue.pdf>

**Note:** CrossJect and Antares are the only two candidates seeking approval for a liquid-stable formulation of hydrocortisone.

#### **TwistJect:**

A dual chamber auto-injector device candidate which is seeking orphan drug status for hydrocortisone administration: <https://solutionmedllc.com/>.

This auto-injector requires reconstitution of hydrocortisone powder.

### **Anticipated Market Entry (North America)**

<b>CrossJect</b>	<b>TwistJect</b>	<b>ATRS-1902</b>
2025	Q4-2024	Q4-2024
FDA 505 (b) (2)	FDA 505 (b) (2)	FDA 505 (b) (2)

## **NEW Pediatric Formulation for Hydrocortisone**

### **Alkindi Sprinkle**

Hydrocortisone granules in capsules for pediatric dosing (ORAL): **0.5 mg, 1 mg, 2 mg, 5 mg**

<https://www.alkindisprinkle.com/>

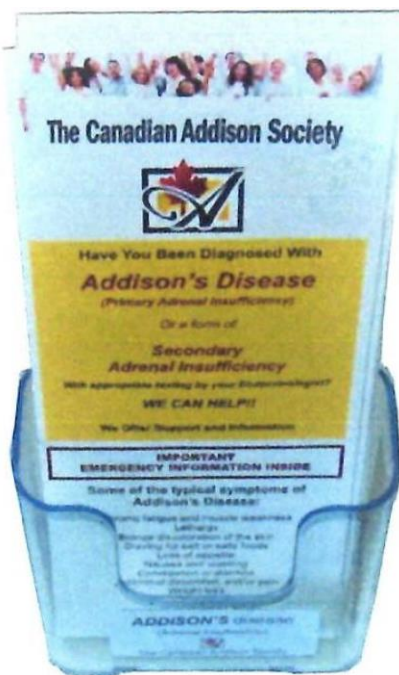
Eton Pharmaceuticals has acquired the North American rights for this product.

<https://ir.etonpharma.com/news-releases/news-release-details/eton-pharmaceuticals-announces-availability-orphan-drug-alkindir>

**Attention: Healthcare providers**

## Information Brochure & Holder

*Complimentary package includes brochure holder, plus 50 brochures.  
Re-order of brochures available at no charge  
English brochure only at this time. French version available soon.  
All materials and shipping are free*



Small countertop footprint  
4-3/4" W x 3-1/4" D  
(12 cm W x 8.25 cm D)  
May also be hung on wall

To order complimentary brochures and countertop holder contact:

[lucilia.addisons.distribution@gmail.com](mailto:lucilia.addisons.distribution@gmail.com)