



The Canadian Addison Society La Societe Canadienne d'Addison

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

The contents of this newsletter are 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 and newsletter contributors. Meeting minutes/notes are prepared by non-medical volunteers. There are links to websites not managed by The Canadian Addison Society in our newsletter. The Canadian Addison Society cannot be responsible for the content of these websites mentioned in our newsletter or reached from links in our newsletter. Readers are advised to consult their own doctors before making changes to their Addison's/Adrenal Insufficiency management program.

Passing of Harold Smith



We are saddened to announce that our previous President, Harold Smith, passed away with his family at his side on Thursday October 6th, 2022. To most of us, Harold was the Canadian Addison Society. Harold became involved in 2007 as the Regional Representative

for the South/Central Ontario local support group. In 2013, he was elected President, but continued with his Regional Representative duties for several years. Harold retired from the President's role in 2019, but his retirement didn't last long. Harold's replacement found the strain of managing her own business in the early stages of the COVID pandemic too demanding and had to resign from the President's role. Fortunately, Harold agreed to step back in and provide the needed guidance to help us manage through the challenging years of the pandemic. He was set to retire at the AGM on October 15th, 2022.

Harold led numerous initiatives which have had significant impact on the lives of people living with Adrenal Insufficiency. First and foremost, he led a national advocacy initiative, (along with Gino Innamorato, Researcher-Educator) to have Provincial health authorities approve paramedics injecting hydrocortisone for patients in adrenal crisis. This involved advocacy with each Province and Territory individually. Almost all provinces have adopted this approach, which is quite an achievement for a small volunteer group. He also designed the current membership card, which included spending time to work out the process to cut and fold the paper so it could be made wallet sized.

Harold always took the time to answer phone calls from people newly diagnosed, or sometimes family members, who were frightened by the diagnosis they had received and were trying to come to grips with living with a lifetime medical condition, and a rare one at that. Harold's understanding of the condition, and his compassionate approach brought comfort to many people. He will be greatly missed.

President's Message



Hello everyone,
We have all been shocked by Harold's passing and I'd like to extend again my sincere condolences to his family and recognize all of the important work Harold led during his time as President.

Since October, I have been getting up to speed with the many Canadian Addison Society activities. My apologies if you are a volunteer and I haven't reached out to you yet. Please feel free to drop me an email at president@addisonsociety.ca, I'll be very happy to set up some time to chat with you.

With a transition in leadership comes a time to reflect on the Society and how we collectively want to move it forward. I'm therefore excited to share with you our new member survey. This is a formidable tool to learn what our members expect from our Society, as well as to get to know who our members are more in depth.

Please take some time to complete the survey here: <https://tinyurl.com/25mfvbn3>

We are always looking for volunteers and have several positions to fill. If you have some time to dedicate to the Society, please mention it in the survey or drop me an email at president@addisonsociety.ca. Among others, we are looking for regional reps in various locations.

AnnMarie West, our New Brunswick Regional Representative, will also be taking over the Materials Distribution Coordinator role from Lucilia in the coming weeks. Lucilia has brought many improvements to the role, and I wholeheartedly thank her for all the work she has done in the past 2 years. Please note, it may take a little bit more time to get your orders processed while we work through the transition.

I am really excited about the recent announcement by the Honourable Jean-Yves Duclos, Minister of Health, regarding the first-ever *National Strategy for Drugs for Rare Diseases*, and hope this will bring the necessary improvements in timely diagnosis of Adrenal Insufficiency and access to the medications we need. (<https://tinyurl.com/ttr8hrcj>)

I am also thrilled to share that the Society is collaborating with [SOLUtion Medical](#) who is developing an innovative hydrocortisone auto-injector called Twistject. Stay tuned for more information.

Finally, when calling emergency services, be sure to specify "**Possible Adrenal Crisis**" to prevent verbal miscues wherever you are located. Always carry the medical information card and stock multiple vials of injectable hydrocortisone (e.g., Solu-Cortef) at home and in the community, so they are available if you need to inject an emergency stress dose.

Happy reading,
Pascale

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CAS Survey



Are you a person with adrenal insufficiency or someone supporting persons with adrenal insufficiency?

We need your input to help drive the Society's work in the next few years.

Complete our survey and submit your feedback at: <https://tinyurl.com/25mfvbn3>

New Twistject Collaboration



We are thrilled to share that we have agreed to collaborate with SOLUTION Medical on TwistJect, their innovative hydrocortisone auto-injector which is currently under development.

The purpose of the collaboration, which consists of an international network of patient support groups, is to authentically engage with patients across identities and lived experiences to ultimately improve adrenal crisis management in Canada. Stay tuned for more information.

To learn more about Solution Medical and the Twistject, visit <https://www.solutionmedco.com/>

EMS Status Update

British Columbia

Currently there is no injectable glucocorticoids (e.g., Solu-Cortef) in Pre-Hospital Care program in place for paramedics to assist or administer injectable glucocorticoids even if you carry your own

In 2019, the BC Government commissioned a complete review of BC Provincial Health Service Authority (BCPHSA). While the review, known as the Cayton Report, was being undertaken all programming and organizational changes were put on hold. In 2020, the Cayton Report was submitted. At the end of June 2021, the Cayton Report recommendations were in place.

British Columbia Emergency Health Services (BCEHS) expanded their protocol Handbook during the Cayton review in which they added a section on treating Adrenal Insufficiency with glucocorticoids in Pre-Hospital Care. The Clinical Practice Guidelines (CPG) was drafted and approved but not entered as it is still out of scope. The Handbook lists the treatment procedure, and paramedic levels of authority to inject glucocorticoids. The administration of glucocorticoids as listed in the Handbook is not included in the current training program for paramedics and does not grant paramedics the authority to inject or license them to administer glucocorticoids. At present, only Critical Care Paramedics can administer glucocorticoids, but they work on very few ambulances.

In the present BCEHS system, BC Paramedics can provide assistance to someone who has Adrenal Insufficiency provided the individual is conscious, carries documentation as to their medical condition, and has their own glucocorticoids and syringe. Assistance does not mean authority to inject glucocorticoids and it is up to the individual paramedic to set their own limit as to the meaning of assistance with respect to the situation.

On September 29, 2022, Adrian Dix, the BC Minister of Health, announced a number of very significant changes to be made in the delivery of health care within BCPHSA and specifically

BCEHS. This was great news as there is now a plan forward with funding to implement paramedics' scope of practice, eventually giving them authority to inject glucocorticoids to patients who are in pre-hospital care. In order to change BCEHS training and in-field practice, the BC Legislature was required to change Emergency Medical Assistants Licensing Board (EMALB) regulations to give authority to PHSA to make the necessary regulatory changes enabling BC Paramedics to inject glucocorticoids.

Since Adrian Dix's announcement, Gerry has had a number of discussions with BCEHS about the extent of their plans for moving forward injectable glucocorticoids in pre-hospital care. Over the next two years funding will be in place for training and licensing of paramedics giving them authority to inject glucocorticoids to identifiable AI patients in pre-hospital care situations. Over this two-year term, the end goal is to have all paramedic levels, Primary Care Paramedics (PCP) and Advance Care Paramedics (ACP), authorized to inject patients who carry their own supply of glucocorticoids. As well, the end plan is to have ambulances carry onboard a supply of injectable glucocorticoids. In the next two years all field paramedics and new recruits will be trained in the administration of injectable glucocorticoids, and this is going to take time and great deal of money. Hopefully, this plan stays on track, and we can celebrate when this actually becomes a reality. In mid-February, Gerry met with Dr. Michael Christian, Chief Medical Officer: BC Emergency Health Services, Provincial Health Services Authority Provincial Medical Director. Michael advised that BCEHS is ready to advance the implementation of injectable glucocorticoids into field practice.

Continued on next page

British Columbia Continued

However, BCEHS cannot move this forward until the organizations that train paramedics have developed the training curriculum and the licensing board has approved the curriculum for certifying paramedics. This process is now already three months behind.

For anyone in BC who is AI and/or has Addison's Disease and needs to call 911 for assistance, it is important to advise the dispatcher that you are experiencing a Possible Adrenal Crisis. BCEHS will automatically code you as "Acute adrenal insufficiency/crisis or Addison's disease". This coding requires an advanced life support response if available.

Please Note that 9-1-1 calls may not work for all areas of B.C.

Areas where 9-1-1 is not available:

Call Toll Free

1-800-461-9911

Cellphone/SAT Phone/Outside BC Call:

250-374-5937

Materials Requests

Health Care Providers



Order your complimentary package including a brochure holder and 50 brochures (English only). Additional brochures available at no charge.

The brochure holder has a small countertop footprint and can also be hung on the wall. 4-3/4" W x 3-1/4" D (12 cm W x 8.25 cm D).

Follow this link to order: <https://tinyurl.com/4kcytwm4>

Members Only

Demo injection training vials and/or laminated Emergency Medical Information Cards are available for order at this link:

<https://tinyurl.com/2p8ppb8z>

Youth Ambassador

Kyle Yeates – youthambassador@addisonsociety.ca



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 old. 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 if you'd like to connect!

Advice for Exercising with Addison's

Maintaining an active lifestyle is important not only to stay healthy, but to also improve your stamina and help reduce fatigue in your day to day life. One of the hardest parts of incorporating exercise into the routine of someone with adrenal insufficiency (AS) is the fear of overextending yourself and risking an adrenal crisis. To help manage those fears, here are a few pieces of advice.

First, it is important to keep your emergency injectable hydrocortisone nearby at all times. Do not keep it in your locker unless you have someone nearby who has access as well. It also helps to notify the gym staff, your coach, or your fellow players about your condition and what they can do to help you in an emergency. They will be more than happy to accommodate.

When exercising it's also important to recognize when you should up-dose. While difficult to identify when first diagnosed, the skill of

differentiating physical fatigue from AS-induced fatigue is crucial to develop and will come over time. The signs vary for everyone but in my experience, AS fatigue tends to feel more intense than general exercise fatigue, so be sure to keep track of how you're feeling while exercising and don't be afraid to take a break!

Finally, if you suffer from adrenal insufficiency or other endocrine disorders, it is crucially important to stay hydrated and relaxed while working out. Be sure to drink lots of water before and after your work out and take breaks often.

Naturally a lot of this advice is true for those that don't suffer from adrenal insufficiency, but it is particularly important for those of us that do as our bodies are far less forgiving to neglect. So keep these tips in mind and don't be afraid to get out there and have fun!

- Kyle Yeates

Online Resources/Support for Youth and Young Adults

Follow @addisonsadvocate on Instagram and YouTube. He shares his experience living with Addison's and has recently started doing a live podcast featuring Addison's patients where they are able to tell their story and listeners can join in and ask questions.

Join 'NADF for Young Adults' on Facebook. This is a group for individuals 18-29 years old with adrenal disease. This is a great space to ask questions, find resources/support, and interact with other young people living with adrenal disease.

Congenital Adrenal Hyperplasia (CAH) Support

Candice Johannesson



Hello everyone! Thank you to the Canadian Addison Society for including a CAH specific section to support patients and families living with this rare condition. I am the current Newborn and Canada Support Group Leader for the CARES Foundation, as well as the Executive Director of the CAH Advocates Canada Support Group. Kindly see below for ways to support your family affected by CAH. Take care and be well!

- Candice Johannesson (cahadvocatecanada@gmail.com)

Support/Resources

Current Clinical Trials

- Tildacerfont Clinical Trial for Adults with SWCAH (18+) in select Canadian cities:
<https://sprucebio.com/cahme lia/>

International Organizations

- CARES Foundation (Congenital Adrenal Hyperplasia Resources, Education and Support):
<https://caresfoundation.org/>
- MAGIC Foundation:
<https://tinyurl.com/2vdvyba2>

Online Resources

- CARES Ask the Expert Dr. Su:
<https://caresfoundation.org/ask-the-expert/>
- CAH Canada:
<https://cahcanada.ca/>
- CAH Guidelines:
<https://tinyurl.com/4f8m7upw>
- Monitoring Treatment of CAH in Children:
<https://tinyurl.com/mt9um8pb>

- CHEO Congenital Adrenal Hyperplasia:
<https://tinyurl.com/2p9yujw3>
- BCCH CAH Booklet:
<https://tinyurl.com/ytj4ey67>
- I-CAH: <https://home.i-cah.org/>
- RQMO:
<https://tinyurl.com/45ht84ss>

Online Support Communities

- CAH Advocates Canada:
<https://tinyurl.com/bddkvv6k>
- Canadian Support for CAH:
<https://tinyurl.com/3f9y443a>
- Adrenal Insufficiency Support Canada:
<https://tinyurl.com/39bsevum>

Are you an adult in Newfoundland and Labrador who has Congenital Adrenal Hyperplasia (CAH)?

Do you have CAH due to 21-hydroxylase deficiency based on genetic mutation in CYP21A2 and/or elevated 17-OHP?
Consider participating in our study:

What is the study about?

Most individuals with CAH require high-dose prednisone or cortisol replacement therapy, and suffer the long term consequences of that treatment as well as persistent overproduction of androgens and other steroids.

A new oral medication for CAH, Tildacerfont, acts at the level of the pituitary to reduce the production of unwanted androgens and other steroids, and enables a lower dose of prednisone or cortisol replacement to be used. It is currently being studied in two different multicenter clinical trials at the Health Sciences Centre in St. John's, Newfoundland.

Who can participate?

Adult residents of Newfoundland and Labrador who have CAH and are interested in trying a new treatment in the form of a clinical trial.

If you have questions regarding your rights as a research participant please contact the Health Research Ethics Authority at (709) 777-6974 or info@hrea.ca.

Study title: A Randomized, Double-Blind, Placebo-Controlled, Dose-Ranging Study to Evaluate the Efficacy and Safety of SPR001 (Tildacerfont) in Adult Subjects with Classic Congenital Adrenal Hyperplasia

Principal Investigator:

Dr. Christopher Kovacs

Interested? To ask questions contact:

Krista Cuff, nurse coordinator

Tel: 709-777-6996 or Email: krista.cuff@easternhealth.ca

News & Announcements

Canada Rare Disease Strategy

The federal government announcement on March 22 the plan to provide up to \$1.5 billion over three years to implement the Rare Disease Drug Strategy.

<https://tinyurl.com/vr7fa6du>

Webinar on Emergency Injection Training for Adrenal Crises

On January 20th 2023, Le Regroupement Québécois des Maladies orphelines (RQMO), in collaboration with the Society, held a free webinar on administering injectable hydrocortisone for the treatment of Adrenal Crisis. Dr. Cheri Deal, pediatric endocrinologist at Sainte-Justine hospital, kindly prepared an injection training video and was present at the webinar.

Ingrid Younes from the RQMO noted “The webinar was a real success in terms of fulfilling a need in the lack of knowledge and in terms of feedback. Participants were very thankful and appreciative of this initiative and of everyone who participated to make it happen. They mentioned the fact that they are, in a way, fighting a battle all alone which makes it even harder for them morally. The webinar offered

them valuable information especially because it is difficult to gather relevant information to adapt to the situation. Moreover, the webinar helped some participants realize the importance of having the injection kit ready and knowing how to use it. One participant said that she realized after the webinar that all her vials were expired and so she started the process of updating. People are eager to help and eager to learn about their disease. This webinar gave them the support and hope they needed to continue their battle”.

The webinar is available for viewing at the following link. Please note is it in French, but English subtitles can be added directly on YouTube.

<https://www.youtube.com/watch?v=muggq2xMwBtc>

Public Health Presentation on Adrenal Crises



Congratulations and thanks to Marie Budden, Western Regional Community Health Nurse Consultant in NL and B.P., the Public Health Nurse responsible for facilitating the presentation.

Marie initiated a school education session on adrenal crisis that took place in early October 2022. There were 18 participants, and it was very well received. Marie collaborated with the Society for education materials and training vials.

This resulted in greater awareness about the treatment timeline for adrenal crisis. The school community had the opportunity to get hands-on training with the emergency practice vials for injection.

Increasingly, training is occurring in school authorities across the country to meet the emergency needs of students/staff with adrenal conditions. The School Nurse in Western NL, BP, took the time to bring the community together to save lives. What a wonderful example of care and kindness!

News & Announcements

Useful Links

medSask Updated Drug Conservation Strategy Documents:

Hydrocortisone tablets:

English: <https://tinyurl.com/mu4522xs>

French: <https://tinyurl.com/2p9hak6k>

Solu-Cortef:

English: <https://tinyurl.com/4va3ve5e>

French: <https://tinyurl.com/yckmesv9>

Florinef:

English: <https://tinyurl.com/mrv2za99>

French: <https://tinyurl.com/yckmesv9>

Adrenal Insufficiency United Facebook Group for Parents of Children with Adrenal Insufficiency: <https://tinyurl.com/mrcea8f8>

Guidance on COVID-19 Booster Doses

On March 3, 2023, the Public Health Agency of Canada published guidance from the National Advisory Committee on Immunization (NACI) on an additional COVID-19 vaccine booster dose in the spring of 2023 for populations at high risk of serious COVID-19 outcomes.

Other populations are still recommended to receive all previously NACI recommended doses, but not an additional spring 2023 booster dose at this time.

English: <https://tinyurl.com/r3tajxyf>

French: <https://tinyurl.com/2p892mx4>

Share your views on Adrenal Insufficiency & Cushing's syndrome with Bionics+ researchers

The Bionics+ research team includes researchers based at University of Birmingham, University of Kent and University of Warwick. We are interested in hearing from:

- People with lived experience of Cushing's syndrome or adrenal insufficiency
- People caring for others with Cushing's syndrome or adrenal insufficiency e.g., the parent of a child with one of these conditions or a caregiver

Healthcare professionals and other scientists who are involved in the study or medical care of Cushing's and adrenal insufficiency patients

- We would like to learn about your experiences of managing or supporting others to manage Cushing's syndrome or adrenal insufficiency.

This survey is completely anonymous, and you are under no obligation to take part. It is open to people with Cushing's syndrome and adrenal insufficiency, as well as their family or caregivers and healthcare professionals or other researchers who study this condition. The time taken to complete the survey will partly depend on how much you want to say in the free text responses, but we estimate this at approximately 15-20 minutes. You are welcome to share the survey with others.

<https://tinyurl.com/2p8c5693>

News & Announcements

Health Care Professionals can nominate a drug to National Priority List of Pediatric Drugs

Would you like to nominate a drug for the National Priority List of Pediatric Drugs? Currently, pediatric formulations for certain corticosteroids are not available in Canada. Are there other drugs you would like to include on the list? The nomination form has recently been posted on Health Canada's website. Healthcare providers are being invited to share their expertise in identifying pediatric

drugs or formulations which will improve patient health and safety. The nomination form will be accessible online from March 15, 2023, until May 14, 2023.

<https://tinyurl.com/yff3dcsn>

Drug Shortage Updates

To receive updates on drug shortages, create an account on drugshortagescanada.ca and sign up to receive drug shortages notifications.

To find a drug's ATC code, click on Search in the top menu bar followed by Product.

Products can be searched based on DIN, drug name, ingredients, etc.

The ATC Code to receive notifications about Cortef and Solu-Cortef shortages is H02AB. For Florinef, it is H02AA

The screenshot shows the 'Drug Shortages Canada' website interface for a user. The navigation bar includes links for HOME, SEARCH, SUMMARY REPORT, TIER 3 DRUG SHORTAGES, ABOUT & RESOURCES, CONTACT, and PROFILE. The user's profile page is titled '- User' and features a sidebar with 'YOUR DRUG NOTIFICATIONS' and 'CONTACT INFO'. The main content area is titled 'Saved searches' and contains a form to 'Enter an ATC code (3-5 digits) in the box below to receive notifications for any products that have that ATC code'. Below the form are buttons for 'Follow', 'Unfollow All', and 'Remove Selected'. A section titled 'Followed notifications' contains a table with columns for Name, Type, and Last notification. The table lists one notification for ATC code H02AB.

Name	Type	Last notification
H02AB	ATC code	...

Travelling to the United States? Be sure to bring your supply of medications with you as there are shortages there as well.

Solu-Cortef shortage:
<https://tinyurl.com/3u9y2ec6>

FDA Drug Shortages:
<https://tinyurl.com/yz42c6pk>

Support Group Contacts

Region	Regional Representative	Email	Phone Number
Alberta	Rosemary Brown	hdbrown52@outlook.com	403-391-1507
Atlantic Canada	Annmarie West	AtlanticProvinces@addisonsociety.ca	506-333-1034
BC – Lower Mainland	Geoff Metcalfe	calfe579@telus.net	604-533-0579
BC – Northern	Tyanna Trottier	tyannatrottier@gmail.com	250-845-9446
BC – Vancouver Island (Victoria)	Derek Clarke	vancouverislandaddisons@gmail.com	250-857-4320
BC – Vancouver Island (Nanaimo)	Sharon Erickson		250-729-1446
Manitoba	We are searching for a volunteer to become our Regional Representative. If you can assist in this volunteer role, please contact president@addisonsociety.ca		
Ontario – Eastern	David Sparks	davidsparks04@gmail.com	-
Ontario – South/Central	We are searching for a volunteer to become our Regional Representative. If you can assist in this volunteer role, please contact OntarioSouthCentral@addisonsociety.ca or president@addisonsociety.ca		
Québec - Montreal	Shelley Saklatvala	shell326@hotmail.com	514-991-0294
Québec – Québec City	We are searching for a volunteer to become our Regional Representative. If you can assist in this volunteer role, please contact president@addisonsociety.ca		
Saskatchewan	Nicki (Barr) Clarke	nclarke@hotmail.com	306-531-4567
The Territories	We are searching for a volunteer to become our Regional Representative. If you can assist in this volunteer role, please contact president@addisonsociety.ca		

Newsletter Editor

Carly Charron - newsletter@addisonsociety.ca



Hi everyone! My name is Carly Charron, and I am happy to be taking on the role of Newsletter Editor. I am a PhD candidate in Biology at Western University in London, ON, where I am working on developing an edible Salmonella vaccine for chickens. I have been living with Addison's Disease for the past 3 years since I was diagnosed at 23 years old.

I hope you enjoyed the newsletter! If you have any comments about this issue, or any suggestions for the next issue, please send me an email.