2024 Spring Edition
ISSUE NO. 99

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The Canadian Addison Society
La Société 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.

President's Message

In December 2023, I answered an email that would change my life. I emailed Rick Burpee and volunteered to take on the position of President of The Canadian Addison Society. Little did I know when I wrote that email how much I would learn in the next few months. My understanding of adrenal diseases was based on my personal experiences and limited research. What I could offer the CAS was experience as president of several non-profit societies.

In the twelve years since my retirement from teaching in Northern BC, I had become involved in several Nanaimo organizations.

I was President of the Nanaimo Newcomers and the Nanaimo Marine Rescue Society. I developed a boating safety classroom program for the Royal Canadian Marine Search and Rescue and taught it in many classrooms.

After the pandemic, I realized it was time for a fresh start and to learn new things, so here I am today.

I am impressed with the CAS. This is an active group of volunteers who are following their passions. One of the strengths of this group is that members have a strong personal reason for belonging. We all want to find ways to live stronger and healthier lives, despite our adrenal disease challenges.

In the past months we have worked on projects that were started by Pascale and her team. Thank you for all your hard work! The website, Facebook page, survey, and Google workspace are all in progress. At meetings of the board and the Regional Reps, we discussed these projects and others.

It has been suggested that we explore re-branding the Canadian Addison Society to create a more inclusive name for the organization. Perhaps something as simple as the 'Canadian Adrenal Society'. We are also working on an updated brochure for CAS. The new Facebook page should be up and running soon. We will also update the website in the next few months.

We also would like to create our own videos for the Solu-Cortef emergency injection. Watch the Website and Facebook pages for more info on that.

For those that are curious, I was diagnosed with PAI in 2012 after about a decade of a darkening, permanent tan. I celebrated my 40-year anniversary of Type 1 diabetes survival in April 2024. With thyroid issues, I am a classic "Schmidt's Syndrome".

President's Message - Continued

I am currently taking Prednisone as my replacement steroid. I have used an insulin pump for over 20 years, and I am now researching the possibility of pumping hydrocortisone. I would love to hear about your experiences with a pump.

We are looking for more Regional Representatives for the various parts of Canada.

Let me know if you are interested in helping with this or with any other initiatives.

I am looking forward to continuing to learn about the many adrenal diseases and how we as Canadians deal with them.

If you have suggestions, stories, feedback, or information to share with me, I can be contacted at: **president@addisonsociety.ca**

- Debby Thomson, CAS President

In this issue

News & Announcements

Spring COVID-19 Immunization Guidance for AI Patients

As of April 2024, it is recommended that individuals who are at an increased risk of severe illness from COVID-19 receive an additional dose of a COVID-19 vaccine. See below for provincial recommendations.

Quebec:

https://www.inspq.qc.ca/publications/3471
https://www.inspq.qc.ca/sites/default/files/2024-03/3471-vaccination-covid-19-printemps-2024.pdf

Ontario:

https://www.ontario.ca/page/covid-19-vaccines#section-1

British Columbia:

https://www2.gov.bc.ca/gov/content/covid-19/vaccine/register

The following is an article summarizing recommendations from the National Advisory Committee on Immunization and across the country: https://www.cbc.ca/news/health/spring-covid-vaccine-1.7156121

The Addison's Disease Self Help Group also has a comprehensive info link for COVID-19 vaccines and AI patients: https://www.addisonsdisease.org.uk/coronavirus-vaccines

News & Announcements

Invitation for Study on Addison's Disease

Contact: Mathew Horodner
mathew.horodner@waldenu.edu

Study Supervisor: Ethel Perry, PhD
ethel.perry@mail.waldenu.edu

There is a new study about the experiences of managing and living with autoimmune Addison's disease in younger and newly diagnosed adults.
For this study, you are invited to share your meaningful experiences.

About the study:

- The study will help advance the understanding of Addison's disease, which will help providers better serve patients and potentially allow patients to learn how to manage Addison's disease
- One 60-90 minute video interview that will be audio-recorded
- To protect your privacy, the published study will not share any names or details that identify you
- If you feel uncomfortable at any time, you may choose to leave the study
- Participants will not receive any payment for participation in the study

Participants must meet the following requirements:

- Individuals with autoimmune Addison's disease between the ages of 18 and 30
- Participants who communicate in English
- If participants are newly diagnosed, they will have to receive a diagnosis within the last eight months
- Individuals with other kinds of adrenal insufficiency and individuals with comorbid conditions involving severe physical or psychological symptoms will be excluded

If you are unsure about eligibility, please call or e-mail the researcher Mathew Horodner at 602-708-4798 or mathew.horodner@waldenu.edu.

This interview is being conducted as part of a doctoral study at Walden University.

Proposed Name Change – 'Canadian Adrenal Society'

At our February board meeting we voted to explore possibility of changing the name of our organization. The suggested new name would be he Canadian Adrenal Society, which would keep the current acronym for The Canadian Addison Society (CAS) the same. This name changing process will begin in 2024.

There is much history, support, and advocacy work that this charity has achieved since it was founded. Our charity has evolved over time alongside science and medical research to become more inclusive. We now support and serve Canadians affected by all forms of adrenal insufficiency and diseases caused by any condition of the hypothalamus/pituitary/adrenal glands that carry risk of insufficiency or suppression. Thus, our charity name should clearly represent this.

As progress is made, we will keep our members updated. Thank you for your support as we navigate this very exciting change.

- *Candice Johannesson, CAS Board Member*

Online Resources and Support

We are excited to announce that our new **Facebook** page '**Canadian Addison Society**' is up and running! Please follow us and share your stories and questions about living with adrenal insufficiency.

'Adrenal Insufficiency Support CA', 'Addison's Disease Self-Help Group', 'NADF for Young Adults', 'Team Addison Canada', and 'Parent and Caregiver support for Children with Adrenal insufficiency' are other useful Facebook pages.

Questions about any form of adrenal insufficiency can also be submitted on our website:
https://forms.addisonsociety.ca/ask-a-question/

Check out 'Chronically Fit Canada' on YouTube and Facebook and listen to the podcast 'The Pickle Jar' to hear about host Jill Battle's experience living with Addison's, as well as interviews with others living with Adrenal Insufficiency.

News & Announcements

ISMP Safety Bulletin – Important Information for Pump Users

For Members currently pumping hydrocortisone (HC), be aware that there are dangers of emergency bolus of HC NOT working. It is ALWAYS recommended that you carry Solu-Cortef in the event your pump fails. When a switch to EMERGENCY BOLUS does not work, it will be potentially fatal if you are in adrenal crisis.

It is also recommended that you perform regular maintenance checks and have a backup pump available.

https://ismpcanada.ca/wp-content/uploads/ISMPCSB2023-i1-Smart-Pumps.pdf?utm_source=safetybulletin&utm_medium=email&utm_campaign=sbv23i01#page=1

Useful Links & Articles

5 Questions to Ask about your Medications:
https://www.ismp-canada.org/medrec/5questions-newsite.htm

Canadian Dental Care Plan
https://tinyurl.com/y7ef2zmv

Daily Glucocorticoid Replacement Dose in Adrenal Insufficiency, a Mini Review:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9276933/

Diagnosis and Management of Secondary Adrenal Crisis:
https://link.springer.com/article/10.1007/s11154-024-09877-x

ISMP Canada Safety Bulletin:
https://ismpcanada.ca/wp-content/uploads/ISMPCSB2022-i7-Care-Plans.pdf

Medication Safety Alert – EMS Protocols for Adrenal Crisis:
https://caep.ca/wp-content/uploads/2019/12/EMSAdvisoryFINALGIEDIT.pdf

Safe Medication Use:
https://safemedicationuse.ca/
https://safemedicationuse.ca/newsletter/downloads/202110NewsletterV12N9-Care-Plan.pdf

Thematic Issue: Adrenal Disease 2024:
https://academic.oup.com/endocrinesociety/pages/adrenal-disease-2024?login=false

Usefulness of Time-Point Serum Cortisol and ACTH Measurements for the Adjustment of Glucocorticoid Replacement in Adrenal Insufficiency:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4552782/

Drug Shortage Updates

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

To find a drugs' 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.

Travelling to the United States?

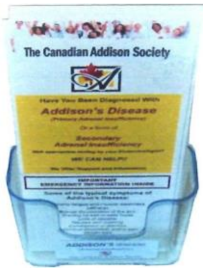
Be sure to bring your supply of medications with you as there are shortages there as well.

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

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

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

Medical Information Cards (https://www.addisonsociety.ca/medical-information-card.html) and Emergency Injection Instructions (https://www.addisonsociety.ca/injection-kit.html) are available to print as well.

Canadian Addison Society 2023/2024

Officers	
President	Deborah Thomson
Vice President	Derek Burpee
Secretary/Treasurer	Rick Burpee
Past President	Pascale Schicks

Important Support	
Newsletter Editor	Carly Charron
Technology	Pascale Schicks
Facebook	Catherine Gélinas
Website	Alex Leuschner

Medical	
Medical Researcher-Educator	Gino Innamorato
Medical Support	Dr. Stan Van Uum
	Dr. André Lacroix

Mark your calendars for our **Annual General Meeting** on **October 5th, 2024, at 1PM EST** to meet the Executive Board and learn more about our efforts. Details will be sent via email closer to the date.

We are in search of a new **Secretary/Treasurer**.
If you are interested in this volunteer position, please contact president@addisonsociety.ca.

Board Members	
British Columbia	Derek Clarke
Saskatchewan	Brenda Dinsdale
Manitoba	Candice Johannesson
Ontario	Derek Burpee
	Melanie Westover
	Roger Steinmann
	Sheri Thiffault
New Brunswick	Pascale Schicks
	Dany Desjardin

Support Group Contacts

Region	Regional Representative	Email
Alberta	Rosemary Brown	alberta@addisonsociety.ca
	We are looking for a volunteer to share this area. If you can assist in this role, please contact president@addisonsociety.ca	
Atlantic Canada	Annmarie West	atlanticProvinces@adddisonsociety.ca
BC – Lower Mainland	Geoff Metcalfe	bclowermainland@addisonsociety.ca
BC – Northern	Tyanna Trottier	bcnorthern@addisonsociety.ca
BC – South/Central	*We are looking for a Regional Representative for this area. If you can assist in this role, please contact president@addisonsociety.ca*	
BC – Vancouver Island/Victoria	Derek Clarke	vancouverislandaddisons@gmail.com
Manitoba	Deb Will	manitoba@addisonsociety.ca
Ontario – Eastern	David Sparks	ontarioeastern@addisonsociety.ca
Ontario – South/Central	Melanie Westover	ontariosouthcentral@addisonsociety.ca
	We are looking for a volunteer to share this area. *If you can assist in this role, please contact* president@addisonsociety.ca	
Québec	Shelley Saklatvala	quebec@addisonsociety.ca
	Julie Collette	quebec@addisonsociety.ca
Saskatchewan	Brenda Dinsdale	saskatchewan@addisonsociety.ca
The Territories	*We are looking for a Regional Representative for this area. If you can assist in this role, please contact president@addisonsociety.ca*	
Youth Ambassador	Kyle Yeates	youthambassador@addisonsociety.ca

Support Group Meeting Reports

Vancouver Island/Victoria - April 16th, 2024

After a long layoff that began before the pandemic, we had a very successful Zoom meeting. It was good to reconnect with both long-time and new CAS members. We had a total of 12 people attend the virtual meeting.

We began the meeting by reminding everyone how important it is to have both a family doctor and an endocrinologist. As well, we encourage an annual visit with your doctor and/or endocrinologist. We asked people about adrenal crises and how well they had coped. There were people who have had none and people who have had a crisis quite frequently. It's clear that not everyone's experience with Addison's disease is the same.

We reviewed the procedure for opening Solu-Cortef bottles and reminded everyone that they must have an emergency injection kit. You should always carry your kit and know how to use it. Refer to the CAS website for our downloadable injection guide. Remember, it may be easier to use your palm to push the rubber cork into the bottle. Importantly, if you are having an adrenal crisis, expired Solu-Cortef is better than none.

Allowing an adrenal crisis to continue unchecked is dangerous. If you are interested in purchasing a bag for your injection kit, visit https://clearlyaliveart.com/.

As well, the Etsy shop 'SewMoreDesigns' has a new Addison's seat belt cover that could alert first responders and others of your Addison's condition.

We discussed the early onset of menopause caused by adrenal insufficiency. Sadly, there is very little information available on this subject and we suggest you speak with your endocrinologist about this.

The UK "Living with Addison's Disease" manual (https://www.addisonsdisease.org.uk/news/living-with-addisons-disease-book) only deals with the need to avoid early onset osteoporosis. Everyone should read through this manual; it's extremely detailed and includes a lot of advice for everyday life with Addison's.

We were fortunate to have Debby Thomson, the new president of The Canadian Addison Society, on the call with us. She was helpful with many answers and revealed that the CAS is considering a name change to the 'Canadian Adrenal Society' to better represent the people in our society.

Our next meeting will be in the fall, details to be announced. In the meantime, stay healthy!

- Derek Clarke, Vancouver Island/Victoria Regional Representative

Saskatchewan - March 9th, 2024

The Saskatchewan chapter met on March 9th. 9 people were present, with four being Addisonians.

We were educated by Bonnie Cockrum, a nurse, on emergency injections using oranges and practice vials. This was a wonderful session, and many questions were answered. It's always a fun time and alleviates the stress around self injecting.

We talked briefly about current drug shortages in general and the potential for more in the future. We also shared information regarding the reporting of medication errors etc. to the Canadian non-profit agency (ISMP: https://www.ismp.org/).

Current handouts were distributed on surgical guidelines, emergency medical information cards, physician sample letter, and hospital protocol.

We discussed sick day dosing guidelines and the importance of always carrying up to date information.

It was agreed that we need to reach all doctors offices and specialist offices with CAS information in case we are missing some who have adrenal insufficiency but do not know that there is support for them. We also discussed reaching ambulance services with information on adrenal insufficiency.

Everyone present at the meeting agreed that the name 'The Canadian Addison Society' is outdated and should include all forms of adrenal insufficiency.

The chapter will meet again in the fall, details to be announced.

- Brenda Dinsdale, Saskatchewan Regional Representative

Support Group Meeting Reports

Ontario South/Central - April 11th, 2024 and May 15th, 2024

Ontario South/Central has begun holding monthly virtual support groups meetings. Thank you to those who have attended and shared information with the community. We are invaluable resources to each other.

We discussed the basics of what adrenal insufficiency is, as well as the different types and causes. We also discussed signs and symptoms of low cortisol, and the importance of keeping emergency injection kits in places you frequent (around the house, work, friends, family, etc.) It is also important to train yourself, and those around you, on how and when to administer your emergency injection. https://www.addisonsociety.ca/injection-kit.html.

Your emergency injection kit should include:

- Solu-Cortef Act-O-Vial (2)
- Alcohol wipes (2)
- 2 syringes (3 ml) & 2 needles (22 gauge)
- Gauze pads/cotton swabs
- Band aids

It is good to include extra supplies as well and ensure your kit is in a clearly marked container or bag. You can purchase stickers to label as such. AI United has them, and you can also find them on Etsy. https://aiunited-store.company.site/products/Emergency-c165770789.

A blood pressure monitor is another important thing to have, especially for those of us with salt-wasting Addison's. I recently bought one and really like the free app you can download on your phone to track your readings and enter notes about symptoms, steroid dosages, etc. The one I have is ‘Omron BP7455 Blood Pressure Monitor With Bluetooth Connectivity’, but there are many great ones on the market.

It is also very important to always wear a medical alert ID. Suggested wording: ‘Adrenal Insufficient’, ‘Steroid Dependent’. Some popular places to get them from are:

https://www.medicalert.ca/

https://www.laurenshope.com/

https://www.roadid.com/

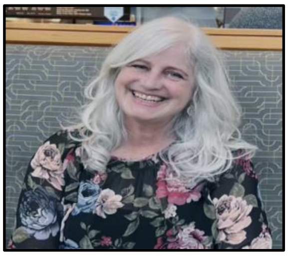
We also discussed the importance of creating a Care Plan at your local hospital so that your file has the information up front if you present to the ER with symptoms of adrenal crisis. Talk to your endocrinologist for guidance on treatment for adrenal crisis that is appropriate for you, including injection of Solu-Cortef and replacement of fluids and electrolytes via IV. Timing is important here too (how often dosages should be given). Also ask what blood labs should be performed (this should not delay treatment but rather provide guidance).

Contact the Patient Relations or Patient Experience department at your hospital and request an appointment to put a care plan in place. Bring your medical information with you, including medical conditions and a list of current medications and dosages. Make a list of how you present with adrenal crisis symptoms, as these may differ slightly from person to person. You can also contact your local paramedic station to have your address flagged, in the event you need emergency assistance.

We will meet again in mid-June and then we will break for the summer, with meetings resuming in September.

- Melanie Westover, Ontario South/Central Regional Representative

Introduction to Deb Will - Regional Representative, Manitoba



My name is Deb Will and I’m honored to represent The Canadian Addison Society as the Regional Representative for Manitoba. I’m a 62-year-old retired teacher and mom to five adult children. I have three biological sons and two adopted daughters from Ethiopia. Like many of you the journey towards diagnosis was bumpy. For me it started with Raynaud’s disease and no appetite in childhood. In my twenties I presented with the classic symptoms, but it took another ten years for diagnosis. After many doctor and emergency visits over the years, it was a new resident doctor in my small community clinic that diagnosed me. The steroids were incredible, and I embraced life with all my being, thinking this is an easy fix.

With no guidance or education and very little to find on the internet, life soon proved challenging. Fast forward to a year ago when I almost lost my life. As I’ve been recovering, I’ve done a deep dive into learning more about Addison’s Disease and found many resources.

Until now, I had not heard of another person with Addison’s Disease. I’m looking forward to meeting others with similar challenges, learning more, and being a source of encouragement.

- Deb Will, Manitoba Regional Representative

Member's Stories

Hilary Richardson

Before I was diagnosed at the age of 10 in 1955, I remember school as being incredibly stressful and it was very hard keeping up with everyone. For some time, I had been adding teaspoonfuls of salt to every meal. I also ate very meagerly. My parents had tried all manner of bribery and punishment to persuade me to eat more, but nothing had ever worked. 'You eat like a bird,' my mother said constantly. 'Your legs are like sticks. People will think we don't feed you enough.' Not only was I very scrawny, but winter or summer my skin was a dark colour. 'Your elbows and knees are still dirty. You haven't scrubbed them well enough,' my mother would complain. Little did she realize that the dark skin, the craving for salt, and the reluctance to eat with its ensuing thinness were all symptoms of Addison's Disease, or non-functioning of the adrenal cortex.

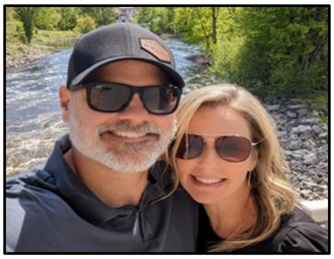
Because in my weakened state I was getting lots of colds and throat infections, my doctor suggested a tonsillectomy. The stress of the operation put me into a coma, and I was very close to death, when a few days later, on a hunch, an internal medicine specialist replaced my sugar- and-water IV with intravenous Solu-Cortef, and I woke up.

Although I spent at least a month in hospital, participation at school was much easier when I returned, as my energy levels had increased on the cortisone replacement medication. Hydrocortisone was not available in Canada then, so every week my father and I would go to the home of a man who had obtained the adrenals from a slaughterhouse and must have had enough chemical knowledge to dry them. We carried the precious brownish-grey powder home, and it was my job to put it into capsules, which were stored in the fridge. Luckily after about a year we were able to get HC. It took me about a year or two to fully recover.

Since then, I feel I have lived life to the fullest (work, lots of travel, marriage, children, grandchildren, etc.), and am still in reasonably good health. I very rarely up-dose, except for fever, anything involving anesthetic, and gastrointestinal infections. I follow the rule of 'Vomit once, take extra cortisol. Vomit twice, go to the emergency department.' I also up-dose if I am ill enough to need antibiotics.

My experience has been that once you get used to the management of Addison's it becomes part of your life without much thought and then you carry on. I don't want to downplay the struggles some people have, but newly diagnosed people need to understand that a normal, active life is still a possibility.

Susan LaBrie



I was diagnosed with Addison's on November 5, 2022, after being unexpectedly hospitalized two days earlier. Like many working moms with kids, I was too busy to be sick, so I brushed my symptoms off for a LONG time.

I finally got to the point where I knew something wasn't right, as the exhaustion was becoming more than I could deal with, so I made an appointment with my doctor. Convinced that I must just have low iron, she sent me off for some blood work.

That evening, I got a call from my doctor who advised me to go straight to the ER as my sodium was critically low. That one little blood test triggered a landslide of tests over the next couple of days to figure out what was going on. Once I was told that Addison's was suspected, I started Googling and realized that I checked off every symptom on the list – weight loss, nausea, tanned skin, lightheaded & dizzy, extreme salt cravings, and anxiety.

The whole experience was extremely scary and surreal, however, I feel extremely lucky and thankful that the health care system worked for me that day.

Member's Stories

Susan LaBrie - Continued

After I started treatment, I couldn't believe how much better I felt within just a few days. I had energy again. I felt hungry again. I could eat food without retching. I could cook a meal for my family without needing to take breaks and my anxiety seemed to be magically disappearing!

The last year has obviously been an adjustment however, I am happy to say that my most recent blood work was all normal for the first time since diagnosis. Being relatively new to this disease I still have a lot of worries for the future, but as time goes on and I become more confident in managing this illness, I remind myself that none of us are guaranteed a tomorrow. Even when I am not feeling great, I try to appreciate each day as many people have to deal with so much worse.

Rosemary Brown

In the summer of 1994, I was surprised by my body twice - unintentional weight loss (making me happy) and the disappearance of my underarm hair. Even though this was accompanied by a heightened bronze skin colour, I didn't consider it life threatening and I didn't tell my doctor. By November I started to feel ill with nausea, vomiting, accelerated weight loss, falling blood pressure, and muscle cramping. Then I was seeing many doctors. I was 42.

After multiple tests and referrals, I was diagnosed with Addison's in January 1995. The doctor told me I was lucky, but I didn't feel lucky. I had always recovered quickly, and I didn't have any peers with a chronic health condition. I said, "what do you mean - it's not going to get better?" He said I should be happy that I had something which didn't have many complicating factors. I resumed my life with elation - and two days after beginning treatment I was at a banquet and dance, celebrating my second chance at life.

One lesson I've learned is to be proactive about my health. This was reinforced early when my first endo consult yielded the information that the doctor really couldn't tell me about specific dosing, and I would have to figure things out for myself.

While disheartening at the time, it gave me latitude to experiment with replacement.

Over time I learned that I did not like the ups and downs of hydrocortisone, so I now use both that and prednisone - prednisone for even coverage and hydrocortisone for times when I need to elevate levels quickly. My goal has always been to keep my cortisol within normal limits and so far, I have not suffered any unwanted side effects. It took several years but my skin tone did become normal (very similar to my husband's, as before).

Another lesson is to think like a Boy Scout and always be prepared. It is better to prevent an Adrenal Crisis than to treat one. In any foreseen circumstances I try to think like an Adrenal Gland and emulate what I expect it would be doing.

It is sad to say that my biggest problems have occurred with hospital care where you must deal with staff who do not recognize the implications of Addison's and therefore, ignore them. In hospital has been the only place where I could have benefited from my injection but due to various post-op constrictions, could not. Being prepared means you must always have access to hydrocortisone, so be creative about how you keep it with you.

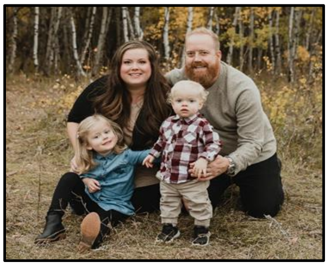
Three decades on I do feel lucky. Addison's has taught me some life lessons, but I do not feel it has impacted my quality of life or influenced what I am able to do.

Congenital Adrenal Hyperplasia (CAH) Support

Hello everyone! 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



Johannesson Family, Candice (back left)
Arlo (front right), thriving with SWCAH

Support/Resources

Current Clinical Trials

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

International Organizations

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

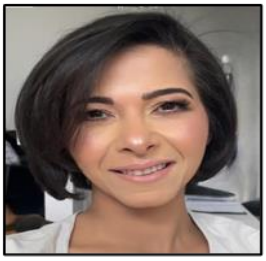
Online Resources

- 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

Adrenoleukodystrophy (ALD) Support



Hello! I am Riham Badawy from Ontario, a mother of three boys. My middle son (8 years old) started showing some symptoms like nausea, reduced appetite, inability to do any activities in addition to noticeable hyperpigmentation for 3 years. In August 2022, he was diagnosed with primary adrenal insufficiency (AI) followed by X-linked adrenoleukodystrophy (ALD), then by checking his two siblings, my eldest (14 years old) was also diagnosed with ALD in November 2022 and borderline AI. It was determined that I am the ALD carrier who passed it down to them.

I can't deny how much The Canadian Addison Society helped me through all of this, especially Gino Innamorato, who added to my knowledge and helped me immensely.

After the diagnosis of my children, I became addicted to reading about these diseases, reaching out to ALD experts, attending virtual conferences, reading books, and finally studied physiology to know as much as I can about these diseases to fully understand my children's conditions.

In April 2023, my husband and I created a nonprofit organization "ALD Hope", the first Canadian organization that raises awareness of ALD and the first organization worldwide raising awareness of both AI and ALD in Arabic as well as English.

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Serving as the co-founder and CEO, my mission is to raise awareness about these rare diseases, advocating for ALD newborn screening in Canada, and providing emotional and financial support to patients and their caregivers.

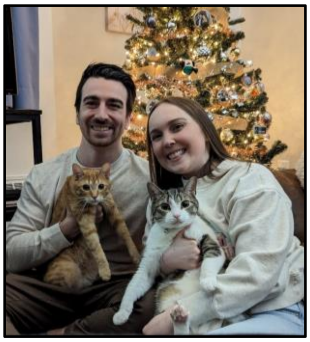
Through the dissemination of posts and videos in both English and Arabic, I aim to educate and empower others, ultimately working to save lives and improve outcomes for those affected by adrenal insufficiency and ALD.

I recently organized an event presenting my story and talking about these diseases, where two Addison's disease patients attended and were happy that their voices could be heard. I am also highlighting the challenges faced by AI patients so that maybe one day my voice can be heard by someone who can help at overcoming these challenges for a better future for my sons and the patients with the same condition, and help find a cure for ALD. I will continue advocating for my children and help AI and ALD patients and their families.

Please visit our website https://www.aldhope.org/ and explore ALD Hope on YouTube, TikTok, Instagram, Facebook and LinkedIn so that we can save other lives.

- Riham Badawy
info@aldhope.org

Newsletter Editor



Hi everyone! My name is Carly Charron, and I am the Newsletter Editor for The Canadian Addison Society.

In October 2019 I started experiencing symptoms of adrenal insufficiency (salt cravings, exhaustion, nausea, vomiting, and weight loss). Being a 4th year university student at the time, I equated my symptoms to stress and brushed them off. While my health rapidly declined, I continued to push on to Christmas break, which I thought would give me the rest I needed to get back to normal.

By the end of December, I had lost almost 15 lbs and barely had the energy to stand. I was admitted to the hospital on December 31st and rang in 2020 while getting swabbed for MRSA. A very memorable New Year's Eve.

In less than 48 hours, I was diagnosed with Addison's disease. Once I started on hydrocortisone, my energy rapidly returned, and the normal that I was waiting for started to appear.

I am fortunate that I have lived a healthy life following my diagnosis and Addison's has not impacted what I have been able to do. Since September 2020 I have been working hard towards earning my PhD in biology, where my project is focused on developing an edible Salmonella vaccine for chickens. I often work very long, busy, and stressful days in the lab, and while some days are harder than others, overall, I do not feel that Addison's impacts what I am able to accomplish. I have had the opportunity to travel to Italy and South Africa to present my research, and I am very thankful that I have been able to make the most of these trips without any limitations because of my disease.

Although I have not struggled physically with my illness, I have struggled emotionally. Coming to terms with having a chronic illness was very difficult for me, especially being diagnosed at only 23 years old. There are still times when taking my morning meds that it hits me that I will need them for the rest of my life.

While I am grateful that hydrocortisone has restored my health, upon starting treatment I was devastated by what it did to my appearance as I quickly gained back all the weight I lost and them some. This caused me to be very self-conscious, especially of my face and arms which seemed to puff up the most. While I try to be grateful that I am healthy, this is something that I still struggle with. I am extremely thankful for my fiancé (husband come September) for always being by my side and reminding me every day that I am strong and beautiful.

I hope you enjoyed reading the newsletter. If you have any comments or suggestions for future issues, please send me an email at newsletter@addisonsociety.ca.