



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



Dr. Donald Killinger

It was with a profound sense of loss that we learned of Dr. Killinger's passing on August 14, 2020. He was a great friend of this Society, its members, and adherents, serving as our volunteer Medical Advisor for over 20 years. It was only a few months prior that he retired from that important position.

For all those years, Dr. K. had been answering the medical questions of the Society's members and others, regarding Addison's/Adrenal Insufficiency through our 'Ask the Doctor' feature on the website. In addition, we so often relied on his medical wisdom, guidance for the Society, and advice over those many years.

He changed many people's lives for the better, both members and non-members, with his compassionate medical care and advice. His kindness, empathy along with his ability and willingness to listen, made him a gem. We owe him a great deal and he will be missed by so many.

Our most sincere condolences were sent to the entire Killinger family, as well as our thank you for sharing a small piece of this special man. <https://morleybedford.wordpress.com/2020/08/21/donald-w-killinger-md-phd-frcpc/>



Welcome Dr. Van Uum

Stan Van Uum, MD, PhD, FRCPC

Professor in the divisions of Clinical Pharmacology and Endocrinology and Metabolism at the University of Western Ontario (Western).

Dr. Van Uum's clinical practice is located at St. Joseph's Health Care, London, Ontario. It is focused on Endocrinology, with a particular interest in pituitary and adrenal diseases, and secondary hypertension.

At the time of Dr. Killinger's retirement as our Medical Advisor, another dear friend of the Society was approached to take on this volunteer role. Dr. Stan Van Uum, whom many of you already know, has agreed to be our Medical Advisor. This is a 'big ask' as all positions within the Society are volunteer roles. We are most appreciative of his acceptance of this role. Dr. Van Uum is already a very busy man as this information indicates:

CORONAVIRUS

Please refer to the information posted on the website BULLETIN BOARD on the Home Page or follow this link: <http://www.addisonsociety.ca/> This information is updated regularly, as required so check it often.

All support group in-person meetings continue to be on hold due to the ongoing risk of spread of coronavirus. Some virtual meetings have been occurring. Watch the meeting schedule table for updated information.

[Canadian Addison Society - Support Group Meetings](#)

Annual General Meeting – Saturday October 3rd, 2020

Minutes of the Annual General Meeting are available for review on the website.

The AGM was Director Elizabeth Hill's final as a member of the Board of Directors. The Society owes Elizabeth a huge thank you for her many years of service. Elizabeth acted as both Director and Regional Representative in Saskatchewan for many years and has assisted many with adrenal insufficiency.

With Elizabeth's retirement from the Board, we welcomed Nicki Barr who has stepped up to fill these important responsibilities, Director and Regional Representative, in Saskatchewan.

In Ontario, Director Nancy Bingeman also retired from the Board. Our most sincere thanks to Nancy for her years of service on the Board of Directors. Melanie Westover was elected as Director to fill Nancy's position. You may read more about Nicki and Melanie in the Annual Report notes, on the website.

We also need to express our most sincere thanks to Directors Derek Clarke and Holly McLean who have once more been elected to another term as Director. Thank you. More elections for the other Director positions will occur at the 2021 AGM. See you then.

News and Announcements *continued*



President's Comments

Greetings everyone. I am sure it is no longer a surprise to learn that our Society President, appointed September 2019, Carolynn Yeates, found it necessary to resign after 10 months in office, leaving us during the summer of 2020. This was attributed to family health issues as well as unanticipated business challenges due to Covid-19. I am sure many can relate. We wish Carolynn and her family well. Possibly we will see Carolynn back on the Board of Directors in the future.

My retirement from the Board and the President's role was obviously short-lived. I was just getting used to a more relaxed pace when Carolynn's resignation became reality. While I am 'back in the saddle', it is intended as a stopgap measure while we search for a new President. Please contact me directly if this is something that may interest you. hsmith.addisonsociety@outlook.com

We were beginning to feel confident we were back on track regarding this newsletter and its frequency of publication, but it was not to be. While not etched in stone, we have always tried to publish a newsletter each quarter. This has not happened over the past year as we were without a Newsletter Editor. More recently, we believed we had a new Editor on board however that has not worked out after all. As a result, and without an Editor to keep the newsletter viable, I will pinch hit here as well, for now.

We have a new volunteer now taking care of the distribution of Act-O-Vials to our Regional Representatives, brochures, and brochure holders to doctor's offices as requested, as well as the distribution of other items. We are pleased to welcome member Lucilia Vicente as the new volunteer in charge of this function. Thank you for stepping forward to assist the Society in this most important role Lucilia. Lucilia may be reached at lucilia.addisons.distribution@gmail.com Nothing happens in the daily operation of our Society without volunteers.

As you will have read earlier in the newsletter, we are still coming to terms with the loss of Dr. Killinger. While the news may now seem a little dated due to the delay in newsletter publication, I encourage you to read the article on page 1, including the link. Dr. K, was qualified far beyond anything we knew or imagined. He was a very humble but brilliant man and we will miss him in so many ways.

With the loss of Dr. K, we were faced with a massive hole in the heart of the organization, and we are so grateful to Dr. Van Uum for stepping forward to fill this critical volunteer role. Dr. Van Uum has also been a great friend of the Society for many years, and we look forward to his wise medical guidance as we move into the future.

News and Announcements *continued*

Youth Ambassador for Canadian Addison Society



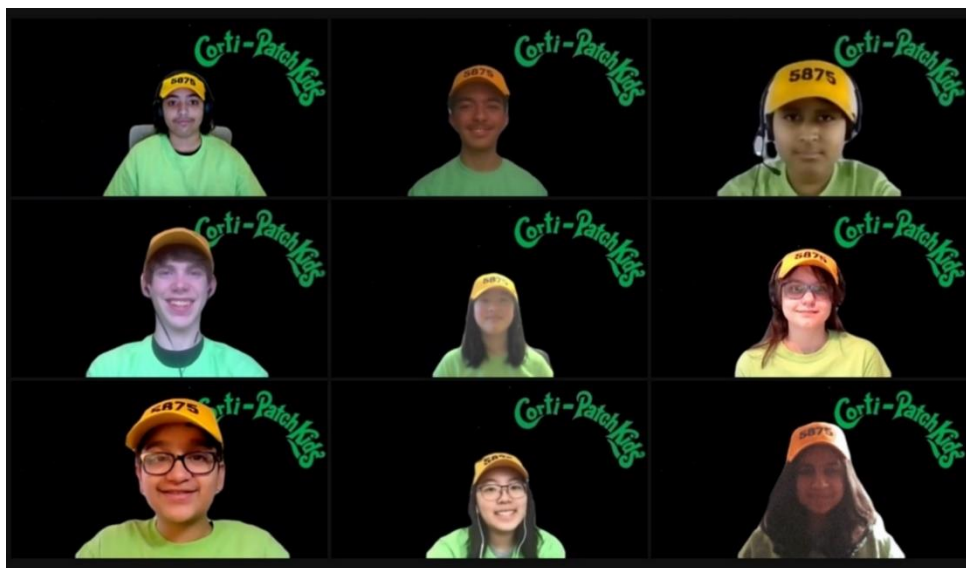
Many may recall a previous newsletter article introducing Kyle Yeates. As part of the 30th Anniversary of the United Nations Declaration of the Rights of the Child on November 20, 2019, the Addison Society had representation via Kyle, our Youth Ambassador, who represented the Society by attending the UNICEF Summit in Toronto.

Kyle is available as a contact to any youth who would like to connect with him regarding adrenal insufficiency. Kyle is a physics student at Laurentian University. He commented that when he was first diagnosed (via crises at 18 years of age); "It would have been great to be able to talk to someone else who had experienced a new diagnosis. Kyle may be contacted at: kylegveates@gmail.com

Team 5875

We are team 5875, The Corti-Patch Kids, a FIRST® LEGO® League (FLL) team from the Halton region in Ontario. First Lego League is a program where children ages 4-16 compete in competitions along with over 35,000 teams in 3 categories: An Innovative science project, a programmed LEGO® robot, and team values.

FIRST® LEGO® League introduces science, technology, engineering, and math (STEM) to children ages 4-16 through fun, exciting hands-on learning. Participants gain real-world problem-solving experience through a guided, global robotics program, helping today's students and teachers build a better future together. A common theme is given to all students each year, to focus their innovation. This year, we have been given the topic of getting people more active.



Top Row from L to R; Neil, Marcus & Avi
Middle Row from L to R; Will, Vera & Sarah
Bottom Row from L to R; Samyak, Kallie & Aariana

The approach we feel most people took after looking at what other teams have been working on, is incentive, or rewards for being more fit, but we felt it was unfair to leave all those who are willing to be fit, and have the determination, but lack the physical means to do so. After looking into ways someone might encounter this predicament, we came upon Addison's disease.

After speaking to Harold Smith, President of Addison's Canada, we realized that the process Addisonians have to undergo to obtain their cortisol levels is completely inefficient. Knowing when to up dose, and how much to up dose is purely based on feeling and is currently impossible to measure in real time. This means that if an Addisonian wants to up dose on their hydrocortisone in advance of exercise to compensate, they will take years to properly understand how much to take. Even Canadian Olympic Gymnast Nathan Gafuik admits he doesn't have it perfectly down pat after being diagnosed at 15.

In sight of this, we designed The Corti-Patch that not only allows for one to keep up with the correct amount of hydrocortisone when a low amount of cortisol is detected in their sweat, but also allows one to track their cortisol levels in real time. Our product is very consumer friendly, with an easily refillable cortisol injection system. Our cortisol sweat sensor detects the absence in ions such as potassium and sodium, as cortisol is a blocker, or inhibitor of these. This way, we are able to detect cortisol efficiently. Any questions, concerns, or comments, can be left on [our survey](#) specifically pertaining to Addison's patients.

The Corti-Patch project paired with our robot performance scores and teamwork skills has won us a place at the FIRST LEGO League Ontario Provincial competition being held in May. On its own merit our project is also being considered for another competition (Ontario Innovation Celebration) that will be taking place in the coming weeks.

News and Announcements *continued*

Team 5875

The Teams Coach and Instructor, Stephanie Sutherland, explains: "The Corti-Patch is the theoretical system the kids designed as part of their innovative solution for the FIRST LEGO league completion. Their "problem" for the competition was regarding; Addisonian patients experiences, or lack thereof, when trying to obtain live up to the moment cortisol readings.

These are students grades 6-10 so their project is of course theoretical at this stage but is based on science that is currently "out there". For example, the sweat sensor they want to use for their solution is currently in research at Stanford University, however the people who have designed it aren't aware of Addison's and how much it would help Addisonians. The students are drawing awareness to this. The Corti-patch is the students own design."

Editor Note: Thanks to Team 5875 and congrats for a 2nd place finish in your regional competition. Now it is on to the provincials. Addisonian readers, please consider filling in [our survey](#) to help the Team carry on their research into the viability of the Corti-Patch.

Editor Note #2: With the ongoing delays in publication of this Newsletter, the Team went on to win the First Place Champion's Award in this year's provincial competition! Not only that, but they were also selected as one of three teams from Ontario presenting in a global event (Global Innovation Awards) with our project, and as of now are in the top twenty teams moving on to the next stage. Every forward movement represents more exposure of Addison's/Adrenal Insufficiency and the challenges of monitoring cortisol.

Support Group Contact Information & Meeting Reports

B.C. - Vancouver Island (Victoria) Support Group

For information on the Vancouver Island Support Group, please contact Derek Clarke at vancouverislandaddisons@gmail.com or 250-857-4320.

B.C. - Vancouver Island (Nanaimo) Support Group

For information on the Vancouver Island Support Group, please contact Sharon Erickson at 250-729-1446.

BC - Lower Mainland Support Group

For more information on the BC Lower Mainland Support Group, please contact Geoff Metcalfe at 604-533-0579 or calfe579@telus.net

BC- Northern BC Support Group

For more information on the Northern BC Support Group, please contact Tyanna Trottier at 250-845-9446 or tyannatrottier@gmail.com

Alberta - Support Group

For information on the Alberta Support Group, please contact Rosemary Brown at 403-391-1507 or rhdbrown52@outlook.com

Saskatchewan - Support Group

For information on the Saskatchewan Support Group, please contact Nicki Barr at 306-531-4567 or nclarke@hotmail.com

Manitoba - Support Group

We are searching for a volunteer to become our Regional Representative for a Manitoba Support Group. If you can assist in this volunteer role, please contact Harold Smith hsmith.addisonsociety@outlook.com

Ontario - South/Central -Support Group

The South/Central Ontario Support Group held its Virtual Spring Support Group Meeting on Saturday, April 17, 2021. The meeting started off with a brief self-introduction from Sheri Thiffault, South-Central Ontario Regional Rep along with an introduction of her daughter Taylor, who has Adrenal Insufficiency and has never attended a meeting. Then continued with some other members sharing their stories/experiences.

We had over 80 participants join us for this meeting! Many individuals joined for the first time and many returning individuals, we had a couple other Regional Reps (Eastern Ontario and BC Lower Mainland) join us as well.

Guest Speaker

Michael Roffey, Coordinator of Paramedic Practice, Sunnybrook Centre for Prehospital Medicine, Toronto

Topic - Prehospital Treatment for a Patient with Suspected Adrenal Crisis

The presentation included information regarding the system and structure, education of paramedics, medical directives for paramedics with focus on the treatment of an adrenal crisis along with the signs and symptoms. Ways to go about being your own advocate along with how to prepare for emergency situations, including important documentation to have ready and available were highlighted.

Michael Roffey's presentation was both informative and engaging. His PowerPoint slide show presentation can be obtained by contacting Sheri Thiffault, Regional Representative at thiffaultsheri@gmail.com.

Melanie Westover presented our emergency injection demonstration. She discussed the materials needed for your emergency injection kit. She showed the emergency documents which she has in her kit which include her Canadian Addison Society membership card, the emergency injection instructions, emergency medical information and a letter from her doctor. Hers has a sticker on the front that says Emergency Medications Inside. Your doctor needs to provide the prescription for the Solu-Cortef and the rest of the materials you gather on your own. Melanie also discussed the importance of training people around you, so they know what to do in a crisis. While preparing your materials for the injection she reminded everyone to make sure the needle is tightly attached to the syringe by twisting it so that it does not fall off. Any specific questions regarding size of needle should be addressed with your doctor, however, the specifications are listed in the society brochure <http://www.addisonsociety.ca/pdfs/cas-brochure.pdf>.

Harold Smith, President discussed release of the EMERGENCY MEDICAL INFORMATION CARD. This came as a result of requests from specialist doctors who for years had been obtaining similar cards from European sources. You will note that the information on the card has been endorsed by two highly credible Canadian medical organizations *The Canadian Society of Endocrinology and Metabolism (CSEM)*, *The Canadian Pediatric Endocrine Group (CPEG)* and of course, our own Society name, having received the approval of our Medical Advisor, Dr. Stan Van Uum. The card may be printed at home as per the instructions shown. Anyone in Canada with adrenal insufficiency may request a pre-printed card if preferred, as explained on the instruction sheet attached. Members of The Canadian Addison Society, may request a 'laminated' version of the preprinted card by contacting lucilia.addisons.distribution@gmail.com, remember to include your name and date of birth with your request so they may be applied before lamination.

Support Group Contact Information & Meeting Reports *continued*

Ontario - South/Central -Support Group *continued*

Melanie informed individuals that if they are interested in practicing the emergency injection to reach out to Sheri the Regional Representative and that connection can be made. Melanie announced that we are looking to have a more socially focused type meeting. Information will be sent out for individuals to let us know if they are interested. A feedback form will be sent out to everyone along with an email including all the links Michael posted in the chat.

For information on the South-Central Support Group, please contact Sheri Thiffault at 647-406-7780 or thiffaultsheri@gmail.com

Ontario - Eastern Support Group

For information on the Eastern Ontario/Western Quebec Support Group, please contact David Sparks at davidsparks04@gmail.com

Quebec - Montreal Region Support Group

For information on the Montreal Region Support Group, please contact Shelley Saklatvala at 514-991-0294 or shell326@hotmail.com

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 Shelley Saklatvala, email shell326@hotmail.com or telephone 514-991-0294.

Atlantic Canada Support Group

For information on the Atlantic Canada Support Group, please contact Holly Mclean at 506-546-1687 or hquilter@nb.sympatico.ca. Holly lives in New Brunswick.

We are now searching for a volunteer to take over from Holly as our Regional Representative for the Atlantic Canada Support Group. Holly would like to now step down from this role. If you can assist in this volunteer role, please contact Harold Smith hsmith.addisonsociety@outlook.com

Medical Q & A's

Question 1

Hi there, I'm just looking for some information, hoping maybe this will be a good place to get it. I'm wondering what the chances are of someone being misdiagnosed with Addison's. What would happen to someone taking 30mg of hydrocortisone daily who didn't actually need it? How long can someone with Addison's generally go without taking hydrocortisone before having an adrenal crisis? Is there any way of testing for Addison's when you are already being treated for it?

Response 1

You have asked some very interesting and important questions.

Because some of the early symptoms of Addison's disease such as weakness and fatigue are non-specific, a diagnosis of Addison's is occasionally made without proper testing and the individual is started on hydrocortisone or another steroid. They initially feel better because of non-specific effects of the steroids but since the underlying problem is not treated, they continue have their original symptoms. There is then an ongoing

Medical Q & A's *continued*

process of changing steroid doses to try to correct the situation but since they are not treating the original problem the individual continues to feel unwell.

Once someone is on steroids for any length of time it is difficult to test for Addison's disease without gradually withdrawing treatment.

Taking 30 mg of hydrocortisone if you do not need it would do 2 things.

1. It would suppress the individual's adrenals if they were on it for more than a few weeks. So if they suddenly stopped taking the hydrocortisone they could have adrenal insufficiency i.e. weakness, low blood pressure and possibly death if the situation was not recognized.

2. They may develop signs of too much steroid such as weight gain, rounding of the face and easy bruising.

An individual with true Addison's disease would go into a crisis in about 48 hrs without replacement. This is a rough estimate. It could be sooner or could be later.

Medical Questions and Answers

Dr. Stan Van Uum, MD, PhD, FRCPC

Medical Advisor to The Canadian Addison Society

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

By emailing 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 (anonymously) in the Newsletter and/or on the website.*

Medical Information Card

We are very excited to announce the completion and availability of the Society's new MEDICAL INFORMATION CARD. The card was developed with the assistance of dedicated volunteers from among the membership of the Society and many in the Medical field, to whom we are deeply indebted. It is endorsed by The Canadian Society of Endocrinology and Metabolism (CSEM), The Canadian Pediatric Endocrine Group (CPEG) and of course The Canadian Addison Society (CAS).

Preprinted cards are 'No Charge' for anyone in Canada on corticosteroid therapy or may be corticosteroid-dependent (Addison Disease, Adrenal Insufficiency, etc.) courtesy of The Canadian Addison Society. Please carry them in either your purse, wallet, and/or emergency injection kit. Medical organizations may also request quantities for their AI patients. These cards are now an integral part of our medical community emergency awareness campaign. Please see the attached information sheet for ordering details. If requesting a pre-printed card, please include your name and full mailing address.


Society members only: If you are requesting a laminated card, please be sure to also include your date of birth as this along with your name must be applied to the card by us, prior to lamination.



The Canadian Addison Society / La Société canadienne d'Addison

EMERGENCY MEDICAL INFORMATION CARD / CARTE D'INFORMATION MÉDICALE D'URGENCE

IMPORTANT MEDICAL INFORMATION
ADRENAL CRISIS



This patient needs daily replacement therapy with hydrocortisone.

IN CASE OF SERIOUS ILLNESS, TRAUMA, COMA, VOMITING OR DIARRHEA, ADMINISTER HYDROCORTISONE

< 3 years	25 mg (IV, IM, IO, SC)
3 - < 10 years	50 mg (IV, IM, IO, SC)
10 years and older	100 mg (IV, IM, IO, SC)

AND IV SALINE INFUSION WITHOUT DELAY

NAME: _____

DATE OF BIRTH: _____

The Canadian Society of Endocrinology and Metabolism
Canadian Pediatric Endocrine Group
Courtesy of The Canadian Addison Society

INFORMATION MÉDICALE IMPORTANTE
INSUFFISANCE SURRÉNALIENNE AIGÛE



Ce patient a besoin d'un traitement substitutif quotidien d'hydrocortisone.

EN CAS DE TRAUMATISME, VOMISSEMENTS, DIARRHÉE, COMA OU MALADIE SÉRIEUSE, ADMINISTREZ HYDROCORTISONE

< 3 ans	25 mg (IV, IM, IO, SC)
de 3 ans à < 10 ans	50 mg (IV, IM, IO, SC)
10 ans et plus	100 mg (IV, IM, IO, SC)

ET SOLUTION SALINE NORMALE (IV) SANS DÉLAI

NOM: _____

DATE DE NAISSANCE: _____

La Société canadienne d'endocrinologie et de métabolisme
Groupe canadien d'endocrinologie pédiatrique
Gracieuseté de la Société canadienne d'Addison

Print in colour.

For a sturdier version, use card stock if available.

Trim both English and French versions with scissors.

Glue them back-to-back and let dry.

Place in wallet and/or with Emergency Injection Kit.

Imprimez en couleur.

Pour une version plus robuste, utilisez le papier cartonné, si disponible.

Couper les versions anglaise et française avec des ciseaux.

Collez-les dos à dos et laissez sécher.

Placer dans le portefeuille et/ou avec la trousse d'injection d'urgence.

If you prefer to have a preprinted card, please send your request to lucilia.addisons.distribution@gmail.com and request an EMERGENCY MEDICAL INFORMATION CARD. If you would like your card to be laminated to provide longer life, please include your name and date of birth so they may be applied before lamination. Please note that the corners on the printed cards will be rounded.

These preprinted cards are 'No Charge' for anyone in Canada on corticosteroid therapy or who is corticosteroid-dependent (Addison Disease, Adrenal Insufficiency, etc.). Laminated cards are offered to Canadian Addison Society members only.

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Si vous préférez avoir une carte préimprimée, veuillez envoyer votre demande à lucilia.addisons.distribution@gmail.com et demandez une CARTE D'INFORMATION MÉDICALE D'URGENCE. Si vous souhaitez que votre carte soit laminée pour une durée de vie plus longue de celle-ci, veuillez inclure votre nom et votre date de naissance afin qu'ils puissent être appliqués avant le laminage. Veuillez noter que les coins des cartes imprimées seront arrondis.

Ces cartes préimprimées sont « sans frais » pour toute personne au Canada sous corticothérapie ou corticodépendante (maladie d'Addison, insuffisance surrénale, etc.). Les cartes laminées sont offertes seulement aux membres de la Société canadienne d'Addison.

Personal Experiences

Not Your Average Expedition **A 50 Year Chronicle of Living with Addison's Disease** **Susan Thomas** **January 2021**

I have essentially lived my whole life with Addison's Disease. But what the mind harbours the body manifests. I have never thought of myself as being sick, just feels like I live with different levels of the flu some of the time.

What is Addison's Disease or adrenal insufficiency that is indicated on my medical alert bracelet? I have read that Addison's Disease is a destructive atrophy caused by an overactive immune system. Was tested for tuberculosis upon diagnosis, was negative. I am no stranger to experiencing allergic reactions though.

Had a set of Encyclopedias from 1935 that describe it as such:

A disease associated with diminution of the functions of the suprarenal glands. It is characterized by a general depression of the mobility, as evidenced by pronounced muscular weakness, by anemia, lowered tone of the circulatory apparatus, irritability of the stomach and pigmentation of the skin. This last symptom is the most pronounced and was fully described by Thomas Addison in 1855. The disease is more common in men between 20-40. The heart muscle also suffers very markedly, there being frequent attacks of rapid and feeble pulse with vertigo and fainting, sometimes fatal. Headache is frequent. In the pronounced types there is usually a severe disease of the suprarenal structures, most often tuberculosis, less frequently a malignant disease. In mild inflammatory states of the adrenals, recoverable hypoadrenalemiias may occur. Sudden death is a not infrequent result in acute hemorrhagic disease of the adrenals. A number of irregular forms of suprarenal disease or known, Addison's disease being but one of the more pronounced and terminal states.

The starting point contributing to our better understanding today, I am at least 50 years of current history.

My younger sister was born in 1963 and passed away in 1968 during an operation for appendix removal. Thought to be her cause of ongoing sickness. The morning after she passed my brother 9 and myself 7 were in the care of a neighbour who reported seeing a small, bright light asking, "where is my mommy"?

After that I always had the feeling I was going to die young. Several years later, I started feeling unwell all the time but not wanting to distress my parents anymore, kept it to myself. I was weak, easily nauseated, fatigued and dizzy. Symptoms were not very debilitating at first but over the course of several years the insidious nature of onset were becoming more problematic to hide from anyone. Just before my 13th birthday I was staying with my grandparents for a week during which time I was starting to experience distress. Every morning in private I was so sick and couldn't stand until I vomited, then I felt not too bad. I came back home in December and between then and beginning February I was seen by physicians and ultimately hospitalized. Even experienced a striping pattern along my back. I remember finally someone coming to tell me that they knew why I was sick and the next day I would be better again. Because an intern was working late on a Friday night, I was saved from the fate of my sister.

What followed was almost as distressing as the disease itself. Suddenly I was a celebrity, I remember lying in my hospital bed unclothed and my curtained area full of medical staff, poking, questioning and staring. This event happened many times, I was very glad to finally go home. But before I left hospital I was photographed, unexplained, unclothed, in my still sickly state. These dramatic events never leave you.

Six months after my Addison's diagnosis, I started experiencing numbness on the full left side of my body. Randomly, the tingling sensation would start in my small finger and work its way very systematically down the tip of my finger to the next one and gradually down my whole thumb then up my arm. Down my arm and my side, down my leg to the tip of my big toe and again through each toe until it all ended in my little toe. As the sensation progressed down from top to bottom on the left side then the initial tingling would go away. The whole

side of my body was not numb at the same time but in segments and would fully disperse after maybe 20 minutes. Then wham! The headache was to follow. Debilitating. Tried many different ways to overcome the pain, sometimes distorted vision and nausea. What worked best was going outside and diverting my thoughts.

Back to the hospital. Was tested for brain tumours. Negative. This same pattern of debilitating migraines lasted for 10 years, less frequent as the years went on. Very seldom get headaches now, after stressful situations or trauma might experience an aura for 25 minutes and very little headache. Did not rely on any medication for any of my migraine history.

At the time prior to diagnosis, I knew I was dying, the experience being very peaceful. But after cortisone and florinef treatment I started to see the symptoms of extreme fatigue, extreme dizziness, extreme weakness, difficulty standing, nausea/ gastrointestinal disturbance, sweating, and not feeling like I was in my body seem to subside somewhat. There were still traces of all symptoms but not as severe, I also came to the early conclusion I prefer no attention to myself anymore. At the time of diagnosis, I weighed 69 pounds, several weeks before my 13th birthday.

So now I am approaching my 20's, I have had several relapses, in and out of hospital but I am working full time in oil and gas in Calgary. In my mid 20's I had my last hospital stay, was feeling stable enough to start college and got married. Never did expect to live to be 20 so had some living to do before I didn't make 30. Very important to get a post-secondary education before I died.

Prior and during diagnosis, half my hair fell out and never grew back. I was touched very inappropriately during a hospital stay by someone in authority. I was now learning this disease isn't for the faint of heart or personality. I have seen more stars than an astronomer, I have a 4-poster bed to keep me from loss of balance when getting up. The morning sickness has followed me throughout, different degrees on different days, I always feel better after 10am and my second dose of steroids in the pm even better.

I will lick, eat, drink, dream about anything salty. I feel better after eating protein, meat protein especially. I first treated my very painful, debilitating stomach with Gelusil antacids, they now travel with me everywhere. Mint chocolates also seem to work in a pinch and Perrier sparkling water. I still experience nausea, not wanting to eat or difficulty touching and preparing food, so I go get my favourite takeout. Have experienced extreme nausea if I eat too much before 10am.

Now, my older brother. In around his 40's he started becoming continually sick to the point where one year he was taken to emergency 52 times. The BC government sent him to the Mayo clinic and as far as we know he produces too much adrenaline and has a sensitive stomach. My two younger siblings 8 and 10 years after I, display no symptoms of chronic sickness.

I was told point blank as a teenager that I would die having children. But it didn't matter, I wasn't going to live long. How could I feel that sick all the time and live a long life? But I have since discovered my scrawny little body can endure a lot. I didn't know anyone with Addison's so just went about it by trial and error on my own. Some days I still prefer to be alone so I don't have to pretend I am well. Determined at a young age I didn't want to be treated differently and once you feel sorry for yourself, your ship will sink.

So when the Kennedy's physician came to spend time with me at the Foothills hospital in Calgary during one of my stays he was just part of the long line of very interested members of the medical community. I have seen documentaries on JFK, and it isn't long until they talk about his experience with the disease and how he always thought he would die young, had his last rites read 4 times and battled chronic fatigue. It all sounded so familiar, and I felt comforted.

Once the physical ailments are more under control, this disease becomes a mental exercise. I find myself talking my way out of the very uncomfortable parts. Have gone by ambulance twice, once for the flu and once for food poisoning. I was also stung by a Portuguese-man-of war jellyfish but could limp my way to hospital. I have broken my arm but drove myself home in a sling and stolen hospital gown. Obviously, I didn't stay home much. Between the ages of 20 up to 60 I have traveled to many inspiring destinations. The only obstacle I had was a bit of nausea. No injection kit or emergency letter at that time. Did have the opportunity at 59 to travel to Columbia but upon further research into live vaccines, was a risk to Addison's patients, there being case studies of the live, mutated virus going back to its original form becoming deadly. Other than Yellow fever vaccine, I have tolerated every other vaccine available.

So, in between feeling faint when I am hot, faint and sweaty when hungry, sporadic nausea, faint when I stand up sometimes, or hot and cold at the same time, things are quite stable. I do get reminded that ordinary healthy people do feel unwell at times. I do go hiking but do limit my physical activities to every other day or if I feel well.

I have gone through medication reductions from 7.5mg prednisone daily to 3.5 mg. I understand the need for drug rehabilitation centres, very painful experience lasting months. I originally started treatment with cortisone and florinef, then in my 20-30's switched to prednisone 7.5 mg daily. Any medication change was painful as well. Then in my 50's tried switching out prednisone to Cortef, because of the longer half-life. I did feel I had more energy but soon developed a very debilitating reaction/ rash. Went back to Prednisone. Benchmark replacement on Prednisone has been explained to me to be 2.5mg daily to protect bone density but was a bit too low for me and an active lifestyle so currently at 3.5 mg. Quality of years not quantity.

So now I am turning 60. Made the most of my 20's, did not expect to live to 30, shocked when I turned 40, amazed at 50, unfathomable at 60. I have outlived 2 endocrinologists and the third is contemplating retirement. They provided medical support but again, nothing after I walked out the door. Thankfully an Alberta Addison's support group is in existence now for those who are in need of extended one-on-one. I have always had a tendency not to micromanage the chemistry or over-engineer anything I have read. Only you know how you feel and must find what makes you feel better. Need to change your connotation of feeling well.

What gets me through the hard days is being mentally occupied, hiking, protein, lots of rest and low stress, which is difficult to manage. When I used to frequent the children's hospital and going through life, I am inspired by others in more challenging circumstances than myself. And the colour purple, have read it stimulates the adrenal glands. Obviously my favourite colour.

I have come across a Globe and Mail article that Addison's disease affected the doomed Franklin expedition. A professor of dentistry and colleagues has published a theory that seeks to explain why Inuit who encountered members of the doomed Franklin Expedition in the 19th century noticed the men had hard, dry and black mouths. Have come across medical literature that indicates tuberculosis combined with scurvy or lead poisoning can promote Addison's.

My heartfelt thanks to Bernard Corenblum who has put up with my complaining over the years and always tries to pound into me I am the healthiest person he knows. My tough love angel.

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