



# 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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2021

Summer Edition

ISSUE NO. 95

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## 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**

### CORONAVIRUS Survey

Have you responded to our survey? While we are not in the business of designing or running surveys, we believe this unscientific survey will provide some interesting information. At the time of writing, 338 responses have been received. This includes responses for both first and second shots. If you responded for your first shot but not your second, please do so. If you have not participated at all, please do so for both shots. The survey is quick and simple. Please follow this link to participate. [The Canadian Addison Society](#)

If you have completed the survey (twice), thank you for helping. We will soon summarize the results and will report these results to you.

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### Support Group Meetings

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. Check the meeting schedule table often for updated information. [Canadian Addison Society - Support Group Meetings](#)



### **President's Comments**

#### *Volunteers Needed:*

As most know, the Canadian Addison Society is an all-volunteer organization operated by those with adrenal insufficiency, or family members of those patients. As a result, the Society can and will only continue to function, offering support, connecting with the medical community, providing the website, this newsletter, and absolutely every other single function of the Society, if there are volunteers available to do all these things.

Offering to volunteer is not a lifetime commitment nor is it usually something that consumes time and energy every day. Some volunteer roles are on a 'as required' basis, or monthly, or quarterly, etc. Some may be a one-time project. The primary criteria are that you be a member and that you have some experience in the area for which you would like to volunteer.

At present we have the following important volunteer roles open. If one of these are your calling, please contact me directly at [hsmith.addisonsociety@outlook.com](mailto:hsmith.addisonsociety@outlook.com)

We are in need of a volunteer to take on the important role of Newsletter Editor. Some experience would be helpful but not a deal breaker. Four Newsletters per year are published, when possible.

There are several Regional Representative volunteer positions open as follows: The Territories, Manitoba, and the Quebec City region.

And finally, there is a member out there somewhere in Canada, with the free time and management skills to become our next President. The Society will not continue as we know it without a qualified volunteer ready to step forward and take over the reins at the President level.



### **Youth Ambassador**

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. [kylegyeates@gmail.com](mailto:kylegyeates@gmail.com)

### **Team 5875 *The Corti-Patch Kids,***

For those of you following the progress of Team 5875, *The Corti-Patch Kids*, we heard from the Team mid-July. Following are selected excerpts from their email to the writer.

*"In the final week of June, we participated in the Global Innovation Awards, as one of the 20 teams selected in the world, and were recipients of the Innovation Impact Award. This places us in the top 6 in the world! We are very proud of this achievement, along with our provisional patent that was secured before the event. Unfortunately, we have not been able to manufacture any parts of our solution, but we will keep you updated when such changes do occur.*

*Thank you so much,  
The Corti-Patch Kids"*

(If you would like to review the previous Newsletter article, please follow this link: [spring2021.pdf \(addisonsociety.ca\)](#) )

## Support Group Reports

### Alberta

'Greensleeves' If you live with Adrenal Insufficiency in Alberta and are over 18, you need to follow this program. It is simply a green plastic sleeve containing a piece of paper with some of your health info and future care, signed by your doctor and kept in your home. It is also the correct place to have your steroid needs information as you can be sure the content of this Greensleeves is going to be read. It is meant to be kept on top of your fridge, to be readily accessed by paramedics should they be picking you up in an ambulance. It should also be taken by you any time you go to medical appointments or the hospital. The following news article partially explains the program from a patient's point of view.

<https://www.albertaprimetimes.com/alberta-news/advance-care-planning-a-voice-when-you-cant-speak-for-yourself-2255221>

### Atlantic Canada

Saturday, August 21 was a very special day in Atlantic Canada as the Society held its first ever Support Group meeting (*virtual of course*). Attendance was small but that did not stop an excellent sharing of information and experiences. It was a great beginning, and we hope to see these meetings continue and grow in attendance.

Sincere thanks to Board member Melanie Westover of Toronto for handling all the 'techy stuff' and more, making the virtual meeting possible. In addition, our thanks to Lucilia Vicente of Guelph, ON who joined us to share information on how to access the various items available to members, from the Society.

### Ontario - South/Central

A few months ago, the South/Central Ontario Region started hosting Monthly Support and Share Virtual Meetings on the 3rd Wednesday of the month. These have provided an opportunity for those looking to connect with others who have Addison's disease and other forms of Adrenal Insufficiency. As our in-person meetings switching to virtual meetings have made this piece more challenging.

These meetings have provided opportunities for members to share personal stories/experiences, ask questions or just listen. For those who have attended we hope you have found them beneficial, please feel free to share any feedback you may have. For those interested in obtaining more information, please contact Sheri Thiffault, South/Central Ontario Regional Representative at [thiffaultsheri@gmail.com](mailto:thiffaultsheri@gmail.com) or (647)406-7780.

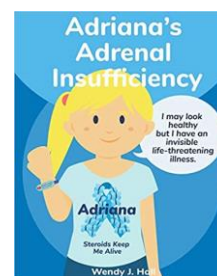
We are in the process of planning the Fall Support Group Meeting for Saturday, October 23, 2021. Keep an eye out for an email with further information or check the Canadian Addison Society website for more details.

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*This book is mentioned here for your awareness as recommended by a South/Central Ontario member; however, The Canadian Addison Society has not reviewed the book or its contents. For your consideration*

This is the amazon link for you to look inside:

<https://www.amazon.ca/Adrianas-Adrenal-Insufficiency-Wendy-Hall/dp/1727304438?asin=1727304438&revisionId=&format=4&depth=1>



## **Support Group Contacts**

### **Alberta**

For information on the Alberta Support Group, please contact Rosemary Brown at 403-391-1507 or [rhdbrown52@outlook.com](mailto:rhdbrown52@outlook.com)

### **Atlantic Canada**

For information on the Atlantic Canada Support Group, please contact Harold Smith at [hsmith.addisonsociety@outlook.com](mailto:hsmith.addisonsociety@outlook.com)

### **BC - Lower Mainland**

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

### **BC- Northern BC**

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

### **B.C. - Vancouver Island (Nanaimo)**

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

### **B.C. - Vancouver Island (Victoria)**

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

### **Manitoba**

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](mailto:hsmith.addisonsociety@outlook.com)

### **Ontario - South/Central**

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

### **Ontario - Eastern**

For information on the Eastern Ontario/Western Quebec Support Group, please contact David Sparks at [davidsparks04@gmail.com](mailto:davidsparks04@gmail.com)

### **Quebec - Montreal Region**

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

### **Quebec - Québec City Region**

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](mailto:shell326@hotmail.com) or telephone 514-991-0294.

### **Saskatchewan**

For information on the Saskatchewan Support Group, please contact Nicki Barr at 306-531-4567 or [nclarke@hotmail.com](mailto:nclarke@hotmail.com)

### **The Territories**

We are searching for a volunteer to become our Regional Representative for a Territories Support Group. If you can assist in this volunteer role, please contact Harold Smith [hsmith.addisonsociety@outlook.com](mailto:hsmith.addisonsociety@outlook.com)

## **Personal Experiences**

### **Lisa's Story**

I am a new member of the Canadian Addison Society and I thought I would share my personal experience to raise awareness of Addison's Disease. It was in 1986 early in the year that one night when I was getting my daughter Lisa ready for bed that I noticed an unusual white spot on her tummy that was the size of a loonie. I panicked and took Lisa right away to the nearest ER. The doctor on-call ridiculed me for having wasted their time in the ER over a spot. I was so upset and immediately the next morning took Lisa in to see the family doctor. I cried recanting to him what happened in the ER the night before. I remember the family doctor staring at the unusual spot for quite a while. He told me not to worry that he thought he knew what it was and would send me to the best dermatologist in the city. I was relieved to think that the spot did not seem to be anything too serious.

It was a few weeks later that we saw the dermatologist who told me that Lisa had a skin disorder called vitiligo. She explained that this skin disorder would not affect Lisa's health except that if it spread it could bother her cosmetically. Months went by and Lisa's spots were spreading. Lisa also had a bout of the flu that the family doctor claimed she was catching at the school. I also had taken Lisa in to see him because Lisa was being told by the school to keep washing her hands. The family doctor looked at the darkened pigment on the back of her hands and told me it was just her pigment. About a month or two later Lisa was back at the Dermatology office where I freaked out at the doctor. I questioned why Lisa was getting so many little flus and viruses and why were the spots spreading all over her skin. The Dermatologist exclaimed that maybe she did not know everything about this and did I want to send Lisa for a second opinion. I told the doctor to rush the appointment as I was very worried.

About a month later we were seen at a world class children's hospital for a second opinion. The Dermatology department did all kinds of blood work. The doctor that was seeing Lisa told me that yes Lisa just had a skin disorder and again I was told it would not affect her health. Lisa threw up in the blood lab, but I guess the doctor thought Lisa was just nervous getting the blood work done. Lisa was again given Cortisol cream to try and even out the spots. More time went by with Lisa going back and forth to dermatology. I was getting upset because I told them Lisa seemed to be getting too many flus and viruses. So finally, a week after Lisa's tenth birthday when she threw up again in the blood lab, they sent Lisa over to paediatrics to be checked over. The pediatrician looked over Lisa's chart and started doing his examination. When he took Lisa's blood pressure he frowned, He made Lisa stand up and took it once again. Her blood pressure now seemed okay. Lisa told the doctor she did not feel very well and that she had pains in her tummy. The doctor looked her over and told me he thought Lisa had a virus. I argued with him about why was Lisa always getting sick. He explained that kids her age catch stuff all the time at the school and that in two days Lisa would be okay. He sent Lisa down to have her appendix checked out. When everything seemed okay with the x-ray again, he told me that Lisa would be alright and if not to bring her back to the hospital. I got mad at him for implying that kids her age make a big deal about being sick. I told him Lisa was not like that and does not make up stories. We left the hospital and I had to leave Lisa with my mom for a few days because I had to get back to work and I did not want Lisa going to the daycare when she was under the weather.

I had checked in with my mom every day and was so excited to be picking Lisa up after work on the Friday. As soon as I walked in the door I was immediately upset because I noticed that Lisa had a strange masky look on her face. I told my Mom I was taking Lisa into the hospital to get checked over. My Mom did not think Lisa was sick enough to go to the hospital, but I was sure something was very wrong. At the hospital Lisa perked up and started chatting to people waiting to see the doctor. I almost left the hospital thinking that maybe Mom was right, and I was wasting our time in there. Not long after seeing the doctor in the ER I was told they were keeping Lisa in for observation. I was scared for Lisa and yet relieved that maybe now they would find out what was really wrong with her.

*...continued*

Once up in Lisa's room they immediately put an IV in that I assumed was maybe for dehydration. The young doctor told me that there was more to this and that we would talk later. I told Lisa not to be scared and the doctors were going to make her better. I remember looking at Lisa and she suddenly flinched kinda funny. I took her head in my hands and I told Lisa to try and stay still as not to knock her IV out of her arm. As I was holding her Lisa looked up at me with the most beautiful smile. I asked Lisa if she was okay. She said, "Mommy, I am okay". I put her head back down on her pillow. Without warning Lisa chest jolted up and her head swung back. I looked at Lisa and I immediately saw death on her face. Shocked I ran out of the room and could not move. It was like I was paralyzed in fear. Crash carts flew past me. A nurse grabbed my arm and took me to a room to cry and pray. When they told me Lisa had died — I thought I would die too — just hearing those words. That night was the worst night in my entire life.

The coroner who did Lisa's autopsy told me that Lisa had died from an adrenal crisis because of Addison's Disease. That the disease had stopped her adrenal glands from working and without those hormones the disease is usually fatal. Yet, I was angry to find out that there was medication that Lisa could have taken, and she could have lived a normal life. He also told me that Lisa had also developed a condition called Myocarditis that had affected her heart. And that even if they had diagnosed her that night properly, she probably would have still needed a heart transplant to survive. The Addison's Disease had run down her system so much that is why she got the myocarditis.

It took me many years to try and get over the death of my daughter. During that time my co-worker's 15-year-old daughter got diagnosed and tested because of Lisa's story. This miracle — well — that is what saved me. Lisa's death suddenly was no longer in vain. I always felt if only I had read about a disease that caused darkened pigment or vitiligo (white spots). If only someone had told me about, Addison's Disease, that maybe somehow, I could have saved my daughter Lisa's life. I was in so much pain and despair after Lisa's death. It had just devastated me.

So, along my painful journey to try and heal and forgive I wrote a book called, Lisa's Story. I wrote the story to save lives. I wrote the story to honour Lisa's life because Lisa deserved to live — because — Lisa's life mattered. Lisa was a child with such a big heart. A kid that cared about everybody. My hope is that the book that just got launched on amazon will raise awareness about Addison's Disease. I pledge that any royalties from the book at the end of the year will be going to the Canadian Addison's Society. If anyone would like to read the book for free it was recently added to the e-book Indie Ontario Collection at the Toronto Public Library.

The link is: <http://library.biblioboard.com/content/e3289cf8-fb1e-4de9-bff7-fad4dce3be3d>

