The Canadian Addison Society
La Société canadienne d'Addison

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In this issue:

PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison management program.

Canadian Olympian Nathan Gafuik:

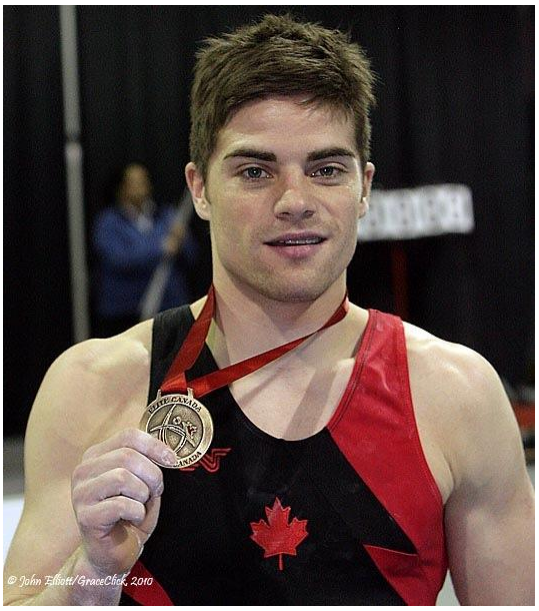
One of Canada's Olympic athletes is an Addisonian. Several inspiring articles have been written about him. Below, we reprint an article that appeared in the U.K. ADSHG newsletter, as you can only access the article if you are a member of their group. However, an article from the Globe and Mail, July 20, 2012, is very worth reading. Just follow this link: http://m.theglobeandmail.com/sports/olympics/addisons-disease-makes-gafuik-a-fighter/article4429100/?service=mobile

Having It All: Nathan Gafuik, Olympic Gymnastics and Addison 's:

This article appeared in the U.K. Addisons Disease Self-Help Group newsletter, and is reprinted here with their permission.

Nathan Gafuik, the Canadian Olympic gymnast, is living proof that you can have Addison's and follow your passion to its limits, however demanding that pursuit may be. In this interview, he talks to Jane Hodgkin about his remarkable life.

“I didn’t want ever to be in the situation, either in the gym or in any part of my day, when I would feel something and blame Addison’s for it. I refused to use it as an excuse.”



Now aged twenty-seven, Gafuik reveals on his Facebook page that he started gymnastics pretty early on. As a toddler in Calgary, Nathan “exhibited a natural inclination toward climbing, running, jumping, and swinging. His grandmother registered him in a community gymnastics program for his fourth birthday and he started competitive gymnastics at five years old.”

The energetic five year-old became one of Canada’s top young gymnasts, training intensively and competing at ever-higher levels. Aged 18, he went to the Athens Olympics as an alternate for the men’s gymnastics team. Four years later, in Beijing aged 22, he achieved 17th overall place. Many international gymnasts retire by the age of 25. Not Nathan Gafuik. This year, in London aged 27, he was Canada’s sole representative in the artistic gymnastics. He had gained that place in prior competitions with his own compatriots. His career now spans three Olympic Games, with additional gold-medal successes in the Commonwealth Games and World Championships.

A History of Childhood Illness

The threat of endocrine disease had always shadowed Nathan’s gymnastic aspirations, at times bringing him close to abandoning it. His family were aware of minor health problems from infancy; by the age of five he had been tested twice for diabetes because he was undersized and drank so much water. Soon he was missing school on a regular basis, with nothing identifiably wrong – but clearly too unwell for school. By the age of 10, he began feeling sick and was unable to eat during and after competitions. At 13, he was seriously ill during the week-long nationals competitions – yet still managed to come second in his category. In his early teens, his energy levels dropped dramatically. He had stopped growing and gaining strength in the same way as other boys his age. His Addison’s was diagnosed at 15.

I was lucky enough to meet Nathan Gafuik during the Olympics, over some soft drinks in the quietest corner of a cafeteria next door to the Olympic Park, to talk about how he has managed the challenge of Addison’s while meeting the massive demands of training and competing.

We started where so many discussions between those who have Addison’s begin: what was his diagnosis like?

The Relief of Diagnosis

"Really it was a relief. The national team coach had said because of my size, and the time it took me to recover, I couldn't be included in the national team. I had been ready to quit gymnastics.

"I had always been used to winning everything and destroying the competition. But then, the other boys had caught me up and passed me. Things hadn't been right for a while.

''I was nauseous after competitions, having two or three days off school and seeing separate specialists. My mum was urging them to look at the whole picture but no-one was putting it all together.

"Then I had an Addisonian crisis just after Christmas, when I was 15. I was deathly ill and lost 10 pounds in 4 days. Finally, on my second visit to ER, a doctor said they'd figured it out.

"At the time they said, take your steroids and life will be as normal. It took a while for me to discover how much of a challenge it was going to become.

"It's so intertwined with absolutely everything you do in your life", he commented.

The Path to Recovery

Gafuik knew he was talented and was determined to develop into the athlete that he wanted to be. Immediately after his diagnosis, he let his mother become the expert on Addison's and concentrated on getting back into training and competing, knowing that if she noticed something was affecting him, she would help him get back on track.

This was part of Gafuik's personal strategy to stop Addison's from getting him down.

"I didn't want ever to be in the situation, either in the gym or in any part of my day, when I would feel something and blame Addison's for it. I refused to use it as an excuse", he explained.

It was at the age of 20 that he came under the supervision of New Zealand-born endocrinologist Stuart Ross, who was himself a former world-class runner. Ross brought a real understanding of the physical and psychological demands of training and competing to Gafuik's treatment. He changed the timing of the prednisone, to better suit his training schedule and to respond to some of his issues with energy and insomnia. Nathan still maintains the same regular training schedule: Monday to Friday, 8.30-10am and 1.30-5pm; 12-3pm on Sundays.

"We had the medications all worked out and then we noticed that emotions – and how you handle them – play a major role."

“If I start to feel tired and tell myself that I’m tired, then I’m going to be tired. So Ross told me to work on having positive thoughts, particularly on stressful days, because those thoughts get your brain working differently and then positive chemicals start flowing and you can pull yourself round that way.

“Also we’re finding all the time that I need to be on top of what I’m eating and how I’m sleeping.

“I need to always be conscious of what’s going on, so that when I notice something I can handle it before things get out of control.

“For example if I notice I’m tired or headachy at the morning training session, I’ll go home and eat a really healthy meal with lots of vitamins and drink lots of fluids.” He pauses and laughs.

“I’ll also drink lots of coffee because I enjoy it, and it gives me a boost. Then I feel I’m good to go, and can get back to the afternoon session in the gym feeling decent.”

Mental Discipline and Self-Awareness

This approach of mental strength combined with physical vigilance means that, apart from illness, Gafuik only varies his twice-daily prednisolone on competition days. Then, he doubles his normal prednisolone dose, spreading out the extra to keep him on the level. If a competition is at 5pm, he’ll take his normal 5mg dose in the morning, then an extra 2.5 at noon, and the same at 2pm and 4pm and then again at 6pm during the competition, ending with his usual 5mg at night.

Ross and Gafuik refined this system, which covers the physical strain and the mental stress of competing, to avoid the trap of too high a dose. Any excess steroid could potentially weaken Gafuik’s muscles – just when he needs to perform at his peak.

On the subject of muscles, Gafuik ruefully indicates his upper arms which, he says, only a week after he has ceased training for the Olympics, have lost muscle bulk faster than would be the case for someone without Addison’s.

“No matter how hard I train and condition, I can never put on, and keep, my muscles as others do.”

As well as being an all-around finalist at the Beijing Olympics in 2008, Nathan Gafuik won a gold medal in the team event, with silver medals for all-around and on vault, at the 2006 Commonwealth Games in Melbourne. He also gained a bronze all-around and a gold medal on the high bar, at the 2007 Pacific Alliance. These are outstanding competitive achievements for any gymnast. To have succeeded like this with Addison’s is breathtakingly exceptional, in a way which, perhaps, only those of us who also live with the condition can truly appreciate.

Finding the Techniques for Self-Control

Based on this experience, does he have any advice for others, in particular to those recently diagnosed with Addison's? True to form, his answer is both realistic and positive:

"Addison's has different effects on different people. The part we're missing intertwines with everything in the body, so first find out how it affects you and then find the techniques to control it."

So what has been his proudest moment to date?

"There've been some good ones. One of my most favourite moments was in 2006 in the Team Final of the World Championships. I was one of the three, that went up on the vault, and Kyle Shewfelt, who got a gold medallist (sic) in Athens in 2004 was another. I went first, and I stuck* perfectly – which doesn't happen very often on vaults. The next guy stuck it and then Kyle finished off, all three of us in a row, which was huge and everyone was going crazy!"

> *Sticking means landing on both feet together at the end of the manoeuvre and standing up in a controlled manner.

Setbacks and Determination

This past year has been hard for Nathan. In June 2012, two months before coming to London, Nathan had surgery for a thumb injury sustained at the World Cup in Slovenia. The delicate tissue repair involved after the surgery meant he was told it would be six to eight weeks before he could start putting any strain on that hand during training. A less determined person might have given up, but Nathan dedicated himself to a complete recovery. He saw physiotherapists and chiropractors, as well as undergoing demanding massage therapy. And he applied three to four hours of laser treatment to himself every day.

"I tried to stay off extra meds as much as possible but I did have some issues with appetite during that period and I was sleeping 10-12 hours a day. Six days before the competition, I had to prove myself fit to compete – and succeeded – but it was all a crazy experience."

When the London Olympic competition began, Gafuik had a fall on the high bar in the qualifying round and was immediately eliminated, to his own huge disappointment. Despite being only one of many athletes similarly eliminated, it was a devastatingly frustrating outcome, which again has required all his self-discipline and resilience. Inevitably, his limited opportunity to participate in the London competitions fails to reflect his high standard and extraordinary preparation.

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What next? After London, he plans to “head for the couch”, and do nothing at all for a month. This will be the longest holiday he’s ever taken. Then it’s back to the gym and training.

“I want to peak at the World Championships in Antwerp in September 2013, and I’m going to take a smart approach to getting ready for that one.”

Hugely talented, very smart and astonishingly resilient, Nathan Gafuik deserves our recognition, much applause, and our heartfelt thanks for demonstrating that so much is possible when living with Addison’s. He may be too modest to accept the idea of being a role model, but by his career he demonstrates that, with good medical support and the right balance of daily medication, coupled with a positive mind-set, self-awareness and physical discipline, a diagnosis of Addison’s need not prevent us from achieving our goals.

Watch Nathan Gafuik performing his

- High Bar routine at the 2012 Canadian Gymnastics Championships: nhttp://www.youtube.com/watch?v=XZ4bwDfJrJU
- At the Gymnix World Cup in 2010: nhttp://www.youtube.com/watch?v=4leqDSso5os
- At the Beijing Olympics in 2008: nhttp://www.youtube.com/watch?v=gFDGMia7oL8

With special thanks to Jane Hodgkin, ADSHG, U.K.

Annual General Meeting:

The 2012 Annual General Meeting was held Saturday, October 13, 2012 in Victoria B.C., Minutes will appear in the January 2013 newsletter.

ACE and ARB Inhibitors:

Recently, we have had a number of questions related to the use of ACE inhibitors and AHA inhibitors by Addisonians. Here is some general information which may be useful. Remember that each problem and combination of medications is specific to an individual and your own physicians are your primary sources of information as they have direct knowledge of your various medical conditions and needs.

General Principles
Angiotensin converting enzyme inhibitors (ACE inhibitors) and angiotensin receptor blockers (ARB) both work on the same system but in different ways. Angiotensinogen originates in the liver and is converted through a series of steps to form angiotensin. ACE is one of those steps and ARBs interferes with the effect of the angiotensin at its receptor.

Angiotensin has several effects. One is to stimulate the adrenal to make aldosterone - this does not happen in Addisonians because the adrenal is no longer functioning. A second function is the constriction of blood vessels and the release of a compound that also causes

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constriction of blood vessels. These contribute to the maintenance of normal blood pressure and can contribute to high blood pressure in some instances.

In a hypertensive person without Addison's disease, ACE inhibitors and ARBs work on both of these systems, decreasing aldosterone production, thereby decreasing salt retention and decreasing constriction of blood vessels. These effects make them very effective in treating high blood pressure. In individuals with Addison's disease who are on Florinef for aldosterone replacement, the drugs will not have any effect on salt retention because the dose of Florinef remains the same. There will be an effect on blood vessel constriction because the angiotensin is still being formed and constricting blood vessels. This can be blocked by both of these drugs and have some effect on blood pressure.

In some instances, in individuals with Addison's disease, the endocrinologist may alter the dose of Florinef when treating high blood pressure to decrease salt retention.

The discussion is whether these ACE inhibitors and ARBs are effective in treating hypertension in individuals with Addison's disease or whether drugs that work on other systems would be a better choice. This is a discussion each individual must have with their own physicians.

Personal Experiences:

Wow! There are so many of us! I'm sad that we have to be sick with this disease, but I'm learning that Addison's does not define me!! I was diagnosed Feb. 2012 at 33 years old. Same story as everyone else, excellent tan, nothing tasted good, big time craving for salt (couldn't get enough pickles!). I was lucky; the ER doctor who diagnosed me was familiar with the disease and its symptoms. I had seen other doctors at this same ER several times within a 1-month period and they would send me home with no explanation. So, I believe there is still some educating needed for medical professionals.

I read somewhere that Addison's is an insidious disease, and I'm not sure why, but that word "insidious" resonated with me. I remember being confused a lot. 'What was happening to me!' was a common phrase. Why can't I walk up the steps without losing my breath, why can't I stand long enough to blow dry my hair, what is happening to my skin, why am I so tired all the time. When I was diagnosed, I threw a little bit of a pity party for myself, but that only lasted a week or two. Shortly after, I felt lucky to alive, happy that Addison's is treatable and that if I pay attention to my body and stick to my medication, I can live a healthy, productive life. So that's where I'm at today, glad to be here. I've started an intense workout regiment, "crossfit", which is awesome and has helped me regain most of my strength back. I hit road bumps from time to time, but these last 6 months have been very revealing. Remember, you have Addison's, Addison's doesn't not have you!

Best of Luck!

Submitted by Anna Johnson

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Highlights from Local Meetings:

Vancouver Island Support Group - Victoria

The Canadian Addison Society AGM was held at Victoria General Hospital on Saturday, October 13, in Room 1814 next to the Cafeteria.

For further information on the Vancouver Island Support Group, contact Jim Sadlish at vanisleaddisons@gmail.com or (250) 656-6270.

Vancouver Island Support Group - Nanaimo

The next meeting in Nanaimo will be held at the Chase River Boys and Girls Club of Central Vancouver Island at 1400 Cranberry Avenue on October 20, 2012, from 1-3 pm. The Boys and Girls Club is a converted firehall located in South Nanaimo near the junction of the Trans Canada Highway and Nanaimo Parkway at Cedar Road.

We hope to establish a regular meeting schedule for mid-island and up-island members so members can get together to discuss their experiences and treatment. Thank you for coming out and supporting this initiative.

Natasha Arntson will coordinate this meeting. Thank you, Natasha! Natasha's sister is the Area Coordinator for the Boys and Girls Club of Central Vancouver Island and has arranged for us to use the Cranberry Avenue clubhouse. To contact Natasha, please email Natasha at nakeeta4@shaw.ca.

For information on Central Island activities, contact Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

The next meeting of the BC Lower Mainland Group will be October 27, 2012, in the Neil Russell Room, Royal Columbian Hospital, 330 E. Columbia St., New Westminster BC (3rd Floor Royal Columbian Tower) from 1:00 p.m. to 3:00 .p.m. The Guest Speaker will be Dr. Ruth Martin, Course Director, Doctor, Patient and Society Year 1 course in the Faculty of Medicine at the University of British Columbia. Her talk will include how our interviews are one of the most meaningful activities for the 1st year students; how they help UBC, future patients, and feedback they've received from the young doctors. 2013 will be our 10th year of participation in their student interview program.

Parking is available on site or side streets. It is also easily accessed from the Sapperton Sky Train Station.

Submitted by Judy Stanley

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For further information on this support group or any upcoming meetings, contact Judy Stanley, (604) 936-6694 or bugbee@shaw.ca.

Alberta Support Group

I continue to get phone calls quite regularly from newly diagnosed Addisonians who get my name from the Canadian Addison website. I hope to attend the annual meeting in Victoria this fall!

Submitted by Ginny Snaychuk

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton, or Peter Little at bettypeter66@gmail.comor (780) 918-2342 in Edmonton.

Saskatchewan Support Group

There are now 5 Addisonians living in and around the Meadow Lake, Sk area.

For information on this support group, contact Elizabeth Hill at (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.

South/Central Ontario Support Group

The group met, Sept. 29, 2012. We welcomed several new members, including some newly diagnosed Addisonians. As usual, we went around the room with each person giving a brief explanation of their connection and experience with Addison's.

Our guest speaker was a regular and strong supporter of the Society's mission, Dr. Stan Van Uum, MD, PhD, FRCPC. Dr. Van Uum observed that there is no "standard" Addison's Disease as the condition is very individual. These meetings are important to share stories to learn from others and it reinforces that you are not alone. It is important to have a support mechanism.

- Every time you have a health issue you have to consider Addison's first.
- Normal stress response – many different reasons as to a breakdown.
- Definition of stress – this varies by individual. Have to decide and know from experience what is stressful for YOU. Includes changes in temperature, pain, fear, anxiety and illness.

Other auto-immune diseases that can also happen in patients with (auto-immune) adrenal insufficiency

- Polyglandular Auto-immune Syndrome Type 1
- Polyglandular Auto-immune Syndrome Type 2

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Over the counter medications (non-prescription) - *beware*

- Real licorice blocks an important enzyme from kidneys, so you will actually be increasing your dose
- St. John's Wort
- Need to share ALL medications, natural health products, vitamins and supplements with your doctor

Aldosterone

- Too much Florinef – increased water retention and salt, swelling, increased blood pressure
- Cut back on the Florinef accordingly under doctor supervision
- If you are going to change doses, try just one small change at a time so you can monitor and track the results.

Situations to Increase Dose

Stress Doses

- Rule of thumb – High stress – i.e. cold, exam, travel – double dose (differs by individual)
- Fever – more significant stress to body – triple dose
- Malabsorption issues (diarrhoea) may need to take that into consideration
- Difficulty measuring the effects of frequently increasing Cortef dose.

Medications – if you change Prescription, you must change dose

Glucocorticoid	Anti-inflammatory	Salt-retaining
Cortisol	1	1
Cortisone	0.8	0.8
Prednisone	4	
Dexamethasone	25	0
Minerocorticoid - Florinef	12	125

Too much Florinef = Potassium too low.
Too little Florinef = Potassium too high
Muscle Cramps – Need to check calcium, glucose, potassium, sodium, magnesium, vitamin D levels

NOTE – Once you have Addison's Disease, you will never get a reliable test for Celiac Disease

- Thyroid hormones – should take separate from iron and calcium – thyroid very sensitive to absorption.
- Also caffeine and fibre may have an effect.

DHEA – part of fine-tuning, only potentially needed in women. Lots of controversy about DHEA. Usually helps if there are pituitary issues to be beneficial.

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Emergency Room Stress Dosing – STAT!

- Can we make this the norm, not a rare exception?
- Need to identify risk in delay in Emergency Solu-Cortef injection
- Suggested Initiative – Develop a Needs Assessment Questionnaire-First – develop a list of relevant questions. Second – Develop the Questionnaire. Educate –individual and health care system – avoid hospitalization.

Example #1: Adrenal Crisis mimics flu, other conditions, need to convince Medical Staff to listen that you think it is more serious. Two categories of questions: pre-diagnosis and post-diagnosis.
1 – if you are not yet diagnosed, how to increase awareness for quicker diagnosis
2 – once you have a diagnosis, doesn't guarantee that you get the right treatment

Example #2: If Adrenal Crisis does not occur frequently, in this stressful situation, patient may forget about the Injection Kit. Told Paramedics he has Addison's. Presented a copy of the Ottawa Protocol but still waited 2 to 2.5 hours to get the injection. Someone vomiting may present not as severe as someone who is bleeding, signs of heart attack, etc. How to raise priority to move to a higher level. EMS staff not currently allowed to inject Solu-Cortef in Ontario.

Example #3: Until you are able to get to "Medical" (beyond ER) within the hospital, it is difficult to advocate. Consensus - ER tends not to listen or pay attention to Medic Alert. Important to have family/friends to advocate. Emergency injection training clinic - become an expert in this potentially life-saving procedure. Symptoms of crisis – can't keep your medication down – vomiting, diarrhoea, loss of consciousness.
All Addisonians need to know how to prepare and administer a Solu-Cortef emergency injection. Please refer to the website for complete instructions
http://www.addisonsociety.ca/injection.html

Brochure Holder Program – Test Program Status
Distribution over the past year to endocrinologists and family doctors has been very slow-going, only about 50% of the original 50 kits have been delivered to doctors by members. However some members are only able to see their endocrinologist every 6 months to one year so we expect the balance of test kits to be placed in the next few months, which will allow the Society to complete a proper analysis of the viability of the program going national.

Facebook
Member Shannon Meister posted a notice of our meeting on 3 Facebook pages (below). Other support groups could do the same to the advantage of local Addisonians who may not be aware of the Society and its meetings. Some are "closed" groups, so click "Join Group" to join.

- Yes, I have Addison's Disease. No, it's not contagious.
- Adrenal Insufficiency/Addison's Disease
- Auto-immune disorders

Follow the “Upcoming Meetings” link on the Society website for more information on our next meeting, tentatively scheduled for May 2013 in Mississauga, Ontario.

Submitted by Harold Smith

For further information on Southern Ontario Support Group activities or meetings, contact Harold Smith in Kitchener at hsmith9995@rogers.com or (519) 742-9995.

Eastern Ontario Support Group

The group met October 13, 2012, with 12 people attending (including 4 supportive spouses).

- Everyone introduced themselves and shared information (when diagnosed, other conditions).
- Steve noted that the Society's AGM was being held on this same day in Victoria BC.
- The Society is looking for a volunteer who can help us set up and use Skype-like technology, so that members can ’attend’ the AGM without travel, local groups can ‘meet’ even when members are geographical far apart, and to facilitate Board meetings.
- Steve also shared some quotes from an interview with Nathan Gafuik, a Canadian Olympic gymnast who has Addison's disease (*Ed. Note: see article in this newsletter.*)
- One member was mentioning her problems with heat. Steve reminded us of the ‘cool vest’ which he uses to enable him to enjoy summer activities (http://www.coolsport.net/index2.html; please note that they are not the only suppliers of this type of product).
- We spoke about Medic Alert bracelets and shared what many of them had printed on them, noting the different information.
- A member from Kingston will help us look into arrangements to try having an "extra" meeting there in winter or spring 2013.
- We spoke about the Emergency Injection Kits and how to assemble one, noting the components (Solu-Cortef vial, alcohol wipe, needle and documentation).
- Copies of emergency kit injection instructions (from our web site) were distributed and Patricia led a demonstration on how to actually do an injection, using out-of-date Solu-Cortef vials and injecting oranges.
- One of the challenges is getting the Solu-Cortef mixed, as it can be difficult to push in the cork that separates the two sections. One approach is to slam the vial (plastic end down) on a table to dislodge the plug; another approach is to put the vial on a table, plastic end down, and ‘hammer‘ with something like a salt shaker (hard enough to dislodge the plug but not too hard as you don’t want to break the vial).

The next meeting will be Saturday, May 11, 2013, the week before the long May weekend, at the same location (Robbie’s Restaurant on St. Laurent Blvd in Ottawa).

Submitted by Steve McKenna

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For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at steveandpat@rogers.com or 613-523-7648.

Québec Support Group

Our representatives in Québec are Georgia Kapralios and Dr. George Kambranis, whose son has Addison's disease. They can be contacted at centresantedentaire@bellnet.ca. They can communicate in English, French and Greek.

Atlantic Support Group

The Atlantic Canada Support Group is looking for a volunteer to act as contact point. If you can do this, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Medical Q & A

There is now a very large and wide-ranging set of questions on both daily living and very situation-specific issues that have been answered by our medical advisor. To review these questions, please go to the Canadian Addison Society website under Education (http://www.addisonsociety.ca/related/FAQNovemberb2011.pdf), or see previous issues of the newsletter.

Before submitting a question to our medical advisor, please consult the wealth of Q&As on our website. Many questions have already been answered.

Q: My husband was diagnosed with Addison's disease about a year ago. He is on Cortef. He has gained about 20 lbs and is drained after going for a walk. What can we do? Does a specialist help?

> **A: Getting the dose of Cortef and Florinef right takes a bit of time and understanding of how the medications work. I definitely think your husband should see an endocrinologist to help work this out. There may be other factors involved to account for some of these symptoms, so get all the help you can.**

Q: I am feeling very ill at this time - all the symptoms I had when I was initially diagnosed 27 years ago with Addison's. My endocrinologist thinks I may have a gluten blockage that may be causing the malabsorption of my cortisone medication. I have had some blood tests done and am waiting for the results. I have had some other medication (anti-depressants) prescribed for me and I have had extreme reactions to the two medications. Could the fact that I am not absorbing the cortisone possibly be the cause for this bad reaction?

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A: If you do have a gluten sensitivity, it could interfere with absorption of many things. I am not aware of cortisone malabsorption but it could be possible. To check this out, your endocrinologist could measure your hydrocortisone levels before and about 2 hrs after taking the medication to see if the blood level increases as expected. You could also try a gluten free diet for a few weeks to see if you feel better.

Q: My last ACTH reading was high, which my endocrinologist says means that I am not absorbing my cortisone medication. One thought was that I am gluten intolerant and this does not allow the absorption of the meds. I have been gluten free for almost two weeks and I still do not feel well. I went to the hospital the other night and was given Solu-Cortef twice, eight hours apart. I felt good the next two days. I had tripled my Cortef for three days, today being my last day - tomorrow I will go back to my 20 mg twice a day. Today, I did not feel well again. What might be other reasons why Cortef might not be absorbed? And furthermore, what other methods are there to get the Cortef into my body?

A: The level of ACTH depends on the time of day and when you last took your medication. If you are on 20 mg of Cortef (hydrocortisone) twice daily, you are probably taking the first pill first thing in the morning and the second sometime in the afternoon. Since hydrocortisone is metabolised quite quickly, the blood levels will be low the next morning and your ACTH will be high, usually 40 to 100 pmol/l. After you take your medication, the hydrocortisone level will rise and the ACTH level will come down, usually to around 10 to 20 pmol/l. You can work with your endocrinologist to determine the dose of hydrocortisone you need, but we usually suggest that the lowest dose that makes you feel well is the dose you need. If your ACTH level is low in the morning before you take your pill, you are probably on too much hydrocortisone. You have to remember that hydrocortisone is not the only hormone missing in Addison's disease. It is important to be on the proper dose of Florinef to replace the missing aldosterone. You should work with your endocrinologist to be sure this is correctly replaced. I would be very surprised if there was a problem in absorbing your hydrocrtisone. It is usually readily absorbed.

Q: I have lost 20 lbs in about two to three months, not by choice. Could that have an impact on my amount of cortisol and Florinef that I need to have? Could that be a problem with absorption?

A: If you are on an adequate dose of cortisol (hydrocortisone) you should not be losing weight. It would be unlikely that you are malabsorbing cortisol. There can be some gastrointestinal problems that are autoimmune that can be associated with Addison's disease that could be associated with weight loss. You should discuss this with your endocrinologist. At the same time you can review your dose of cortisol and Florinef to be sure they are correct.

Q: Is it safe to take probiotics along with my regular medications (Cortef and Florinef)?

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A: Probiotics augment the bacterial content in the gastrointestinal tract. You can take these along with your Addison's medications.

Q: I have panhypopituitarism and, as a result, secondary Addison's. I was recently hospitalized for the third time for acute dehydration due to some food poisoning. During my stay in Intensive Care (in Ottawa), I was informed by one of the nurses that I should look into obtaining a cortisol injection for such emergencies. No endocrinologist has ever mentioned this to me!

There seem to be two products available - Solu-Cortef and Efcortesol. Solu-Cortef needs to be mixed while Efcortesol, is already mixed more concentrated. My question is this. Which is the better product? (In view that I may not be the one giving the injection, it seems to me that Efcortesol is simpler to use.)

A: I agree that you should have an emergency kit at home. It is particularly important if you are travelling.

I do not think that Efcortesol is available in Canada. I think that the Act-o-vial which is available here is as easy to use and has an advantage over the Efcortesol in one way. The Act-o-vial comes with the diluent in the same container and the mixing occurs by pushing a rubber stopper that allows the diluent to mix with the Solu-Cortef. You then use the syringe and needle to draw the solution into the syringe for injection.

The Efcortesol comes in a glass vial already mixed. The vial has to have the top snapped off and since this is glass, this can cause occasional difficulties. The solution is then drawn into the syringe.

I think the Act-o-vial is less tricky but both do the job. Both give you 100 mg of hydrocortisone.

The website gives you the details.

Q: My husband has been diagnosed with Addison's disease. He is on Cortef. Since he started, he has put on 30 lbs. Is there any way of getting this weight off? With the Addisons, he has low energy, doesn't sleep well, etc.

A: If he is putting on weight, he is probably on too much Cortef. The sleeping problem could also be due to the Cortef. It is best to take it earlier in the day, e.g. 8 AM, 12 noon and 4 PM, or 8 AM and 4 PM. The dose of Cortef varies from one patient to another - anywhere from 15 to 30 mg per day.

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Q: My husband has been diagnosed with Addison's disease as well as paracarditis, he was recently given pain medication OxyContin. The doctor is okay with it but we have read that people with Addison's disease should not take this medication.

> **A: If your husband needs pain medication, there is no reason why someone with Addison's disease can not take it. I am not sure if oxycontin is still available but the cardiologist will prescribe an appropriate medication for his degree of pain. Be sure to discuss it with her/him.**

Q: Can cortisone acetate cause anxiety and/or depression? If so, as an Addisonian, how can that be resolved since cortisone is needed?

> **A: Cortisol is normally produced by the adrenal so when you are on adequate replacement, you are close to being back to normal. Newly diagnosed individuals with Addison's disease often take a while to adjust to not being unwell and have the feeling that their problem may come back. After gaining confidence that they are really on the right treatment, the problem with anxiety settles down. Cortisone is converted to cortisol in the body and does not cause anxiety and depression.**

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Send your question to Dr. Killinger directly from the webpage http://www.addisonsociety.ca/faq.html#, by emailing liaisonsecretary@addisonsociety.ca or c/o The Addison Society (see address on front of this newsletter). Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.

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