

The Canadian Addison Society ***La Société canadienne d'Addison***

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ISSUE NO. 58

APRIL 2010

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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.

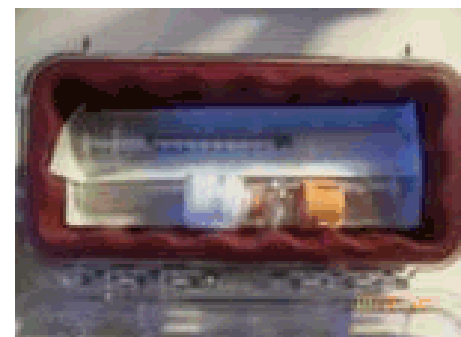
Emergency Kits:



One member has found the 'Pelican Case' ideal for her emergency kit – large enough for all the components, hard-shelled, sturdy and water resistant. She has used it when camping and trekking.

Other members have used pencil cases, prescription bottles from the pharmacy or toothbrush travel

cases to assemble and carry their emergency kits.



For more information on the 'Pelican Case', see
http://www.pelican.ca/cases_detail.php?Case=1030 or
<http://www.pelican.ca/search.php>

Announcements:

- Our heartfelt sympathies go out to the family of Al McConnell, a long-time member of the Eastern Ontario support group, who passed away in February. Al and Doris, his wife, regularly drove from Montreal to Ottawa to attend meetings.

Highlights from Local Meetings:

Vancouver Island Support Group

The group met February 6th, with fourteen people attending, 10 with Addison's.

Each person with Addison's introduced themselves and gave a short description of their diagnosis and treatment including current concerns and questions for the group. Family members also voiced important observations and valuable suggestions.

Each of us is unique in:

- how we came to have adrenal deficiency,
- how we were treated after diagnosis,
- how we react to the various medication choices available,
- what other disorders, if any, accompany our Addison's,
- the amount of medication we take,
- when and how often we take our medication,
- what chronic symptoms we may still have, and our quality of life.

It is generally recommended that we take calcium supplements to offset bone loss caused by our medication. However, it is not as simple as taking a few pills for some people. Two members have parathyroid abnormalities, one hypoparathyroid (too little calcium in the blood), the other hyperparathyroid (too much calcium in the blood, but low bone density). Still, both need supplemental calcium in various forms. Another woman's tests show rising parathyroid readings. (ref: <http://www.endocrineweb.com/parathyroid.html>)

One woman has very high bone density, so takes very little calcium. A man not attending the meeting wrote that he is taking Strontium 2 to counter osteopenia. His bone mineral density has improved after 14 months: the lumbar spine 14%, left femoral neck 7%, total left hip 3%. It costs about \$35 each month and he will continue to take Strontium 2. An active runner has now been taken off Fosamax (alendronate) because running has improved her bone density. Boron supplements (3mg) have improved one woman's bone density so that she no longer requires Fosamax.

Vitamin D is another recommended supplement for improving bone density and is advocated for better overall health. Wintertime without sunshine affects one person's well-being and temperament so much that she has tanning therapy 3 times a week, but only for 5 minutes each session, for vitamin D absorption (ref:

<http://www.cbc.ca/news/background/health/vitamin-d-winter.html>). There is one scientist who cautions against the overuse of vitamin D (ref: Australian Dr. T.G. Marshall. <http://www.ncbi.nlm.nih.gov/pubmed/18200565>).

Emergency situations demand that important decisions be made by spouses and advocates to ensure prompt treatment in an Addison's crisis. One spouse drove his wife to Emergency after she lost fluids with stomach flu and was in crisis. Emergency personnel advised that calling an ambulance was preferable because the patient would have been treated immediately on arrival at the hospital. Other advantages of calling an ambulance are that the patient can be transported more comfortably and safely lying down, and it is conceivable that paramedics could administer saline IV en route. The cost of the ambulance was \$80 for one family and \$60 for another.

Having an emergency letter, a hospital protocol document for treating an Addison's crisis, or a letter from your endocrinologist, will assist the triage nurse and get you treatment more quickly than trying to explain that you are in a life-threatening situation, especially if you are groggy or semi-conscious. An advocate is essential, even if they are the ambulance personnel. Hospital letters and protocols are available through the Canadian Addison Society website at: <http://www.addisonsociety.ca/>

When should we expect a crisis? To avoid a crisis, we increase our cortisol replacement when ill. Doctors recommend increasing glucocorticoids to 2 or 3 times our normal daily dose. Flu is the most often cited cause of a crisis because of fluid loss and not being able to hold down medication. High temperature/fever is an important indicator of illness that requires higher doses of meds. Serious accidents may result in shock. Exceptional physical or mental stress could develop into a crisis, so taking extra replacement may be necessary.

Food allergies developed inexplicably for a woman who has had Addison's for 30 years. Allergy attacks (swelling of the tongue and throat) resulted in 3 trips by ambulance to Emergency, over a two-month period, where she was treated with epinephrine injections and prescribed large doses of prednisone. The foods that triggered these attacks, a bagel and an orange, she usually eats daily without problems.

Daily medication doses need to be adjusted periodically to improve treatment. Several members working with their endocrinologists have increased their cortisol replacement slightly due to either job-related stress or to reach a better balance and stability. Two women have had their Florinef dose increased to raise blood pressure and now they feel better. Both take dexamethasone, a glucocorticoid with a very long half-life.

Surgery requires extra medications. A number of the members present were asked to increase their glucocorticoid medication before surgery and were given more intravenously during the surgery. It is imperative that the surgeon and the anesthesiologist know that you have Addison's and that you require IV cortisol replacement during surgery. One woman wheeled into the operating room queried the anesthesiologist about whether he would be giving her extra meds in the IV during surgery. He did not know she was Addisonian! He

quickly reorganized and had the medication hooked up. It is equally important that the anesthesiologist know what medication we take daily and administer a compatible one during the operation. Hospitals may have prednisone at hand in the OR but not hydrocortisone. Your family doctor and your endocrinologist need to ensure this information is given to the team operating on you beforehand.

A member who is a long distance runner and triathlete has competed regularly before and after her diagnosis 9 years ago. She has been awarded numerous medals for athletic excellence and recently received the "Triathlete of the year" award from her club "Team West Coast", partly because she runs with a disorder, Addison's. She brought some of her 'hardware' to the meeting. It takes a long time to gradually get into the physical condition required to compete. "Gradual" is the important word here. With Addison's, we need to take it a lot slower if we want to train. She does increase her medications when she is competing over a greater distance or for a longer time than her regular daily training. She has very gradually increased her stamina to where she runs an Olympic course regularly without extra meds. She also makes her own salt tablets and has learned to know when she needs them. Her husband and co-runners look out for her and can tell her when she needs to top-up during a competition. She recommends <http://www.addisonssupport.com/> for Dusty Hardman's training tips for running with Addison's.

In the Canadian Addison Society January 2010 Newsletter, Dr. Killinger replies to a question about managing during endurance events. The endocrinologist offers advice on medicating during these strenuous sessions. One key point he stresses is that "you have to think for your adrenals".

Our next meeting will be Saturday, May 15, 2010, in Room 1814 at Victoria General Hospital, 1:00 to 3:00PM.

Submitted by Jim Sadlish

For further information on the Vancouver Island Support Group, please contact Jim Sadlish at wx6999@gmail.com or (250) 656-6270. For information on Central Island activities, please contact Barbara Hunn at bhunn@shaw.ca or (250) 714-0036 or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

The Group met February 20, 2010 with 13 members present and 11 sent regrets.

Judi Whittaker led us through the use of Solu Cortef vials in an emergency. Needles and oranges were supplied to inject into. Judy suggested keeping your supplies in a plastic zip lock bag with your name written on it, a copy of injection instructions and emergency letter (<http://addisonsociety.ca>). Members discussed their use of Solu Cortef and were reminded the emergency kit is just to get you to emergency where you can be checked and have blood work done. You can call 811 to talk to the Nurse Line who can assist you. After talking to the

Nurse Line, should you need to, calling an ambulance is always better than driving to ER as they can start procedures, check your blood pressure and ease entry into the system.

One member suggested checking the side effects of medication. She was prescribed Ditropan/Oxybutynin for sweating which caused severe hallucinations. Another member had a severe reaction to Nexium for excess stomach acid. (Ed Note: These are side effects of the drugs cited, not due to Addison's disease.)

- Anyone who is on disability benefits: members have asked about the process for application, qualification etc. and would appreciate hearing about your process for obtaining them. We will discuss this at our next meeting.
- We will be hosting the 2010 AGM in October. Bring your ideas on how we can host this again. I do not have a date but hope to soon. Arrangements will be made for a guest speaker.
- Jane has had a good response to the UBC student doctor's interviews.
- The next meeting will be held Saturday, May 29, 2010, 1:00 – 3:00 p.m., Sherbrook Building, 260 Sherbrook Street, New Westminster. Parking on Sherbrook Street is \$1.00/hour and \$4.00 for 10. You can also park on the street free for three hours but you will need to walk a couple of blocks. Parking is more expensive on the lots that are adjacent to the south side of the building.

Submitted by Judy Stanley

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

Alberta Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton.

Saskatchewan Support Group

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

Southern Ontario Support Group

The next meeting of the Southern Ontario group is scheduled for Saturday, May 15, 2010, 12:30 pm, at the Erin Mills United Church, Lower Hall, 3010 The Collegeway, Mississauga, ON L5L 4X9. The church is located on the southwest corner of Winston Churchill Blvd. and The Collegeway. There is an elevator available. The agenda has not yet been finalized. In the meantime, please, mark your calendars.

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 next meeting will be at Robbie's Italian Restaurant, 1531 St Laurent Boulevard, Ottawa, at noon on Saturday May 15, 2010. As our guest, we will have Scott Watson, local pharmacist at Watson's Pharmacy and Wellness Centre, who will speak to us on Addison medications and their interactions with other commonly prescribed drugs.

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

We now have a local representative, Marie-Josée Normand, in Montréal. If you wish to contact her, she can be reached at (514) 376-2712, by email at marijonormand@sympatico.ca or through the 'Local Groups' page of our website.

Nous avons maintenant une représentante, Marie-Josée Normand, à Montréal. Si vous désirez la rejoindre, vous pouvez communiquer avec elle au (514) 376-2712, par courriel au marijonormand@sympatico.ca, ou bien par l'entremise de notre site-web.

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/faq.html>), 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: I am going on a vacation to Cuba. I have Addison's, hypothyroidism and am hypertensive. I take Prednisone 7.5 mg/day, Florinef 0.1 mg/day, Atenenol 50mg/day. Although I have

travelled quite a few times, I had never been told about the emergency kit to take on holiday; I only heard about it when I joined the Addisons Society.

I mentioned the kit to my endocrinologist and he disregarded my comment, so I didn't pursue it. I know it is too late to get this organized for Cuba. Should I be concerned? And what, if anything, can I do instead? I do have a letter from the Society to give to medical attendants if need be, and of course I always have extra prednisone on my person.

A: I am sure your holiday will go well: this type of holiday package usually is careful about food and stomach problems, which would be your major concern. When you get back, you should copy some info from our website or the UK website and take it to your endocrinologist. It would be good for her/him to be aware of it and the security it gives to individuals with Addison's disease.

Q: I have just been diagnosed with Addison 's and I would like to know if I may take glucosamine and chondroitin tablets. I have a bad back and this has helped me in the past.

A: There should be no problem continuing with the glucosamine and chondroitin sulfate.

Q: I was diagnosed with Addison's Disease and hypothyroidism about 6 years ago. I am currently taking Florinef, Cortef and Synthroid. Should I be taking vitamins in addition to the medication, e.g. calcium, vitamin D, vitamin B?

A: It sounds as if you are doing well on your current medication. There is no specific reason for you to take vitamins if you are eating a healthy diet. There has been a lot published lately about the benefits of vitamin D. Since this vitamin is made in the skin in response to sunlight, it is a good idea to take vitamin D especially in the winter. The recommendation is to take 1000 units daily. This dose will just bring your blood levels up to the lower end of normal. Some experts recommend 2000 units. The other vitamins you should be able to get from your diet.

Q: Is there any problem with taking a combination of prednisone and cortisol daily for my Addisons? Since prednisone lasts longer in the system, I take it in the a.m., and then the shorter acting cortisol in the late afternoon/evening. I've had Addison's disease for 28 years. I am 50.

A: If you have been taking the combination of prednisone and cortisol that you described for 28 years and have found it satisfactory, there is no reason to change. We recommend using cortisol because it is shorter acting, so blood levels can fall to low levels between doses in the same way they do when the adrenals are working normally. Cortisol is normally secreted in pulses, more frequently in the early hours of the morning and less frequently later in the day, so serum cortisol levels at midnight are barely detectable. These low levels of cortisol are important in preventing excessive

exposure of body's cells to glucocorticoids. If you are happy with your current treatment there is no need to change.

Q: I have secondary adrenal insufficiency and take 30mg cortef a day. Over the course of a few weeks, I started feeling quite tired, nauseous and lost about 7 pounds. Finally, one evening, I became quite weak, unable to walk, disoriented, cold, and shaky and very nauseous. I went to Emergency, where they diagnosed a urinary tract infection and dehydration. My heart rate was over 90 and bp was 145/85. The doctor gave me IV fluids, but no IV cortef as he said I was not in an Addisonian crisis. He also said I did not need to increase my oral cortef dose as the infection was too mild. I doubled my oral cortef dose anyway, and after a few hours of IV fluids and the oral cortef, my heart rate went down to 65 and bp was 105/65 and I felt MUCH better. I believe that if I wasn't in an Addisonian crisis, I would have been in one had I not taken the extra cortef. The doctor said he would only give me IV steroids if my heart rate and blood pressure were low or if my potassium was high. Why would my heart rate and bp be high when I was obviously low in cortisol and then drop when I increased my cortef dose? Also, I have never had elevated potassium and believe this is because I still produce aldosterone and therefore can excrete potassium. What do you think?

A: I think you have a good concept of your situation. You are correct that with secondary adrenal insufficiency you should be making a reasonable amount of aldosterone so you do not need flornidol and it would be unlikely that your potassium would rise. You are also correct that when you are in an added stress situation, whether it is physical or emotional you will need some added cortisol.

When you felt weak and nauseated, it is most likely that you had a virus infection. You would not have become dehydrated without a reason. With any infection, you tend to lose salt from your system along with water, and unless you replace these, you become dehydrated. You can sometimes save a trip to the hospital by taking an extra tablet of cortisol and drinking fluids with salt in them such as soups or a sport drink which contains sodium. Given a little time, you may start to feel better.

Q: I was diagnosed with Addison's in February 2010. I have been thinking about what could have caused this to happen to me, other than destiny. I wonder if a severe shock to my system caused adrenal gland failure to kick into high gear. In July 2009, I was riding my bicycle and was hit by a car; the driver's side mirror hit me in the upper stomach. I was taken to emergency, blood tests showed that my potassium was very high and my salts were low. I just had blood testing done two weeks before this accident and my potassium and salt were just fine. Could this accident have caused the Addison's to start up?

A: This is an interesting sequence of events and it is never possible to be certain that the accident and the Addison's onset are not related. Adrenal insufficiency can be due to several causes. The most common is autoimmune and this causes adrenal destruction over a prolonged period. Other causes such as infection can affect the adrenal and the time required would depend on the type of infection, e.g. bacterial,

fungal etc. The adrenals can also be damaged by hemorrhage in individuals on anticoagulants or with specific infections.

In your case, I doubt if the accident and the onset of your Addison's disease are related. Since your potassium was high and your sodium was low at the time of the accident, it suggests that the process was going on before the accident. It would also be important to know what other findings there were when you were diagnosed and you should review this with your endocrinologist and family doctor.

Q: Is there a cure for this disease? Is there a diet that could compensate for the lack of balance in the body originating from the disease?

A: I am afraid that there is no cure for Addison's disease. It is important to be sure that the diagnosis is correct with the appropriate tests before coming to any final conclusions.

Addison's disease is due to antibodies that are directed to specific proteins involved in the formation of cortisol. Symptoms occur when most of the adrenal has been destroyed by the inflammation caused by these antibodies. Health food stores often carry products that claim to affect adrenal function. These products should be avoided. For someone with true adrenal insufficiency, they are very dangerous.

Q: My husband has had Addison's since he was 14 years old. He is 63 in April. He has thyroid issues for the last 18 years, and B12 deficiency for the last 4 years. He had a B12 shot every month, now every 3 weeks. He has been feeling quite tired, has an upset stomach and his blood pressure is in the range of 109-117 over 62-66 (average readings). Extra cortisone and florinef seem to help some. The tiredness first started about a week to a week and a half before his next B12 shot was due, but now seems to be happening more often. He just retired from a high stress job in Nov, and has had a lot of stress with moving etc. He is 6' tall and lost about 12 lbs last summer. Since then, he will put on 2-3 lbs, then may lose it again. He has stayed at about 160-163lbs.

A: Your husband has been gradually collecting autoimmune disorders commonly associated with Addison's disease and seems to have been doing well until recently. The recent retirement, along with the stresses associated with moving and adjusting to a different daily routine, have undoubtedly created a situation in which his steroid requirements are modified. This can be related to his diet, the amount of exercise and his daily activities.

The monthly injections of B12 (usually 1000ug) should be enough and I doubt that the fatigue is related to the timing of the injections.

You did not mention the dose of cortisol or Florinef, but if he felt better when the doses were increased, you should mention this to your family doctor. His BP is a little low and this may be an indication that his dose of Florinef needs to be increased. Your family

doctor can check his renin and his electrolytes to check this out. The renin is the most important test. The correct dose of cortisol is more difficult to assess, but the smallest dose that makes him feel well is a good guide. Make sure you tell your family doctor and your endocrinologist about any dose changes.

Q: I'm a 54 yr old with secondary Addison 's. One month ago, I caught a cold which then became bronchitis. I doubled my dose of prednisone, but after a couple of emergency visits for breathing problems, I was advised to take 50 mg for 5 days and taper once I was better. At the same time, I was suffering severe fatigue and shortness of breath. I was off work for 3 weeks and tried to start back last week for half-days, but it was a struggle. I've spent this Easter weekend trying to rest. Currently, I'm at 25 mg of prednisone, as I'm trying to work my way down. I wake up feeling OK, although tired, and then within a few hours, I start to feel pain in my chest and between my shoulder blades in the back. Unless I lie down, it increases, and I often cannot sleep unless I take pain medication. I have shortness of breath upon any exertion whatsoever — a month ago I was skiing, snowshoeing and going to yoga on top of working. Now, I can barely walk or even make myself a meal. I also have pain in the large muscles of the legs, and my muscles are cramping. Today, I was worried as the pain is severe, so I went back to emergency. They did another chest x-ray, ECG, and a blood test that ruled out anything 'life threatening'. I'm off work until I see my family doctor (no endocrinologist). Is there anything you can suggest for further testing, or is this a normal part of getting over the bronchitis? My chest is clear and I've had no wheezing for 2 weeks. Also, this is the first time I've suffered such extreme affects after a cold. I'm usually tired, especially as I try to taper, but I get by. Right now, I'm at the point where I can barely function. I have an appointment with an out-of-town endocrinologist in 3 weeks.

A: The pain and fatigue sound like muscle inflammation related to a virus infection. I don't think this is specific to your adrenal insufficiency, but, since you have secondary adrenal insufficiency, you should discuss other possible pituitary hormone problems with your endocrinologist at your visit. You are probably not on Florinef because you have secondary adrenal insufficiency, but with any febrile illness, you tend to lose sodium. Theoretically, your adrenals should be able to respond appropriately, but a little added salt for a while would not hurt.

Q: I am a 60-year-old female diagnosed with primary Addisons Disease in May 2008. I take Cortef 10 mg and Florinef 0.1 mg in the morning and 5 mg. Cortef in the afternoon. Prior to confirmation of Addisons, I experienced visual problems much like the aura of a migraine headache, which would last about 15-20 minutes, but no headache evolved. The internist said that when I started medication for Addisons, this would disappear; and he mentioned something about fluid levels behind my eyes causing this. Indeed, after starting the medication for Addisons, the visual problem was gone. However, since Jan. 2010, the visual problem has returned on a random basis, sometimes 2-3 times a week exactly in the same manner as previously mentioned. I visited my endocrinologist but she said my visual problems have nothing to do with my Addisons. My TSH level is 8.22, Free T4 13 and free T3 is 5.5.

A: These episodes sound like a form of migraine. They tend to come on without any warning and sometimes they will interfere temporarily with a field of vision. The duration is usually a few minutes, as you noted, but occasionally they can last longer. They tend to occur frequently at times and then may not occur for weeks or months. I do not think they are related to the adrenal problem and generally do not get worse. Remember that I am an endocrinologist giving you an answer to a neurological problem. You should discuss this with your family doctor who may want you to discuss this situation with a neurologist.

Q: I have secondary Addisons, after having my adrenal glands removed in 1997 (due to a tumour causing Cushings). Since 1997, I have been on 25 mg of cortisone acetate in the a.m. and 12.5 mg in the p.m. I also take .01 florinef. I did not have any trouble with this dosage of medication for 13 years.

Since August 2009, while taking my normal dose, I have become weaker and weaker, with the usual Addison's symptoms. In October 2009, I was so weak that I was hospitalized overnight for observation and given liquid cortisone. At that time, a blood test revealed that I had NO cortisone in my system. Since I had been feeling weak since August, that morning I tripled my dose, so how could they find NO cortisone in my system. Tests showed no underlying infection. I did have a cold in November but it was not severe and I recovered quickly. In January 2010, I doubled my dose of medication in order to keep functioning and be able to work. My GP in early January told me to continue doubling my dose until I could see an endocrinologist in early February. He told me to take 6 pills a day for 3 days and see how I was doing. I did not improve that much. He then told me to drop down to 4 pills a day and do this for 5 days and call him and let him know how I was doing. I am now taking 4 pills a day (2 at breakfast, 1 lunch and 1 dinner). I am not hungry all the time now and not losing weight. I am feeling a bit better, but I am afraid that if I go down to my usual dosage I am just going to get weak again. Although he said that a different medication that would not make a difference, should I change to hydrocortisone or cortef?

My last MRI was 2-1/2 years ago, and I am currently scheduled to have a new MRI. My ACTH levels have always been high, so there has been no change there.

The specialist sent me for a thyroid and other blood tests, as well as an EKG and they could find nothing. I do not feel sick, nor do I have any gastro problems (we eat very well - lots of fruit and veggies, etc).

A: If the cause of your feeling weak was due to a lack of cortisone, then doubling or tripling the dose should have solved the problem. Your blood levels of cortisone usually drop to levels that are undetectable in our assays. That does not mean that there is no cortisone in your body; there is some in the cells doing what needs to be done. There are usually no major changes in your requirement for cortisone with time although there may be some slight adjustments required.

I am not sure what the problem is but it may be worthwhile doing some basic tests. You are taking two 25mg tablets of cortisone each morning. It would be interesting to measure your serum cortisol and ACTH before taking the pills and every hour for 4 hours after. This would tell us how high your cortisol levels go after taking the pills and whether your ACTH is responding appropriately to the rising cortisol levels. It would also be of interest to measure your renin levels to be sure your dose of florinef is OK.

My concern would be that there may be some other cause for your symptoms. I would be interested to know when you last had an MRI of your pituitary, what your ACTH level was and whether any other pituitary hormones had been affected by your surgery. You should go back to your endocrinologist and discuss other things beside your cortisone dose.

Q: I've been struggling for a year with my health and need some answers. I've lost over 60 pounds, have abdominal pain, fatigue, and fuzzy head (among numerous other symptoms). I am 34 years old and have three boys; I really need to get healthy. My doctor was almost sure she'd find something with a 24-hr urine cortisol test but it came back within 'normal' range. Could the test have been affected by some extremely stressful things happening at that time? The morning I started the test, one of my favourite pets died unexpectedly and I also had a family emergency. I'm concerned that my cortisol levels might have shown as normal instead of low because of what was going on. Should I ask for another test?

A: I am not sure whether the symptoms you have could be related to adrenal insufficiency or not. It depends on what other things are found when your doctor takes your complete history and reviews your physical exam. A single 24-hr urine collection does not rule out adrenal insufficiency because the amount of cortisol that you made that day may be the maximum cortisol that your adrenals can make. The best tests to diagnose adrenal insufficiency are a serum ACTH and a serum cortisol and an adrenal stimulation test in which 250ug of Cortrosyn (synthetic ACTH) is injected intravenously and blood samples for cortisol are taken before and after the injection to see if your adrenals can respond to the stimulation. You will have to discuss this with your endocrinologist to see if her/his findings would suggest this investigation.

Q: For several weeks, I have had inflammation and swelling in my right leg. I was told it was phlebitis and given antibiotics and 50 mgs of prednisone per day. Nothing improved. The next doctor told me it was cellulites, and I was given a stronger antibiotic and told to stop the prednisone. Still no improvement. I ended up in hospital where a culture was taken, and I am now on a stronger antibiotic (doxycycline) used to treat quite serious conditions. Should I increase my prednisone dose, as this infection seems to be quite bad? My doctor was very vague and just said to try and stay on the same amount of prednisone every day.

A: As long as you are not feeling light headed and/or nauseated, you can stay on your usual dose of prednisone. If you feel unwell, it would not hurt to increase the dose by 1/2 or one tablet daily. It sounds as if you have been on antibiotics for a while with no

real benefit. Is it possible that the original diagnosis was the correct one? If so, the treatment would be different.

Q: I have had Addison's disease for 6 or 7 years now. For years, I have suffered shortness of breath where I feel like I cannot take in a deep breath. This is so annoying that it is ruining my quality of life. There are no other symptoms. Lately it seems to be getting worse. It has bothered me enough that I have gone to the doctor and taken a stress test and pulmonary function test. Both came back perfectly normal. My blood pressure is normal (120/80) with a pulse of 60-75bpm. I am 34-year-old male, 6'4", 190 lbs. I am also fairly active.

I would say this is fairly frequent, occurring several times a day. When I forget to take my Prednisone (5mg) it seems to get better. I also take 0.1mg Florinef. Recently I did not take the prednisone for two days and my breathing seemed to get much better.

Could the prednisone be causing this or is it just coincidence? I don't want to play experiments with my medication so I thought I would ask you.

A: This is a new problem for me. If your stress test and pulmonary function tests are normal, it is difficult to know what is causing this problem. Is this something that occurs only when you are sitting or standing? Does it occur when you are lying down or when you are exercising? I don't think you should stop your prednisone. This would be something you should discuss with your endocrinologist and review the circumstances around the times when this comes on.

Q: I have not been diagnosed with Addisons. I have been suffering for 2 years with extreme fatigue, severe joint pain, insomnia, lower back pain, mood swings, tearfulness, low libido, black outs, hair loss, postural low blood pressure, depression and I am convinced I have had 2 Addisonian Crises. First while delivering my 2nd child - it began with diarrhea, I vomited throughout my labour, extreme back pain, and lost consciousness when they sat me up to start pushing. Again, last month, I ended up in emergency with vomiting, fever, chills, dehydration, and extreme back pain shooting down my glutes, blacking out. Once fluids were replaced intravenously, my pain disappeared. I had been suffering miserably until I discovered that Prednisone took all of my pain away and I felt terrific. I took it for 2 weeks only, and have not yet been so ill as I was before then.

Also, I have been on a painkiller called Tridural, which was the only drug that would help my pain. It also gives me energy (I discovered this is likely because it is an NRI: assists adrenal neurotransmission), when I go off that drug I am a wreck and have severe back pain and have no strength. I am convinced I have Addison's, however, my ACTH test showed high cortisol levels. I know that most Addisonians take years to be diagnosed. Do I seem to fit in this category, or is that test a sure thing? Where do I go from here?

A: You have obviously been going through a very difficult time. Making a diagnosis of adrenal insufficiency requires that your doctor take a good history, do a complete physical exam and review your lab work. This basal lab work should include a serum

cortisol and ACTH along with the more general lab work. These tests should be enough to determine whether adrenal insufficiency is possible or probable, and an ACTH test is designed to confirm the diagnosis. If the clinical findings suggest the diagnosis but it is not confirmed by the tests, then your doctor would review the situation to see if there is another explanation for your symptoms or for your lab work. In rare situations, cortisol levels can be high because tissues are resistant to the action of cortisol. It is important that you discuss your situation with your endocrinologist and review your response to prednisone.

The Tridural that you mentioned is an opioid pain medication that has all of the potential problems associated with other opioids. It is not a drug that you should be taking regularly and it does not improve adrenal function.

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.