

The Canadian Addison Society La Société canadienne d'Addison

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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.

President's Message:

At our last meeting in Vancouver, we had a guest speaking on B.C.'s the Advanced Care Planning. (Each province has its own provisions.) This is something that everyone, with or without a chronic condition, should consider talking about with their families. As was brought home to me recently, life is full of unexpected events. During the past week, two good friends of mine passed away – one after an illness of over a year, and the other unexpectedly while on his way to pick up his daughter. It is always best to make your wishes known in advance.

Submitted by Judy Stanley

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News and Announcements:

- We are sorry to inform you of the death of Barbara Hunn, one of the original members in Nanaimo, and one of our regional representatives. Our condolences to her family.
- Membership renewals for 2012 were due in January. If you have not yet renewed, please
 do so immediately using the form included in this newsletter. The form is also available on
 our website.
- The 2012 Annual General Meeting will be held October 13th in Victoria B.C., at the Victoria General Hospital, Room 1814 (near the cafeteria). All members (and family) are welcome. More information on the agenda and guest speaker will follow.

Regional Representative:

The role of regional representative is crucial for the Addison's Society to continue functioning.

The regional representative acts as a central contact person in the local area. As well, the representative arranges meetings of Addisonians, where there are enough people geographically close enough to warrant get-togethers. These meetings have proven to be a strong support for Addisonians, helping them determine what is 'normal', what tricks and tips can make living with Addison's easier, and proving to them that 'they are not alone'. No one understands as well as another Addisonian! Such meetings can also provide great support to family members – they also are not alone in finding ways for life with an Addisonian to be 'normal.'

Please consider volunteering to act as a regional representative/contact person. We especially need people in Manitoba, Quebec, the Atlantic Provinces, and any other regional centre which can act as a gathering point for members (such as Cornwall/Kingston in Ontario).

Below is a brief description of the general functions of the regional representative. This can vary widely from one region to another, and each regional representative will tailor this to their area's needs and to their own capacity.

The Regional Representative usually:

- organizes and chairs two or three local meetings annually (an up-to-date membership list is provided on request by the Liaison Secretary);
- acts as the first line of contact and support to members, new members and potential members (often newly diagnosed people who need support);
- distributes materials to membership if available;
- conveys information between members and the Board;
- informs the Liaison Secretary of updates to membership lists.

Organizing local meetings typically involves:

- contacting members to inform them of the date, time and location of each meeting, and encouraging members to bring others;
- arranging a location (your local police department, community centre or hospital may have space available at little or no cost to the group);
- arranging for a speaker on a topic of interest, such as a paramedic, emergency care worker, nutritionist, endocrinologist, pharmacist, naturopath, diabetes specialist, etc.;
- ensuring minutes are taken and forwarded to the Newsletter Editor;
- arranging for a snack and drinks, where possible (having people take turns in bringing small snacks keeps costs down);
- reminding members to keep their dues current, and handing out copies of the membership form.

You can also find ideas and information on setting up a local support group in the <u>September</u> <u>2005</u> edition of the newsletter.

The regional representative is not authorized to offer medical advice. It is important to advise individuals to check with their personal physician for medical advice.

When the local group has a separate fund balance, reasonable expenses incurred for the meeting, food/drink, gift for speaker, photocopying, postage, etc. can be reimbursed by the treasurer if receipts are provided.

Canadian Addison Society on the Radio:

Recently, the Canadian Addison Society was asked for an interview by Cam Wells from CJAM, 99.1 FM radio station serving the Windsor/Detroit areas. Cam has a regular radio show, *HandiLink*, and wanted to learn more about the Society and how it helps Addisonians. Steve McKenna (Eastern Ontario) and Patricia Hehner (newsletter editor) were interviewed and took pleasure in being able to publicize information about Addison's Disease and what the Society can do to help those with the condition and their families.

Access this 10 minute conversation through a <u>YouTube link</u> on the home page of our web site <u>www.addisonsociety.ca</u>.

Personal Experiences:

I was diagnosed 12 years ago, though I most likely suffered from Addison's long before. Like most others, my diagnosis came at the eleventh hour. Two years ago, my Addison's disease became unstable. I've been struggling since then and have been hospitalised five times in the last year. I was the executive director of an association for several years but I haven't been able to work. My long term disability claim – strongly endorsed by my internist – was denied by The Co-operators Insurance Company (Canada). I have hired lawyers to file a lawsuit

against the company. I have taken the time to write this because I want to know if others have had the same experience.

Submitted by K. Sexsmith

I felt very unwell for about ten years before being diagnosed with Addison's. I had lost weight, my skin was darker and my mouth was discoloured inside. In fact, my dentist thought that I had black relatives and that was why the inside of my mouth was purplish. After being hospitalized two years in a row with what doctors thought was flu, and then wrongly diagnosed, I finally was finally properly diagnosed. I was put on prednisone but ended up in emergency after my muscles completely seized. The doctors in Emergency felt I was suffering from a panic attack and, as my potassium was extremely high, asked me what I ate to cause it. I was sent home with a couple of tranquilizers, and a couple of days later my family doctor called me in and added Florinef. That controlled my blood pressure, enabling me to get out of my chair, to stand and to walk again. I feel reasonably well now. I have been in hospital 4 times with crises since 1990. I have to try harder to control the way I react to stress as that is what can pull me down.

Submitted by J. Taylor

Highlights from Local Meetings:

Vancouver Island Support Group

The group met February 18 with ten people attending, including two from the central island.

The 2012 AGM will be held at the Victoria General Hospital on October 13. We invite suggestions for a speaker.

Gymnast, Nathan Gafuik of Calgary, is a two-time Olympian plus a recent gold and silver Word Cup winner. He also has Addison's disease. Here's a 2009 interview with Nathan Gafuik including a question about his Addison's:

http://www.intlgymnast.com/index.php?option=com_content&view=article&id=746:interview-nathan-gafuik-can&catid=3:interviews&Itemid=56.

Meeting highlights:

One Addisonian had 5 recent operations to correct a detached retina. She has had a previous cataract operation. Another woman is being treated for macular degeneration with bi-annual appointments and daily self-testing. Neither of these conditions is normally associated with Addison's. However, glaucoma and cataracts may be a side effect of glucocorticoid use, so be sure to make an annual optometrist or ophthalmologist appointment.

https://www.inspire.com/groups/national-adrenal-diseases-foundation/discussion/adrenal-hormone-replacement-protocol-from-nadf/

Another Addisonian is experiencing the formation of large areas of hyperpigmentation on her abdomen. She has the darkened skin frequently associated with adrenal insufficiency, but this is another problem since these darker areas have a different texture than her normal skin. http://www.dermaamin.com/site/images/stories/fruit/Primarycaremedicine/sid875412.html

Last meeting in October, a woman had started a meatless raw food diet. She reported at this meeting that she feels great; her vitiligo is receding so that she has stopped her tanning treatments for it. She suggests that Addison's and other autoimmune disorders may be more affected by diet than we might think. She has stopped taking some supplements, including calcium, avoids dairy products, and advises that we should all pay closer attention to eating less acidic foods. Lemon evidently turns alkaline after ingestion.

A member travelling in Sri Lanka went into crisis after a bout of food poisoning. She had inadvertently forgotten to take her emergency syringe on the trip. The doctor in Sri Lanka did not know about Addison's and asked what treatment was needed. She asked for a cortisone shot and survived to tell the tale.

On the topic of bone density, Dennis in Campbell River has kept the group informed about his experience using strontium supplements. He compiled a record of his bone mineral density results over a number of years, which showed an improvement trend. Until recently, he had attributed his bone density gains to costly strontium supplements. However, now he rationalizes that his improvement actually coincided with his retirement from a sedentary job. He walks daily and works long hours in his garden. His bone density tests remain in the normal range and he no longer takes strontium.

After 5 years of taking Actonel, a medication approved to help reduce the chance of osteoporosis-related fractures, one woman finds that her bone density test results are still going down. She walks regularly, does aerobics and weights without seeing improvement. Another member does stretching exercises, walks and works out, successfully gaining back 14% of her bone density. A woman taking an annual dose of medication for osteoporosis stated that her bone density is also going down.

Last meeting, 3 members reported having to take extra meds when getting dental work done. Reading the report of our last meeting in the Newsletter, Susan from Ottawa kindly wrote that she had discovered years ago that the freezing (anaesthetics) used by dentists normally contain an adrenalin constrictor (epinephrine). You can ask the dentist to use an anaesthetic without epinephrine, often given to people with heart conditions. Epinephrine is used to constrict blood vessels and reduce bleeding during dental procedures. Be sure to tell your dentist that you have Addison's disease, and if you have hypothyroidism, as she or he will know what freezing is safe to use. Thank you, Susan, for this vital information.

One recently diagnosed member noted that her thyroid readings were sometimes up, then down, but normalized once she was taking replacement cortisone. She also had a Vitamin D deficiency and was prescribed a weekly large dose of Vitamin D2 to get her back into the normal range.

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Another woman, a diabetic, takes Glucerna at bedtime, a formula drink to maintain blood glucose levels. It also helps her sleep.

Two people have had their Florinef doses increased by a 1/2 pill to help raise their blood pressure. One woman with secondary adrenal insufficiency has been instructed by her doctor to take 5mg more of hydrocortisone when her blood pressure drops due to stress. Using this precaution, she has avoided going into crisis, which frequently happened in the past. Another woman deals with stress by taking extra medication. Evidently, dexamethasone may raise blood pressure. Meditation was used by one woman for overall relaxation.

Several people are taking DHEA as an additional supplement for their Addison's. We noted that many members who once supplemented with DHEA have ceased taking it. Of course, lack of supply and legal restrictions in Canada are issues which limit its use, as well as some side effects. There was a query whether cancer risk might also be a factor. One person's non-Addisonian relative developed prostate cancer after taking DHEA. Of course, without functioning adrenals, our DHEA production is minimal. In a quick search of Google Scholar for 'adrenal insufficiency, DHEA and cancer', there does not appear to be any readily available literature. However, there are many studies linking DHEA and cancer in non-Addisonian women, especially with higher alcohol use. It seems advisable to keep supplementation of DHEA to low doses and have your doctor check your blood levels periodically.

Submitted by Jim Sadlish

Next meeting will be June 2, 2012 at the Victoria General Hospital.

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

BC Lower Mainland Support Group

Thirteen members and several family members attended our February meeting. It was great to see so many familiar and new faces.

2012 membership dues forms are available on line. Thanks to those who have already renewed their membership.

Marilyn (Moh) Thauberger has received the Green Sleeve magnetic holders for medical information. They will be available at the next meeting.

Our guest speaker was Pat Porterfield [VA], Vancouver Coast Health (VCH) Advance Care Planning. Pat is the Regional Lead, Palliative Care; Co-lead, ACP initiative.

The Fraser Health Authority pioneered Advanced Care Planning (ACP) in 1965 and in 2008 the VCH introduced ACP to their region. The Provincial Government standardized the program across BC and legislated ACP in September 2011. It can now be accessed on the internet at http://www.health.gov.bc.ca/hcc/advance-care-planning.html. A booklet will be published and available the end of March.

ACP is planning for your future. Several members already have an ACP plan in place after relatives or friends passed away unexpectedly. Such a plan is an ongoing process about conversations with family to let them know your wishes should an accident or other trauma occur. The ACP Guide (*My Voice – Expressing My Wishes for Future Health Care Treatment*) Sections 7 and 9 provide forms for appointing a representative, one form for a representative who is authorized to make life support and life prolonging decisions, and one form for representatives who do not have such authority.

ACP plans in the past could only be done by a lawyer or notary public but, since the new legislation, Section 9 can be witnessed by anyone. You can designate a Temporary Substitute Decision Maker (TSDM) which applies for 21 days. A list is provided indicating who is eligible to be a TSDM. This removes the burden from others by expressing your wishes on how you want to be treated. It also provides direction to caregivers and medical personnel. Over the past century, people are living longer with new or chronic diseases. Topics to discuss could include prolongation of life, mobility, capacity to recognize, ventilators, tube feeding, dialysis, complying with certain religious practices, quality of life if you are put on a ventilator or other mechanical means of keeping you alive. With regard to total life support, one suggestion was a trial period of two weeks and, if there were no improvement in your condition, an indication of long you want to artificially prolong life.

The legal basis for ACP is the B.C. Healthcare Consent Legislation introduced in September 1, 2011. Healthcare providers must act on the prior expressed wishes and instructions of a capable adult, and use this as the basis for appropriate medical treatment. For example, a surgery consent form could be signed prior to entry to hospital. Decisions made in advance can be used when you are not capable. Each province has its own legislation, i.e. proxy representative or the concept of a Living Power of Attorney for Health Care.

Once you have completed the forms, a copy can be kept with your doctor and/or filed with the Nidus Personal Planning Resource Centre http://www.nidus.ca - a non-profit, charitable organization which operates a centralized Registry for personal planning documents, and provides information to British Columbians about personal planning. Be sure to review and update your file as needed.

Other helpful websites are:

http://www.trustee.bc.ca (Public Guardian and Trustee website)http://www.advancecareplanning.ca (National Website, re: starting the conversation)www.vch.ca/acp

Submitted by Judy Stanley

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The next meeting will be May 26th 1-3 p.m. and will be our appetizer/finger food meeting. The AGM will be held October 13, 2012 in Victoria. More information will be forwarded closer to the date, but please mark your calendar.

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, or Peter Little at bettypeter66@gmail.com or (780) 918-2342 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.

South/Central Ontario Support Group

The next meeting is scheduled for Saturday May 12, 2012, 1.00 pm to 4.30 pm (doors open 12.30 pm) at Erin Mills United Church Lower Hall (elevator available), 3010 The Collegeway, Mississauga, Ontario. Another *Emergency Injection Training Clinic* will be conducted by member Denise Burpee, RN, BScN. We have held these clinics for the last two meetings and will continue to hold them as long as the need is evident. Please bring your expired Solu-Cortef vials for use in training. We will have a small number of vials for use by those who need them.

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 Saturday, May 12, 2012 (the weekend before the May long weekend), as usual at Robbie's restaurant on St. Laurent in Ottawa, starting at noon. Attendance in October was very disappointing, so we hope more members will be able to make the May meeting. While we will continue to meet on a regular basis with whoever is available and interested in attending, we won't arrange for any more guest speakers again until attendance warrants it.

Submitted by Steve McKenna

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

Québec Support Group

We no longer have a representative in Québec. If you can assist us by filling this role for fellow Addisonians in Québec, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

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: I was diagnosed with Addison's in March of 2011. I am now 36 and weigh about 122 lbs. Over the course of the year, my dose of Cortef has gone from 20 mg to 35 mg. as I experience symptoms of low cortisol after a bit of time on any current dose. The endocrinologist suspects that I may have celiac disease, and am not absorbing my cortef efficiently. Any input and information you have relating the two diseases would be appreciated.

A: Addison's disease and celiac disease can occur in the same individual as part of an autoimmune complex. It is unusual to have problems with absorption of cortisol. Your endocrinologist can check this out by measuring your cortisol before taking your morning medication, then rechecking your cortisol and ACTH blood level hourly for the next 3 hours. Your cortisol should rise and ACTH should fall. The amount the cortisol rises would be an indication of the degree of absorption.

Q: I recently filled a prescription for Solu-cortef emergency injection. I take prednisone and florinef for my Addison's. I wanted to know how long do I need to keep my prednisone in my stomach to ensure complete absorption into my bloodstream if I happen to vomit.

A: This is always a difficult question because your stomach may not be emptying normally. I think the best approach is to try taking a second dose if you vomit within an hour of the first. If you can't keep the second dose down and if you are feeling reasonably well, wait 2 hours and try again. If you are unsuccessful on this occasion, you should go to the emergency department for some IV fluids and an injection of solucortef. If you are a significant distance from a hospital, use your emergency kit for an intramuscular injection of solucortef and when things settle down, drink some fluids containing salt such as some type of soup. Be sure to call your family doctor to tell her/him what is happening and get further advice.

Q: My 30-year-old husband was just diagnosed with Addison's disease. He has always been very social and not much of a drinker, but he forgets from time to time that he shouldn't be drinking or having casual drinks with friends. If he continues this, how will it affect him?

A: Everyone has their own opinion regarding the definition of a social drinker. Your description would suggest a very moderate amount and frequency, so this should not pose too much of a problem. People with Addison's disease can drink normally but moderation is always important to keep in mind.

Q: I have had Addison's disease since 1993 and last year was diagnosed as having early osteoporosis in my lumber spine and osteopenia in my hip - this, in spite of regular exercise for the past 30 years, including weight bearing exercise, an excellent diet and healthy lifestyle. I do have a family history of osteoporosis. I currently take Actonel. Very recently, my endocrinologist suggested that I consider the possible use of a small dose of testosterone as an adjunct therapy. I have not received my blood work results as yet to determine if my testosterone level is low but have excellent cholesterol levels, blood pressure and no cardiac disease. In your experience, what has been the use of testosterone in women with osteoporosis, with/without Addison's disease?

A: I have not had any experience with the use of testosterone in osteoporosis, either in Addisonian patients or in the general population. The effect of testosterone on bone is felt to be through its conversion to estrogen. There is no doubt that your testosterone level will be low since half of the testosterone in the blood comes from the adrenals. This would not necessarily be an indication for testosterone replacement. I will let you discuss this with your endocrinologist.

Q: Is it okay to get a TB test? It is required for my job as an intern working with children.

A: There should be no problem getting a TB skin test.

Q: Is there a point when the hydrocortisone a person takes because of his adrenal problem ceases to be effective? What are the dangers for an Addisonian if he gets an infection?

A: There is no time when hydrocortisone ceases to be effective.

When a patient with Addison's disease gets an infection, it is an added stress and they require extra hydrocortisone. The amount depends on the type of infection and this should be discussed with the family doctor or the endocrinologist.

Q: My Dad has Addison's and I was just wondering what the chances are of me or my brother getting either Addisons, or an autoimmune disease. I was conceived right when my dad started to develop the disease and was born when he had a big attack, so do I have a higher chance than my brother?

A: I don't think you should be too concerned about getting Addison's disease. First of all, diseases that are transmitted through genes depend on the chromosomes in the egg and the sperm and these do not change with health problems in either parent. You and your brother both have the same probability of developing the disorder. Secondly, you did not mention that anyone else in the family had any type of autoimmune disorder so your father's case seems to be new. He may carry a gene which makes it more likely that he will develop an autoimmune problem, but this gene may not cause the problem. Other genes may influence whether or not an autoimmune problem occurs. Since we do not know what genes you may have inherited, it is difficult to know whether or not you have an increased probability of getting the disease. The best thing you can do is to look after your health with proper eating and exercise. Your family doctor should be aware of your family history and this should assure you that the proper tests will be done if you have any problems.

Q: My daughter was diagnosed with Addison's in 2005 and since then we have struggled with appropriate medication levels. For almost 4 years, we were in and out of emergency almost quarterly. In the past year, levels always appear normal on our trips to the endocrinologist, which is completely frustrating as she is sick most of the time. We may get one week out of every month where she is happy and can function; all the other days, she is bedridden with nausea, vomiting, dizziness, sometimes hives. I am wondering what kind of testing our endocrinologist should do. We have had absorption tests and gastroscopy; both were normal or non-indicative. Can you offer any suggestions as to next steps? My daughter is 27, hasn't been able to work or keep a job, is getting very depressed and frustrated, and needs a life. Any thoughts or ideas on next steps would be greatly appreciated.

A: It is difficult to watch your daughter go through such a prolonged problem and feel so helpless in trying to assist her. Since I do not know anything specific about your daughter, I can only discuss things in general.

When the response to treatment does not progress as I think it should, I go back to the beginning to be sure I have the correct diagnosis. Since different diseases can present with similar findings, I review the original lab work to be sure there are no other possible diagnoses. I then look at the treatment to see if it is optimized. For cortisol, I check morning ACTH. It is usually high, in the 40 to 60pmol/I range. If it is over 100, I check to see how the cortisol is spread over the day. Sometimes three doses work better than two, e.g. 20, 10, 5mg for cortisol. The morning cortisol is usually at the

lower level of delectability. You can adjust the dose and timing of the cortisol to see if this influences how you feel. The next thing your endocrinologist will want to check is the dose of Florinef, which controls salt metabolism. The best way to see if this dose is correct is to check plasma renin on a fasting sample. Your endocrinologist will be able to tell if she needs more or less Florinef from this result.

If the doses of both cortisol and Florinef are optimal and she is still unwell, I would then tend to look for some other additional diagnosis which might be complicating the situation. Adrenal insufficiency can be associated with other autoimmune disorders such as hypothyroidism, hypoparathyroidism, and colitis.

Q: I was diagnosed ten years ago with primary Addison's disease and am on Cortef and Florinef. I need to have a colonoscopy very shortly and would like to know the protocol for this procedure. Ten years ago, eight months before diagnosis with Addison's, I had a colonoscopy and went into acute adrenal crisis and spent a week in hospital. It was after this incident that my endocrinologist at the time realized what had happened and sent me for an ACTH stimulation test which determined that I had Addison's disease.

A: There is no specific protocol for colonoscopy preparation. It can be very stressful but different people seem to respond differently, so no protocol would fit everyone. The common factor is that you will need extra hydrocortisone (cortisol) before starting the preparation, and during it. It would be wise to have an emergency kit so you could have intramuscular cortisol if you had problems with nausea and vomiting. Since your endocrinologist was aware of your last experience, you should discuss this with her/him so that she/he can pass this information on to those conducting the colonoscopy and provide them with advice regarding the preparation. Make sure your endocrinologist knows when the procedure is going to be done and is available; if not, reschedule the colonoscopy.

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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Membership in The Canadian Addison Society is \$25.00 due January 1st of each year.

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+ Contributions are also gratefully accepted. A tax receipt will be issued for contributions over \$10.00.

Please make cheque or money order payable to The Canadian Addison Society and send c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7

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