The Canadian Addison Society
La Société canadienne d'Addison

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ISSUE NO. 54 **APRIL 2009**

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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.

Announcements:

- The next Annual General Meeting will be held Saturday October 3, 2009, from 12:30 to 4:30 in the Brantford Police Station, Community Room, Brantford, ON.
    1) Registration
    2) President's Report
    3) Minutes of the 2008 AGM
    4) Election of Board Members
    5) Financial Report
    6) Membership Update
    7) Director's Reports
    8) New Business
    9) Guest Speaker - TBA

- Annual **membership dues of $25.00** for 2009 were due in **January 2009**. Please ensure your membership is up to date.

Highlights from Local Meetings:

Vancouver Island Support Group

The Vancouver Island group met, February 14, 2009, with 12 people attending. Each member spoke about their diagnosis and initial treatment, any accompanying disorders and how they are managing on their present adrenal replacement regime. Several are contending with complex difficulties, having shifted between various replacement medications seeking ones most compatible with meds for other disorders and with the least side effects. Everyone attending was in distress for months or years and suffered a crisis or a medical emergency before being diagnosed. Many had other endocrine problems prior to their Addison's diagnosis. Symptoms resolved by adrenal replacement after diagnosis were weight loss, low blood pressure, lack of appetite, low energy, and darker skin in most cases. One woman gained 67 pounds! In some cases, thyroid function returns to normal once adrenal insufficiency is diagnosed and treatment commenced.

Two members increase their cortisol replacement prior to dental work. We discussed the need to double or triple cortisol doses for flu and colds, but also for some anticipated emotional times.

Having to go to Emergency in crisis, one woman handed a copy of the 'Ottawa Protocol' to the triage nurse and was promptly attended to (even then her stay extended to many hours). A Hospital Protocol is available for you to print at the Canadian Addison Society website: http://www.addisonsociety.ca/ohp.html.

There is another new endocrinologist in Victoria, Dr. Sarah Capes (http://fhs.mcmaster.ca/medicine/endocrinology/faculty_member_capes.htm).

Eyesight could be adversely affected by our cortisol replacement. One young woman has experienced vision problems she attributes to her medication. Evidently, Addisonians in B.C. can have eyes examined annually by an optometrist and the fee is waived or reduced when checking for glaucoma and cataracts, which are possible side effects of our medications.

Fosamax may increase cardiovascular risk, and 1 member will be asking if there is less risk with the annual injection Fosamax, rather than the weekly treatment.

It seems blood tests results for thyroid deficiency may vary throughout the year. One non-Addisonian not present adjusts her thyroid replacement medication at different times of the year for optimal benefit. One member's results change from winter to summer.

B12 deficiency can be associated with Addison's. It is important to ensure that our doctors periodically test for B12 deficiency, as B12 deficiency can be quite serious.

Florinef replacement doses differ greatly between attending members, from 0.2 mg daily down to occasionally, "when feeling lightheaded". Everyone's endocrine system is unique. Since the mineralocorticoid quantities within each cortisol replacements vary, some people may require less Florinef than others (e.g. dexamethasone has no mineralocorticoid). Addison's researcher Dr. W. Arlt writes " With regard to mineralocorticoid potency, 20mg hydrocortisone are equivalent to 0.05 mg fludrocortisone." It seems common that as we age blood pressure increases. Florinef has a direct influence on blood pressure. Dr. Arlt also says "If primary hypertension develops during the long-term course of (adrenal insufficiency), mineralocorticoid replacement may be gradually reduced, accompanied by monitoring of serum sodium and potassium." Regular blood tests and blood pressure checks by your doctor will keep him/her informed as to whether your Florinef dose is correct.

Submitted by Jim Sadlish

The Vancouver Island Addison's support group will next meet **May 30**, 2009 from 1:00 until 3:00 PM in Room 1814 by the Cafeteria at the Victoria General Hospital, and again on October 3, 2009.

For further information or to contact 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

Nine members attended our Feb. 21, 2009 meeting. Thanks to those who have renewed their membership for 2009. Congratulations to Klara Dickey and her husband on their 50th wedding anniversary.

Caring for each other: When we are not well, are having surgery, or just need someone to talk to, please call us and let us know, and Marilyn, another member or I will visit you, have a chat on the phone, or help in other ways. Please contact Marilyn 604-941-7051 or me, 604-936-6694 and we will do our best. Meetings are only three times a year, and probably not when we really need the help.

We now have an Addisons Society card that can be used for various occasions.

If you are travelling, take a letter from your Doctor listing all the medications you take, dose etc. Remember, there are versions of a medical emergency letter in various languages available through our website at http://www.addisonsociety.ca/emergencylett.html.

Several members have gone to a Naturopath: one was overwhelmed by the number of supplements recommended and decided not to follow the regime; another went before diagnosis of Addison’s, was given a strict diet to follow for seizures and found that it was helpful, but has not continued it. It was highlighted that, before taking any supplements, be sure to consult your physician about interactions with your medications.

The new protocol for refrigeration of Florinef between 2-8 degrees C is the result of new testing methods for stability of degradation of products. The production hasn't changed for the past 30 years. *(Ed note: Remember – if it was fine before, it's still just fine.)* You can enquire if a test has been done for a specified time i.e. if you are going on a trip. The MedInfo number is 1-888-550-6060 for Canada. Testing done by BMS-Australia did not identify a problem with breaking the tablets in half.

The next meeting, our Pot Luck Finger Food meeting, will be Saturday, **May 30**, with a different format: small groups will discuss a topic of choice (e.g. how do you deal with stressful occasions, what do you do when a situation turns stressful, or managing your medication as weather conditions vary) with a short recap for everyone. Younger members will be grouped to discuss their triumphs or concerns - hopefully we can have members from Victoria attending to increase their group. If you are under 30 and would be interested, please let me know at bugbee@shaw.ca. As everyone always brings lots of food it, should be an enjoyable afternoon.

Thanks to Marilyn again for doing such an excellent job on our behalf of lining up the UBC interviews (we have 14 volunteers this year) and guest speakers.

Our guest speaker was Nana Osei, Public Inspector, New Westminster Health. She inspects facilities such as restaurants and other food premises, swimming pools, hair salons, tattoo parlours, and nail shops. She also teaches a Foodsafe course as part of the education component of the program. When researching the symptoms of Addison's Disease, Nana noticed a couple that are similar to botulism and food poisoning - diarrhea and nausea.

For notes from the meeting, contact Judy Stanley. Or consult the document 'Foods to Avoid for People at Risk of Food-Borne Illness No.76' found at: www.healthlinkbc.ca/healthfiles/index.stm.

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, or Peter Little at 780) 918-2342 litt019@telus.net 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 Southern Ontario Group will meet on Saturday **May 9**, 2009 from 1:00 pm (registration 12:45) to 4:00 pm at the Erin Mills United Church, Lower Hall (elevator available), 3010 The Collegeway, in Mississauga. The speaker will be a Naturopathic Doctor (ND) (or graduating student) from the Canadian College of Naturopathic Medicine in Toronto. The session on the topic of "Quality of Life" will include a presentation and question and answer period. We had great attendance at the November meeting at this same location, and I encourage you to come out again and participate.

Donations to our snack table would be appreciated, as would help with room set up before and after the meeting. A volunteer driver is required to pick up a member in Acton. Please contact me if you are able to do this.

Note that the Church will being holding a Garage Sale upstairs in the Sanctuary, on the day of our meeting, offering a pre-meeting shopping opportunity.

The Fall meeting, which will incorporate the Annual General Meeting, will be held Saturday October 3, 2009, from 12:30 to 4:30 in the Brantford Police Station, Community Room, in Brantford.

Submitted by Harold Smith

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

Eastern Ontario Support Group

The next meeting will be held Saturday, **May 9**, 2009, at noon, at Robbie's Restaurant, St. Laurent Blvd, Ottawa, Ontario.

The Eastern Ontario group is looking for someone to act as contact, and to organize future meetings. If you can volunteer, so that our meetings may continue, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Québec Support Group

If you wish to start a local group in the area, 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/faq.html), or see previous issues of the newsletter.

Q: I'm having a colonoscopy. With the last two, I went into severe Addisonian crisis. I take 25mg. of cortef a day. Could this be the extreme laxatives I have to take for the procedure?

> **A:** Colonoscopies are difficult for everyone, particularly the preparation. The bowel cleanout with the large volume of fluid may well interfere with your absorption of cortef, and since it is a stress, you would need more cortef than normal during the preparation period.
>
> I would suggest that you speak to the individual doing the colonoscopy in advance and explain that you have Addison's disease, and since you cannot rely on oral absorption of cortisol with the fluid prep, you should have 100mg of solucortef given IV just before the colonoscopy. You should also double up on your cortef on the day before the procedure. It would be a good idea to speak to your family doctor first and ask her/him if they would call the person doing the colonoscopy and make this suggestion. After the procedure, you can go back to your usual dose of cortef.

Q: I was diagnosed with Addisons a year ago. I am now in a serious relationship and contemplating sex. I am just wondering if I need more cortisone before having sex?

> **A:** Having sex should put a little stress on your constitution, but under normal circumstances your usual cortisol dose should be satisfactory. I am not sure what dose of cortisol you are now taking, but if you have any problems once you have assessed the situation, you could always take an extra 1/2 tablet prior to the event.

Q: I have spoken to different doctors who say that an Addisonian can consume alcohol like any other person (14-16 drinks per week for males). Other doctors have said Addisonians should not drink at all due to possible pancreas damage etc. Which is true? If the answer is they should not drink, then obviously I would stop, but as my wife and I enjoy wine, I would like to continue to drink a few glasses a week but need to be sure there is no Addisonian risk associated with this.

> **A:** The problem with individuals with Addison's disease is a lack of hydrocortisone, otherwise they are normal. They should be able to drink normally, such as having a glass of wine with meals or the occasional mixed drink. As with everyone, drinking to excess, or binge drinking can get you into difficulty and in individuals with Addison's disease this could cause a stress you may have difficulty responding to. The short answer is that you can drink in moderation if you have Addison's disease.

Q: I took my last issue of the Addisons Society Newsletter to my GP a few weeks ago, to show him the list of suggested tests. Because it was an actual publication, with actual experts in it, he took these suggestions to heart, and not only sent me to have all the tests done, but also referred me to an internist. All the tests came back fine, so on paper I am healthy. When I saw the internist, he agreed that we had everything under control, which gave me peace of mind. However, I have been diagnosed with Raynaud's Syndrome, and he also sent me to have a test for Sjogren's Syndrome. I also have hypothyroidism, chronic ear pain, and recurring skin infections, and no one has ever gone out on a limb to say whether or not all of these things are related to the Addison's, so I asked. With no hesitation, he said "Yes". Do other Addison's patients have a similar laundry list of odd health problems? Has anyone, is anyone, or will anyone research whether these are related?

> **A:** Thanks for your question re Sjogren's syndrome, Raynaud's phenomenon, hypothyroidism, adrenal insufficiency (Addison's disease). ear pain and skin infections. The first two disorders are diseases of connective tissue and are felt to be due to the formation of antibodies directed against your own tissue (autoimmune). The next two diseases are also autoimmune and the antibodies are directed against enzymes involved in the formation of the hormones produced by these glands. Since these two types of problems are autoimmune, they can occur in the same individual, but it is more common for the antibodies to be directed at other organs in the same group. This frequently occurs with the thyroid, adrenal, ovary, pancreas or intestine (celiac disease) in different combinations. The skin infections could be a sign of diabetes, but I am not sure where the ear pain fits in.

Q: I am a recreational soccer player and have just been diagnosed with Addison's Disease. After a very rigorous game last night, I wasn't feeling well. As I came off the field, I felt very cold, which is strange considering I was sweating. Just shortly after that, I started to have vision problems like I was getting a migraine. I had one of my teammates drive me home. My vision returned and the headache started. I have had this happen before during rigorous activity. I am not sure if it is just a migraine, or if I need to be concerned about issues with Addison's?

> **A:** The episode you describe could have come from several causes. After playing soccer, you may have perspired freely and lost a significant amount of salt. This could have caused a drop in your blood pressure. This frequently results in a "cold sweat". Taking salt-containing drinks such as Gatorade during a game may be helpful. It is also possible that you did not have quite enough hydrocortisone to deal with the stress of a strenuous game. Next time, you might try taking an extra half tablet of

hydrocortisone before a game or practice. The third possibility is that it was the start of a migraine. It sounds as if this has happened before in perhaps a slightly different way.

Q: I have just been confirmed with Addison's Disease. The internet has been a wealth of information and has provided me with almost all my information on this disease. However, I cannot find the answers to a few questions. Several sites related to this disease mention that the Addisonian has the responsibility to carry an emergency kit. I have put together every item recommended except for the 100 mg cortisone injection. I cannot find a local pharmacy that supplies this drug. Do I need this item in the kit? If yes, where is it available? I have also read that you need to increase Fludrocortisone and salt intake during hot weather. In the summer, I take a lot of hot saunas ranging from 150-180 degrees and then jump into the lake. Do I have to increase my Fludrocortisone and my salt intake on the days I take a sauna? How does this work?

> **A:** The emergency kit is definitely a worthwhile investment. The solucortef comes in a preparation called the Acto-vial. It requires a prescription from your family doctor or preferably the endocrinologist who made your diagnosis. It is the most important component of your kit. The drug store may not have it in stock but can easily get it for you. You should not have to get all of your information from the net. You should be able to sit down with your endocrinologist and go over these and any other concerns.
>
> When you are taking your saunas, you are going to be losing salt in your perspiration. You have to replace this by taking in more salt and generally the fludrocortisone that you are taking will be satisfactory. If you are doing this a lot, you may need to increase both your salt and your fludrocortisone by 1/2 to 1 tablet while this is going on.

Q: I recently experienced an allergic reaction in which I developed a rash, which over a two-day period covered basically my entire body including my face. I was referred by my family doctor to a dermatologist who diagnosed me with an allergic reaction, with the likely the cause being food or meds related. We never did determine the actual cause, which my dermatologist indicates is often the case. I asked my dermatologist if I should increase my cortef meds and he didn't think I needed to. It took about 2 weeks to clear up. Should I have increased my Cortef intake at least somewhat during the worst part of reaction to help with the healing?

> **A:** The circumstances in which you need to increase your cortef depend on the degree of stress that you are experiencing. In the case you describe, the rash was severe enough to cause significant discomfort and it seemed to persist. In this circumstance, it would be appropriate to take an extra tablet of cortef for a few days until things started to settle down and then go back to your regular dose.
>
> I think it is up to you to make the decision about increasing your cortisol dose because only you know the degree of stress you are feeling. It is important that you feel confident in making these decisions because they will usually come up at times when you may not have ready access to your family doctor or your endocrinologist. You will

not be creating any difficulties if you err on the side of taking an extra tablet or two. The important thing is that you feel confident in making the decision.

Q: I was diagnosed with Addison's disease 4 months ago. I have been trying to become pregnant for 2 years now. My endocrinologist never indicated a problem with my desire to become pregnant but my family doctor has warned me that in the 2nd and 3rd trimesters there can be complications such as diabetes and pre-term delivery. When looking on the internet, I noticed that Addison's may also put you at higher risk for still birth and congenital birth defects. Can you please give me your thoughts on this? My only other health problem is hypothyroidism.

A: I hope that you are feeling much better now that you have been diagnosed and are on appropriate replacement therapy. This should include hydrocortisone or cortisone and Florinef.

As you are probably aware, Addison's disease is an autoimmune disease in which antibodies damage the adrenal glands so that they can no longer secrete hydrocortisone or aldosterone. Hypothyroidism is also most commonly an autoimmune process so that these two problems may be related.

Your problem in becoming pregnant for the past few years may have been due to the fact that your general health was not good or possibly something related to your ovarian function. You did not mention whether you were having regular menstrual periods.

If there are no problems with your menstrual periods and you are comfortable with your replacement therapy, there should be no concern about becoming pregnant. Your hydrocortisone dose may increase a little during the pregnancy, but there is no increase in foetal abnormalities. The pregnancy is likely to go to full-term, and there should be no increase in gestational diabetes unless there are other factors, such as excess weight, which would predispose you to gestational diabetes. Since you have only been on replacement therapy for four months, it may be wise to wait another month or so to be sure you are back to a healthy state.

Q: I read with interest the recommendation of travelling with an injection kit of solu-cortef for emergencies. My endocrinologist has prescribed a pre-loaded syringe of dexamethsone (4.0mg). Do you think this is an acceptable amount to deal with an emergency? It seems to be a simpler way to do it. Thank you for your input!

A: A preloaded syringe with 4 mg dexamethasone is a reasonable emergency kit for use when travelling. The main argument against dexamethasone as compared to hydrocortisone is the fact that dexamethasone has very little salt retaining activity - about 1/100 that of hydrocortisone and during acute situations salt retention is important. This is particularly true if you have a fever because you tend to excrete a lot of salt when you have a fever. There is a second thing you should check and that is the expiry date. The expiry date may be shorter for solutions than for the dry powder in the hydrocortisone Acto- vials. I think the salt retention is the most important consideration.

Q: Do you know if there is any research underway to create a method to administer cortisone similar to insulin delivered to diabetics via insulin pump? Are there complications with using this type of technology for Addisonians?

> **A:** This is an interesting question. Insulin is given to some individuals with a pump to deliver a continuous amount of insulin over a 24-hour period. The pump can be programmed to deliver different amounts of insulin at different times. Insulin is not active orally so requires subcutaneous injection and is absorbed well from this site. The volume of injection is generally quite small. Most diabetics would be ecstatic if insulin was orally active.
>
> Hydrocortisone (cortisol) is rapidly absorbed after it is taken orally. By taking it 2 or 3 times daily, we can get a reasonable approach to the normal daily hydrocortisone pattern but it is not perfect. Since the highest levels of hydrocortisone occur on rising, ideally we should wake ourselves up about an hour before getting up so we could take our morning dose of hydrocortisone. I am not certain how well hydrocortisone would be absorbed from subcutaneous tissue or what the long-term effect of hydrocortisone on the subcutaneous tissue would be. The cost of the pumps and the tubing required are quite significant for continuous injection. It is however an interesting question.

Q: I am a 53 year old and have had a partial hysterectomy. I have been suffering for the past 6 months or so from severe hot flashes that are really disturbing my sleep, and I am having some of the brain fog that also may go with menopause. It is enough to affect how I can function at work. I have also been diagnosed in the last year with Addison's due to long-term steroid use. My family doctor has suggested HRT for the hot flashes. Is this recommended or even effective with Addison's?

> **A:** There is no special problem in using hormone replacement therapy in individuals with adrenal insufficiency. Since you have had a hysterectomy, your HRT will be estrogen alone. The studies have shown that women treated with estrogen alone do not have an increased incidence of breast cancer, so this treatment should be relatively safe. I think even with estrogen alone, the rule still stands - the lowest dose for the shortest period to get the outcome you require.

Q: I was diagnosed last summer with Addison’s, possibly from long term prednisone usage. I say possibly because the symptoms have been going on for about 25 years. Right from the first time I was put on prednisone for a severe asthma attack, I had problems weaning off the prednisone. I would have severe muscle pain and lethargy, dizziness, nausea, and skin rashes. I was sent to skin specialists for the rashes over several years. At one point I asked if I could be allergic to the prednisone not knowing much about it. I was told no, and eventually told it was PMS, then chronic fatigue and fibromyalgia. Also, I would end up back in emergency with an infection of some sort and back on the prednisone. This cycle continued for about 28 years until I finally was diagnosed.

I am taking usually 15-20mg cortef at 6:30am and 10mg at noon, as I seem to need it when working and I have trouble sleeping if I take it later. In the last couple weeks, I have felt terrible - body aches, severe lethargy, rashes, nasal stuffiness and shortness of breath - but haven't noticed a cold or flu. I increased my dose from 25 to 35 – I was afraid to double it as I hadn't seemed to be sick. Maybe I've had a sinus infection without realizing it. That has happened in the past as I have had 5 surgeries for polyps and chronic infections. Since being diagnosed with Addison's, however, I haven't needed puffers or nasal sprays for the first time in 30 years. I took 35 mg of cortef yesterday and I still don't feel well today. Also, my hands and feet are puffy and tingly. If I grab anything too tightly, the blood vessels would break. My family doctor does not know about cortef - I had to tell her about it – and the endocrinologist is away. I am having a hard time to figure out how to regulate this and to do the right thing.

> **A:** I cannot be too specific in answer to your question since I don't know all the details. I am a little puzzled when you say that blood vessels on your hands break if you grasp things tightly. In general, it is reasonable to take an extra 10 or 20 mg of cortef during an illness and since the infection will not be over in one day, it will be necessary to do this for 2 or 3 days until the infection settles down. It will not hurt you to take an extra cortisol tablet for a few days as long as it does not become something that you do regularly every time you have a bad day. Since your adrenals are not able to produce cortisol, you have to do the thinking for your adrenals and decide how much cortisol you need. As you may have read on other places on this website, "the lowest dose of cortisol that makes you feel well is the right dose for you".

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.

New Membership *Renewed Membership* **+** *Plus a Contribution*

Name: ____

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How do you wish to receive the Newsletter?

I will read it on the website at www.addisonsociety.ca

by mail

If you DO NOT want your name to be made available to other Addisonians in your area, please sign here.

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You may also direct $5.00 of your annual fee to one of the local support groups below. Please check a box of your choice.

$25.00 to go to The Canadian Addison Society

OR

$5.00 to Eastern Ontario Support Group – ON + $20.00 to Society

$5.00 to Southern Ontario Support Group – ON + $20.00 to Society

$5.00 to Saskatchewan Support Group – SK + $20.00 to Society

$5.00 to Alberta Support Group – AB + $20.00 to Society

$5.00 to BC Lower Mainland Support Group – BC + $20.00 to Society

$5.00 to Vancouver Island (Victoria) Support Group – BC + $20.00 to Society

$5.00 to Vancouver Island (Nanaimo) Support Group – BC + $20.00 to Society

$5.00 to Atlantic Provinces Support Group (NB/NS/NF/PEI)+ $20.00 to Society

+ *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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