The Canadian Addison Society
La Société canadienne d'Addison

193 Elgin Avenue West
Goderich, Ontario N7A 2E7
Toll free number: 1-888-550-5582
Email: liaisonsecretary@addisonsociety.ca
http://www.addisonsociety.ca

ISSUE NO.48 **OCTOBER 2007**

In this issue:

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

Annual General Meeting: September 22, 2007

Held in Brantford, Ontario

1) Call to Order: The meeting was chaired by: Irene Gordon, Liaison Secretary.

2) President's Message

   Congratulations to the Canadian Addison Society and its membership! In the past year, we have successfully continued to promote information exchange about Addison's disease, and provide ongoing support to people living with the disease and their friends and families.

   Thanks to the hard work of several members of the Society, our website was updated and revised so that it was the source of information for many, many people. Special recognition goes out to Irene Gordon for her hard work in keeping the site going. The Internet is probably the primary source of information for many people living with

Addison's disease, and in the future we may be able to provide exciting new areas in our site.

Over the past year, our regional support groups continued to meet and exchange information about Addison's disease, provide support to new members, and fundraise for the national society. In the coming year, we can look forward to the creation of a new support group in the Atlantic Provinces, and new leadership of the Southern Ontario group.

On a national level, the Board of Directors continues to revise the organization's Bylaws to ensure that the national organization remains relevant to its membership. We also are moving forward with creating emergency medical information cards for our members who request them. These wallet size cards provide essential medical information for medical personnel in the case of an adrenal crisis. In addition, the national organization has provided ongoing quarterly Newsletters to our members via e-mail or by paper mail.

This will be my last year as President of the Society as my term is coming to an end. Please, if you are interested in volunteering for the Society as President feel free to contact myself or Irene. The Society would greatly appreciate your input.

Over the next year, I wish you all health and happiness.

letter from Athena Elton read by Irene Gordon

3) Adoption of Minutes from 2006 Annual General Meeting
Motion to adopt Minutes: Stephen McKenna; Seconded: Harold Smith; Passed unanimously

4) Financial Report: Reports attached to these minutes (annex A)
   - John Gordon highlighted that the Society was very successful this past year, thanks to the generous donation received from June Tyler, member of the Southern Ontario Support Group, and Worthy Matron of the Grey Chapter No. 170 - Order of the Eastern Star. This donation is sufficient for an ad in the CMA journal. Following discussion, it was determined that such an ad would not access those endocrinologists and family doctors we wish to address. Instead, we will examine methods to access endocrinologists in training through the annual endocrine society meeting and medical schools. (Action: I. Gordon) Any use of funds will be submitted to the Board of Directors for approval.
   - The names of four members who died this past year – Terese Sullivan, Don Newman, Valda Cleaves, Shirley Shier– will be added to the Memorial Plaque, which we will look into putting onto the website. (Action: I. Gordon)

Motion to accept the financial statements as presented: John Gordon; Seconded: Stephen McKenna; Passed unanimously

5) Officers and Directors for 2007-2008
   There are no changes to the slate of officers for 2007-08. We welcome Harold Smith as Regional Representative for the Southern Ontario Group, and are very pleased that Kelley Gamblewest has started a Support Group in Atlantic Canada.

6) Changes to Bylaw #10: The wording has been revised to reflect the change made at the 2006 Annual General Meeting in By-law #24.

   MEMBERSHIP

   The membership shall consist of those individuals who are admitted as members by the Board of Directors, and who have submitted a Membership Form and Dues payment to the Society for the current year.

   Members may resign at any time in writing or by telephone, or by electronic means, effective upon notification, or membership will be terminated 4 months following the fiscal year end, for non payment of dues.

   Material costs over and above what is provided by the Society (i.e. booklets) must be pre-paid by any member requesting it.

   Motion to accept the bylaw amended to read as above: Joan Southam; Seconded: Stephen McKenna; Passed unanimously

7) Directors' Reports: These were submitted for information only and are attached to these minutes (annex B).

8) Membership update
   - Membership numbers are down – current membership is about 150. This may be due in part to the fact that access to our website is free. However, this is directly in line with our objective as a Society to provide information and education. Renewals are due in January of each year.
   - Donations (over and above membership fees) are gratefully accepted. We will look at making this more visible on our website. (Action: S. McKenna, I. Gordon)
   - In order to encourage younger members to join, we would appreciate any volunteer who could develop marketing tools designed to access younger Addisonians.

9) Website
   - We have had several setbacks in the past year, including modifications by the service provider that have made changes and updates to the site more difficult. A systems consultant has agreed to take on website administration *pro bono* and is currently working out the bugs.

- Members discussed the possibility of a discussion forum on-line. However, due to the medical nature of the site, such a forum would require considerable time commitment from a qualified medical moderator, which is not available at this time. Members present thought that the current Q&As on the website, also in the Newsletter, fill the need. Regional representatives will be encouraged to use local meetings and networks to facilitate this type of discussion. (Action: I. Gordon)
- A member from Eastern Ontario is currently re-organizing the Q&As on the website by subject matter, and streamlining the document to reduce duplication. We will also examine the use of the 'Search' function to make information more accessible. (Action: C-A. Diguer, I. Gordon)

10) Addisons Medical Information Card

After considerable discussion, the following motion was tabled:

- to amend the current membership card to include this emergency information, if possible; members who want this enhanced membership card will be asked to submit the additional information necessary with their membership renewal;
- to make the large form available on the website and through the newsletter for members to complete themselves.

Motion: John Gordon; Seconded: Joan Southam; Passed unanimously

11) The Annual General Meeting will continue to alternate between the East and the West. The 2008 Annual General Meeting will be held at the Victoria General Hospital, Victoria, B.C., on Saturday, October 11, 2008, noon to 5:00 p.m.

12) Our guest speaker was Stan Van Uum, MD, PhD, Assistant Professor, Endocrinology and Metabolism, Dept. of Medicine, U. of Western Ontario, St. Joseph's Health Care. His presentation is included as Annex C.

The following notes should be read in conjunction with the presentation slides:

- 3 small organs (1 cm) – 2 adrenals, 1 pituitary – affect all body functions
- the adrenal medulla creates adrenaline and epiphenephrine; the cortex creates cortisol, aldosterone, androgens
- patient treatment regimes and levels vary depending which organ parts are affected
- mineralocorticoids regulate sodium and potassium, thereby regulating blood pressure
- glucocorticoids help regulate glucose levels; when glucose levels are too low, the body should put out more cortisol – if there is too much cortisol, glucose levels will go up; too little cortisol, glucose levels go down
- stress activates the hypothalamus, stimulating the pituitary which puts out ACTH, stimulating the adrenals which should produce cortisol – the body is constantly fine-tuning these outputs; it is difficult to fine-tune medication in this manner

- while cortisol levels are highest around 8 am, graphs show the spikes and valleys throughout the day
- each person's biorhythms are different – causing more variations in cortisol outputs
- the natural biorhythm for humans is 25-26 hours, not in sync with our 24 hr day; these variations also affect individual cortisol outputs
- a non-Addisonian might have an output equivalent to 20 mg in the urine one day, 10 mg the next and 30 mg the day after; to replace adequately in the Addisonian, it may therefore be necessary to give 30 mg each day, so not to risk undermedicating on the day 30 mg was needed
- the sensitivity of receptors also varies from person to person, affecting the dosage required
- hyperpigmentation occurs because the overproduction of ACTH, to try to stimulate the adrenals, also produces extra MSH, which causes tanning
- adrenal crisis is caused by shock – a degree of shock which is out of proportion to the illness/trauma
- most Addisonian deaths occur either before diagnosis or in puberty (as some young Addisonians can rebel and experiment)

Symptoms

- 5% of Addisonians suffer from auricular calcification caused by mineral imbalances – but we don't know why this affects specifically the ears
- when undiagnosed Addisonians present with abdominal problems, they are usually seen by surgeons; surgeons don't usually think first of endocrine problems
- unexplained hypoglycaemia – it takes much more than it should to raise the person's blood sugar levels, as they are not producing cortisol which is needed to release the glucose
- if it is secondary Addisons (i.e. from pituitary dysfunction), florinef is usually not needed
- due to the mineralocorticoid content of solu-cortef, florinef may not be needed if in conjunction with large doses through IV or IM solu-cortef
- "rule of three" = 3 times the dosage for 3 days
- "grey fog" – the brain has glucocorticoid receptors, which are affected by other brain chemicals; 50% of Cushings patients present with depression
- one enzyme used in conversion is also present in the brain, so how does the brain use/convert?
- cortisol levels can be tracked through hair analysis; hair grows approx 1 cm per month

Question 1

- Cortisol is the active form; cortisone is the inactive form, which needs to be converted in the liver to cortisol; liver must be functioning to convert cortisone to cortisol; about 80% of cortisone is converted to cortisol (25 mg cortisone converts to 20 mg cortisol);

- Raw licorice increases the effectiveness of cortisone; but licorice is not standardized, so strength and quality vary greatly, so you can never really know how much medication the body is getting; better to leave licorice out of the equation and simply modify the cortisol intake; because the impact of licorice is on the conversion on cortisone to cortisol, its use would not avoid any unwanted side effects of simply increasing the cortisol medication intake

Question 2
- congenital adrenal hyperplasia is a condition where one enzyme in the chain reaction in the adrenals is too low, but there are high levels of androgens; both mother and father must be carriers
- adrenoleukodystrophy – there is too much long fatty acids; the functional cells decrease and so cannot produce cortisol; there are also other physical impacts; it is linked to the X-gene from the mother
- congenital adrenal hyperplasia and adrenoleukodystrophy are congenital inherited problems with adrenal issues associated with them
- Addisons – not clear that there is any genetic link; if there is, it is not direct

Question 3
- Symptoms of overdose are the same or similar to the symptoms of insufficient dosage, which is a real problem when fine tuning your dosage
- effects of too high a dose of hydrocortisone: high blood pressure, blood sugar problems (diabetes), increased weight, decreased mental functions; bone density issues/osteoporosis
- Overdose: see symptoms of Cushings; include weight gain, muscles weakness, bruising, mood change, glucose levels too high

Question 6
- Herbs are not standardized, so the impacts vary on each intake; some may contain licorice which affects conversion; St. John's Wort works on the same enzyme in the liver which converts cortisone; in general, we don't know enough of the contents or action of herbal remedies, so it was suggested that we avoid these unknown variables

Question 7
- If the thyroid function is low, symptoms of tiredness, constipation and low temperature can occur
- hypothyroid – breakdown of cortisol is too slow
- hyperthyroid – breakdown of cortisol is too quick and it is gone from system too soon
- Addisonians should to get regular thyroid and diabetes screening

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Annex A

THE CANADIAN ADDISON SOCIETY
STATEMENT OF INCOME & EXPENSES
FOR THE PERIODS ENDING DECEMBER 31, 2006 AND SEPTEMBER 21, 2007

	January 1, 2007	January 1, 2006
Cash on hand and in banks	**$18,394.25**	**$17,940.37**
Income		
Dues Received - National	**$2,070.00**	**$3,212.18**
- Support Groups	**315.00**	**535.00**
Donations	**2,611.35**	**1,010.00**
Interest	**375.00**	**581.61**
	5,371.35	**5,338.79**
Expenses		
Memorial Plaque	**-**	**15.41**
Newsletter	**736.59**	**653.24**
Web Site	**174.90**	**491.15**
Secretarial	**600.00**	**1,200.00**
Annual Meeting	**-**	**202.31**
Donation	**-**	**-**
Postage, stationery & supplies	**132.71**	**1,078.01**
Telephone	**679.53**	**896.74**
Travel	**-**	**-**
Support Group Expenses	**122.22**	**282.13**
Bank Charges	**53.28**	**65.92**
	$2,499.23	**$4,884.91**
Cash on hand and in banks after adjusting for O/S cheques	**September 21, 2007**	**December 31, 2006**
	$21,266.37	**$18,394.25**

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Analysis of cash on hand & in banks as at September 21, 2007

Equitable Trust -	
The Canadian Addison Society - $6,570.50 @4.41% due November 13, 2007	
- $9,533.39 @4.20% due September 24, 2007	**$16,103.89**
TD Canada Trust -	
The Canadian Addison Society	**1,717.96**
Montreal Support Group - Quebec	**100.00**
Ottawa Valley Support Group - Eastern Ontario	**470.70**
Brantford and District Support Group - Southern Ontario	**1,600.26**
Saskatchewan Support Group	**30.00**
Edmonton Support Group - Alberta	**264.60**
Lower Mainland (Vancouver) Support Group - British Columbia	**518.96**
Vancouver Island Support Group - Victoria	**445.00**
Vancouver Island Support Group - Nanaimo	**15.00**
Total	**$21,266.37**

DIRECTORS REPORTS **Annex B**

BC LOWER MAINLAND GROUP – Judythe Stanley Reporting

The BC Lower Mainland Group meets three times each year at the Sherbrooke Centre. Booking arrangements have been altered and we can now only book three months in advance. The Centre is adhering to their policy of booking educational groups with the hospital taking precedence over non-profit groups. They had a large increase from non-profit groups for meeting space in the past year.

We are able to book our February meeting with UBC First Year Medical students by signing a booking contract to assure that we have the needed space. Fortunately their curriculum now is teaching the required course in their second semester which fits in with our February meeting. Our October meeting was bumped by a conflicting internal group requiring the room. A smaller room will be provided for us to meet in. Thanks to Marilyn Thauberger who will be making unexpected arrangements for a guest speaker.

Confirmed upcoming meeting dates are:
October 27, 2007 – 1-3 pm - Sherbooke Conference Room 2
February 23, 2008 – 1-3 pm –Sherbrooke Lounge and Lecture Room 1

Attendance at meetings has been fairly consistent with a regular attendance of paid or non-members and newly diagnosed referrals. New membership forms and information updates are available at all meetings. Our meeting format of a guest speaker, the interviews with UBC students and the final meeting an informal get-together for members to meet and talk. This seems to meet the energy levels and busy lives for those able to attend. Thanks also to those who let us know that they are unable to attend as it makes planning so much easier.

VANCOUVER ISLAND SUPPORT GROUP – Jim Sadlish Reporting

The Vancouver Island Support Group meets regularly 3 times each year at the Victoria General Hospital. Attendance at meetings has been fairly consistent, frequently the same group of members and spouses. People relax with others they know and relate experiences and changes in treatment to mutual benefit. It is particularly interesting to hear of someone feeling better after making adjustments to their medical regime. We exchange information on how our doctors are treating us and encourage working with these medical professionals to develop optimum treatment. Medical speakers have been relatively scarce at our meetings. This fall, however, we have invited an endocrinologist, Dr. Richard Phillips, to talk at the September 29 meeting and more members are expected to attend.

The University of Victoria has a medical program training doctors. We had hopes of informing new doctors about Addison's by members volunteering for interviews with student doctors studying chronic diseases. Although the Island Medical Program Patient Coordinator has been contacted several times regarding our group's offer to assist, she has not responded.

The Vancouver Island support group looks forward to hosting the 2008 AGM. A lecture hall has been booked for October 11, 2008. Now the challenge will be to line up a qualified speaker.

EASTERN ONTARIO SUPPORT GROUP – Steve McKenna Reporting

Next meeting: we will be discussing the positive and negative effects of Addison's disease on our families, our close friends and us. We hope to have the results of the discussion put on the website in such a way that others can add to it.

May 2007 - Meeting was held in Kingston ON instead of Ottawa ON to allow members from the surrounding area to attend. This was a resounding success. Meeting focused on:
- Our web site and links
- Encouraged members to leave pamphlets in Doctors' offices
- Emergency Kits: contents, letters, Medic Alert Info, etc.
- Were told Paramedics look to person's fridge for a summary of health details, great suggestion!
- Guest speaker: registered nurse with an adult child with Addison's

September 2006 - Guest speaker from Canadian Air Transport Security Authority (CATSA) who dealt with the screening of air passengers. CATSA rep discussed what they do. New security measures and provided helpful tips.

The October 2005 meeting included guest speakers who were Paramedics (one who teaches an Advanced Paramedic course and another experienced Paramedic). This was very educational for both the group and the Paramedics. A wonderful type of guest speaker to have at an Addison's meeting!

Contact: Teresa Seasons (tseasons@magma.ca)

SOUTHERN ONTARIO SUPPORT GROUP – Irene Gordon Reporting

There is nothing new to report since our last meeting in May (report in June Newsletter). We are happy to announce that we have had a volunteer come forward to become the new Regional Representative for this Support Group, Mr. Harold Smith who lives in Kitchener ON.

Harold can be reached through the web site as the new Southern Ontario contact, by e-mail at hsmith9995@rogers.com or 519-742-9995. We welcome Harold to the support group. Joan and I will continue to be involved with the support group and try to assist wherever we can.

The Southern Ontario Support Group's next scheduled meeting is Saturday, May 17th, 2008, 12:30 – 4:30 pm. at the Brantford Police Station Community Room, 344 Elgin Street, Brantford.

ATLANTIC PROVINCES SUPPORT GROUP (NS, NB, PEI, NF) – Irene Gordon Reporting

We are so happy to report the establishment of an additional Support Group for the Atlantic Provinces.

Kelley Gamblewest (formerly from BC), lives in Fletchers Lake, NS, and has taken on the role of Regional Representative for our members in the East. Kelly can be reached through the web site as the Atlantic Provinces contact, by e-mail at kdgwest@eastlink.ca or 902-452-1581.

ALBERTA SUPPORT GROUP – Ginny Snaychuk Reporting

I don't have much to report - will try to have a meeting in late October. Status on the 'Hospital Emergency Protocol' - got word last week from the endocrinologist involved and he said it is 'almost completed' - no firm date as yet, but soon.

Presentation by Dr. Van Uum — Annex C

This presentation is attached at the end of this Newsletter.

Announcements:

- As this is the last year Athena will serve, it is important that we start immediately looking for our next President. This position serves to focus the Society and to act as a spokesperson, but is not a labour-intensive role. If you are interested in volunteering for this position, or have someone to suggest, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or 1-888-550-5582 as soon as possible.

- The 2008 Annual General Meeting will be held at the Victoria General Hospital, Victoria, B.C., on Saturday, October 11, 2008. Please note that this is the Thanksgiving long weekend and make your plans accordingly. We hope many of you can attend.

- We are pleased to announce that Joan Hoffman (USA) and her husband Ron are new first-time grandparents. Her Addisonian daughter Amy and husband Justin Hamilton have a new baby boy - Alex Troy Hamilton.

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Highlights from Local Meetings:

Vancouver Island Support Group

The group met Saturday, September 29 at the Victoria General Hospital in Victoria. Endocrinologist Dr. Phillips addressed 18 people present. Dr. Phillips comprehensively answered pre-submitted questions from support group members. He began with diagrams describing the location in the body of the pertinent organs and glands, then gave an understandable review of their functions.

Following is a brief report of the general questions and topics Dr. Phillips dealt with:

- Skin pigmentation - in primary Addison's, a slightly darker skin may indicate you are not over-replacing medications. A pale skin may mean you are over-replacing. There is no browning of the skin with secondary Addison's.
- The difficulty replicating the body's natural rhythms when replacing hormones with medications.
- Addisonians should be no more likely to get diabetes than non-Addisonians because our replacement doses are low. Large pharmacological doses of a glucocorticoid may increase the risk of diabetes.
- DHEA helps some people but not others.
- The chance of inherited Addison's is small although a blood relative may experience another more common autoimmune disorder.
- Thinning skin and red bruises on forearms are indicators of over-replacement.
- High blood pressure seems common among older Addisonians. Is Florinef dose a factor? In Conn's syndrome, hyper-aldosteronism, too much aldosterone leads to high blood pressure and cardio problems. When we take our medications, the doses are higher at first, peaking hormone levels beyond what a normal endocrine system would experience. Florinef may require adjustment.
- Licorice root can interfere with the conversion of cortisone to cortisol in a normal person, and may affect aldosterone replacement levels in Addisonians.
- Flu shots are recommended to reduce the effects of the flu but will not prevent getting the flu.
- Autoimmune diseases are more prominent in northern climates.
- Vitamin D supplements are relatively safe and have recently been shown to improve long-term health.

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- Addisonians should take dietary salt moderately, as per the Canada Food Guide, although in very hot climates we may need to increase salt intake and/or adjust Florinef dose.

Dr. Phillips' talk was concise and instructive, a valuable help, much appreciated by those attending.

Submitted by Jim Sadlish

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at jsadlish@horizon.bc.ca or (250) 656-6270. For information on mid-Island activities, please contact: Christy Lapi at clapi@shaw.ca or (250) 245-7554; Barbara Hunn at bhunn@shaw.ca or (250) 714-0036; or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

Our October 27th meeting is in Sherbrooke Conference Room 2, 1:00 to 3:00 p.m, 260 Sherbrooke St., New Westminster. The meeting room is up the stairs from the Lecture Theatre (Lecture Room 1) and is not wheelchair accessible. Guest speaker will be Gerry Kaftan, a nutritionist for the Fraser Health Authority. Parking in the Public lots ($6.50 for 12 hours) is more expensive than on the street. Sherbrooke St. and Kerry St. - $4.00 for 10 hours or $1.00/hour, Columbia St. - $1.00/hr (2 hour limit)

UBC has moved their First Year Medical Student interviews from the first semester to the second semester and has a new co-ordinator. We booked Lecture Room 1 and the Sherbrooke Lounge for February 23, 2008 from 1:00 to 3:00, our usual meeting times. We shall update you at the October meeting and have a sign up sheet for interviews with students. This is part of our ongoing advocacy for Addison's Disease etc. In the past, we had excellent participation from members and cards of appreciation from the students who do the interviews. The interviews are part of their curriculum and require research, an oral presentation and a paper which is part of their grade.

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

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kesahill@sasktel.net or elizabeth.h@pnrha.ca.

Southern Ontario Support Group

The Southern Ontario group is very pleased to have a new regional representative. Thanks to Harold for taking on this important role.

The next meeting will be Sat. May 17, 2008, 12:30 to 4:30 pm, Brantford Police Centre, 344 Elgin Street, Brantford, Ontario.

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

For information on Eastern Ontario Support Group activities or meetings, please contact Teresa Seasons at tseasons@magma.ca (613) 761-1195.

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

We are extremely pleased to announce that Kelley Gamblewest, who was previously a member in B.C., has moved to Nova Scotia and has agreed to be regional representative for a new support group to serve Atlantic Canada. Kelley is hoping to get regional members together, so if you are in the area, get in touch with her. Kelley is just outside Halifax, and can be reached at (902) 452-1581 or kdgwest@eastlink.ca.

Medical Q & A

Q: For the past year, I have had increasing episodes of dizziness, two of which resulted in falls. My body has felt weak and I have had several infections, both respiratory and bladder. My family doctor did a cortisol test, which came back as very low. An endocrinologist repeated the morning cortisol level, agreed that the cortisol was low and suggested an insulin hypoglycaemic test. This indicated that I have cortisol insufficiency. She now wants to do an MRI of my pituitary gland.

She thought the problem was Addison's disease (adrenal insufficiency), and has prescribed Cortef 10 mg twice a day. My questions are: why is an MRI being performed? Is Cortef a safe drug to take for cortisol insufficiency? She has prescribed it for at least one year. I am

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a bit concerned about taking a steroid for such a long period of time. I have heard that they can cause weight gain, etc.

Does this sound like Addison's disease or are there other causes for cortisol insufficiency?

> **A:** The fact that your cortisol response to insulin-induced hypoglycaemia was low would be in keeping with adrenal insufficiency. This problem can be due to destruction of the adrenal glands or to a problem in the pituitary gland that controls the adrenal gland by its production of ACTH. Usually, ACTH is measured along with cortisol during the insulin test and this helps to determine the cause of the problem. The MRI is done to visualize the pituitary, if there is any concern that you could have a pituitary problem. I am glad that you are going to talk to your endocrinologist to find out exactly what was found during testing. If it was shown that you have adrenal insufficiency, the treatment is usually lifelong. Your endocrinologist will follow you, be sure the dose is correct and you should not gain weight. If the problem is in the pituitary gland, you would require other investigation and treatment. It is important to discuss the tests and the treatment with your endocrinologist so you truly understand the cause and the management of the problem, so that you will be able to make the right decisions if you have any problems in the future.

Q: I have secondary Addison's and am wondering about the general protocol for having a colonoscopy prep and procedure? I have heard that people with Addison's may have to spend the night prior to the procedure in the hospital? I also have a high steroid requirement and am on 43.75 - 50 mg. cortisone acetate split over three times per day and various other meds. I've never shown signs of Cushings on this dose other than bone loss but am also on Tegretol and low dose synthroid. I'm also managing a well controlled seizure disorder. I haven't discussed this with my endocrinologist yet but will soon. Please give me your opinion on this procedure.

> **A:** Having a colonoscopy is getting to be a fairly common procedure but that doesn't make it any easier for those going through it. For some people, the prep is more stressful that the colonoscopy itself. It depends on the type of prep. The one involving drinking a large volume of fluid can cause nausea and vomiting and can make it difficult to keep down your cortisone. You should review this with your gastroenterologist. He/she may have a protocol to cover this situation. It depends on the hospital where this is being done. If the prep is going to be done at home, you should take some extra cortisone when you start, in your case, an extra tablet so you would be taking 75mg that day. On the day of the procedure, there are 2 options: to be given 100mg of solucortef intravenously before the procedure; or, to take double your usual dose of cortisone on the morning of the procedure. It also depends on the time of day it is to be done. Usually, it is in the morning and you could request this since it would be easier for you. It would be much less stressful if you were admitted to hospital the day before and you can also discuss this with your gastroenterologist.

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All of this should first be discussed with your endocrinologist who can coordinate the procedure with the gastroenterologist. They may have been through this before and have a plan all prepared. An open discussion always makes everyone feel more comfortable.

Q: We just survived our first Addisonian crisis at home. My question now is: Is it common for an emergency injection (we used solu-cortef, my wife normally takes about 5mg prednisone) to disrupt the menstrual cycle?

A: Any significant stress can interfere with the regularity of the menstrual cycle. Since there are possibly many factors involved, including why the crisis took place, you should review this with your family doctor or endocrinologist who would know your wife's complete history and would be in a position to assess the circumstances.

Q: I am struggling trying to keep my weight down as I am also diabetic and just newly on insulin. I keep gaining weight. I am on cortef. What can I do?

I am on 15 mg of cortef, I go to the gym 4 times a week, walk over l0,000 steps a day, and am very careful what I eat because of my diabetes. Nothing is helping. I do all the exercise I can do, and don't know what else to do. I will ask my specialist when I see her at the end of September.

A: I am assuming that you are on cortef because you have Addison's disease. If you are gaining weight, there are a variety of possibilities:

1. You are on more cortisol than you need.
2. You are not as active as you should be.
3. You are taking in too many calories.

The easiest of these possibilities is the dose of cortef. The dose requirement for cortisol is variable from one person to another, usually between 15 and 30 mg per day. The lowest dose that keeps you feeling well is the best for you. Too much cortisol will also make your blood sugar more difficult to control so it is worthwhile taking a careful look at it.

Being careful about what you eat does **not** mean that you are eating the number of calories that you require to lose weight. There are genetic factors that influence body weight so that the number of calories eaten by one person may result in weight gain while another person eating the same number of calories may actually lose weight. You have to cut back on your intake and increase your activity to find what works for you. As you cut back on your food, your blood sugars will come down so you will have to make adjustments

Q: I have seen many specialists over the past 2½ years, struggling with some type of endocrine disorder. I am taking florinef and midodrine to elevate my blood pressure. All this

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time, I have been concerned with Addison's disease because of my symptoms, I have Celiac disease which is rampant in my family, and my cousin has a confirmed diagnosis of Addison's disease.

My question is: I have undergone the insulin tolerance test and did not have a significant enough rise in cortisol level, nor did it reach a high enough number, yet the doctors are left baffled. I have passed the synacthen test (ACTH stimulation test) five or six times. How can this be? No one has been able to explain to me why the different results. Any information you can provide would be helpful. I will discuss any information with my doctors.

A: I am sorry to hear that you have been going through such difficulties. You have a family history of Addison's disease and Celiac disease, and this makes you statistically more likely to develop an autoimmune disorder than those in the general population, but it does not mean that you will develop one of these problems.

The investigation, as I understand it, has shown a subnormal response to insulin-induced hypoglycaemia but normal responses to ACTH stimulation. The first question is to find out what your morning level of cortisol was. If it was over 300 nmol/l, the probability of adrenal insufficiency would be low.

The next question would be to check and be sure that your blood sugar fell to a low enough level to cause ACTH stimulation (it should go down to about 2.5 nmol/l).

If there was a low fasting cortisol with a subnormal response to insulin but the response to ACTH stimulation is normal, your endocrinologist would be looking at a possible pituitary cause for your low cortisol. Since I don't know your whole story, there may be other factors accounting for your symptoms. It is important for you to discuss your concerns with your endocrinologist so you can get her response to your questions.

Q: I was diagnosed with Addisons when I was 12 years old; I am now 46. I have been taking cortef 10mg TID and florinef 0.1mg "OD" since I was 20. Two years ago, I started to show signs of perimenopause. I recently found a book stating a "normal" person would produce extra hormones from the adrenal glands since the ovaries decrease production while going through menopause. My question is: how much extra cortef should I be taking? I have also been having problems with increased BP. Is this related to the menopause?

A: The comment that you heard stating that the adrenal increases its hormone output after the menopause is not correct. At the menopause, the ovary stops producing estrogen but continues to produce androgens for 1 to 2 years. The adrenal continues with its usual hormone output of cortisol, aldosterone and some weak androgens (DHEA and androstenedione). These weak androgens can be converted to estrogens in fat tissue. The conversion is small - about 1% -, and this contributes to the estrogen production after the menopause. No change in your cortisol dosage is

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required. The dose of cortisol that you are on is already at the high end of the usual cortisol replacement.

Q: I had both of my adrenal glands removed due to the spread of lung cancer. My lung cancer has been under control for 3 years now. No chemo or treatments. I am now taking 75 mg. of cortisone a day and .01 mg of florinef. My family doctor says one thing and the endocrinologist says another, while I suffer with this problem. I feel tired most of the time. Any small jobs I try to do really tire me out. Are there any special tests I could have done to correct my problem?

A: Your situation is more complicated than a loss of adrenal tissue. If you are being treated for the lung cancer, both the treatment and the underlying problem could cause fatigue. From the standpoint of your adrenal status, you should be on cortisol and florinef. The dose of cortisol should normally be between 15 and 30 mg/day and the dose of florinef between 0.1 and 0.2 mg/day. The tests that will guide your doses of medication (but will not give you absolute criteria) are - blood pressure, electrolytes (sodium, potassium and chloride) and renin for the florinef and a morning ACTH which should be slightly high for the cortisol. Your endocrinologist will probably have already done these tests so you can review them with him/her to be sure everything is in order. Unless there is something you haven't mentioned, a dose of cortisone of 75 mg/day is too much for adrenal replacement. Cortisone at those doses has a tendency to decrease muscle build-up and cause protein loss - causing things like thinning of the skin and bruising. I don't know what you are hearing from your physicians, but they should be talking to each other and to you to explain their views. You should not be caught in the middle.

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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The Canadian Addison Society
La Société canadienne d'Addison

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http://www.addisonsociety.ca

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

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

Name: _____

Address: _____

Postal Code: _____ *Telephone:* _____

E-mail Address: _____

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.

_____

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*

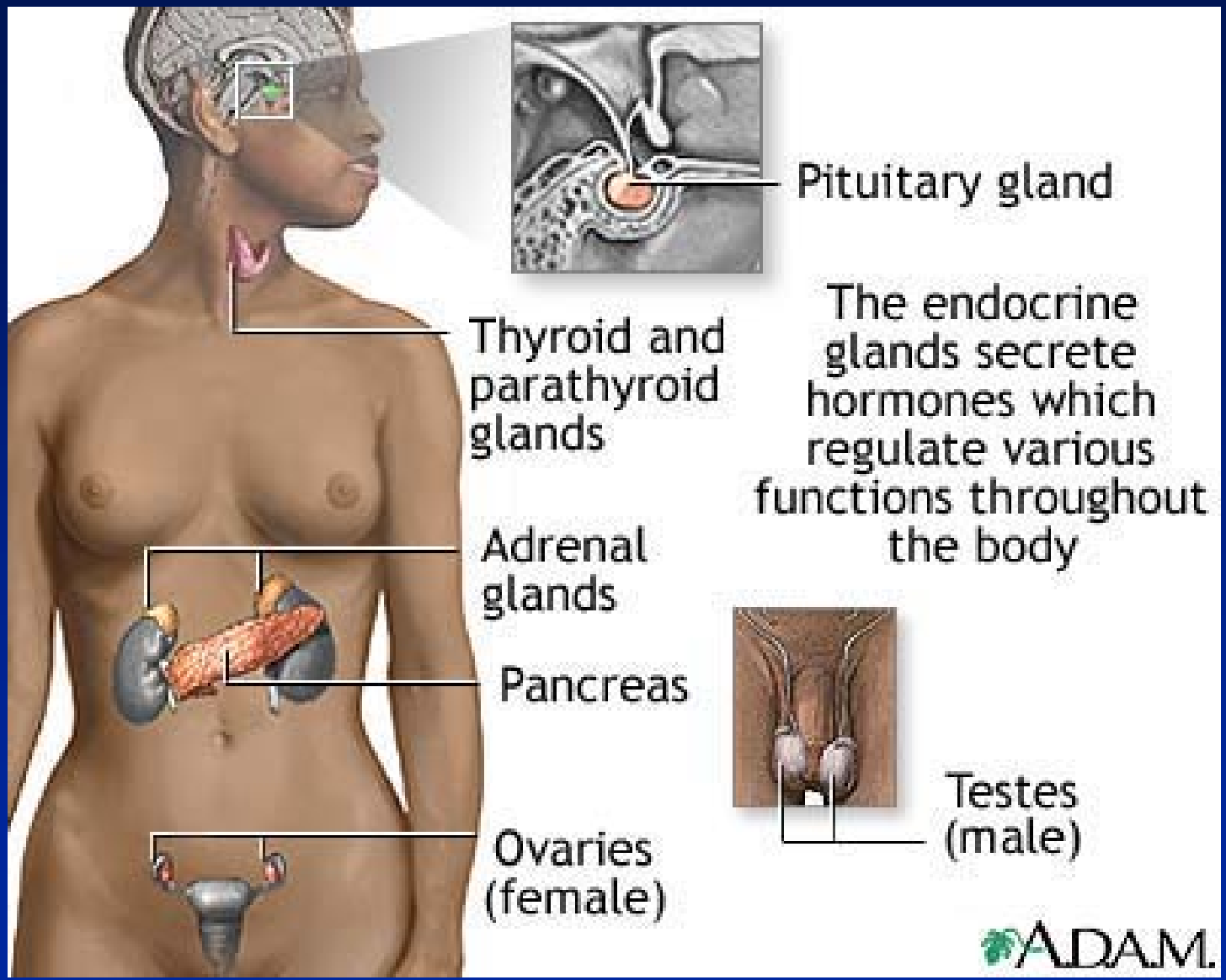
+ *Contributions are also gratefully accepted. A tax receipt will be issued for contributions over $10.00.*

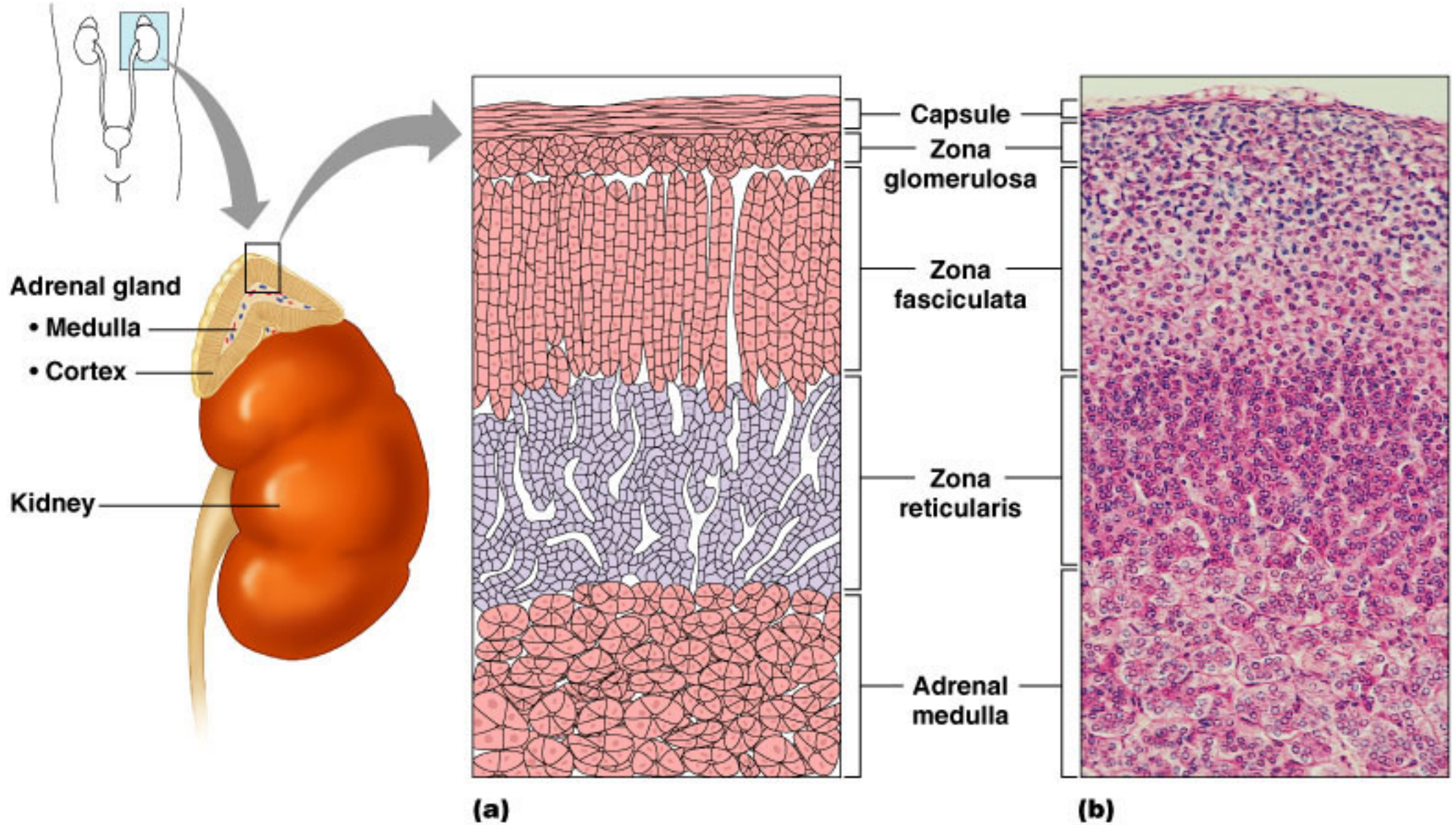
Please make cheque or money order payable to The Canadian Addison Society and send c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7

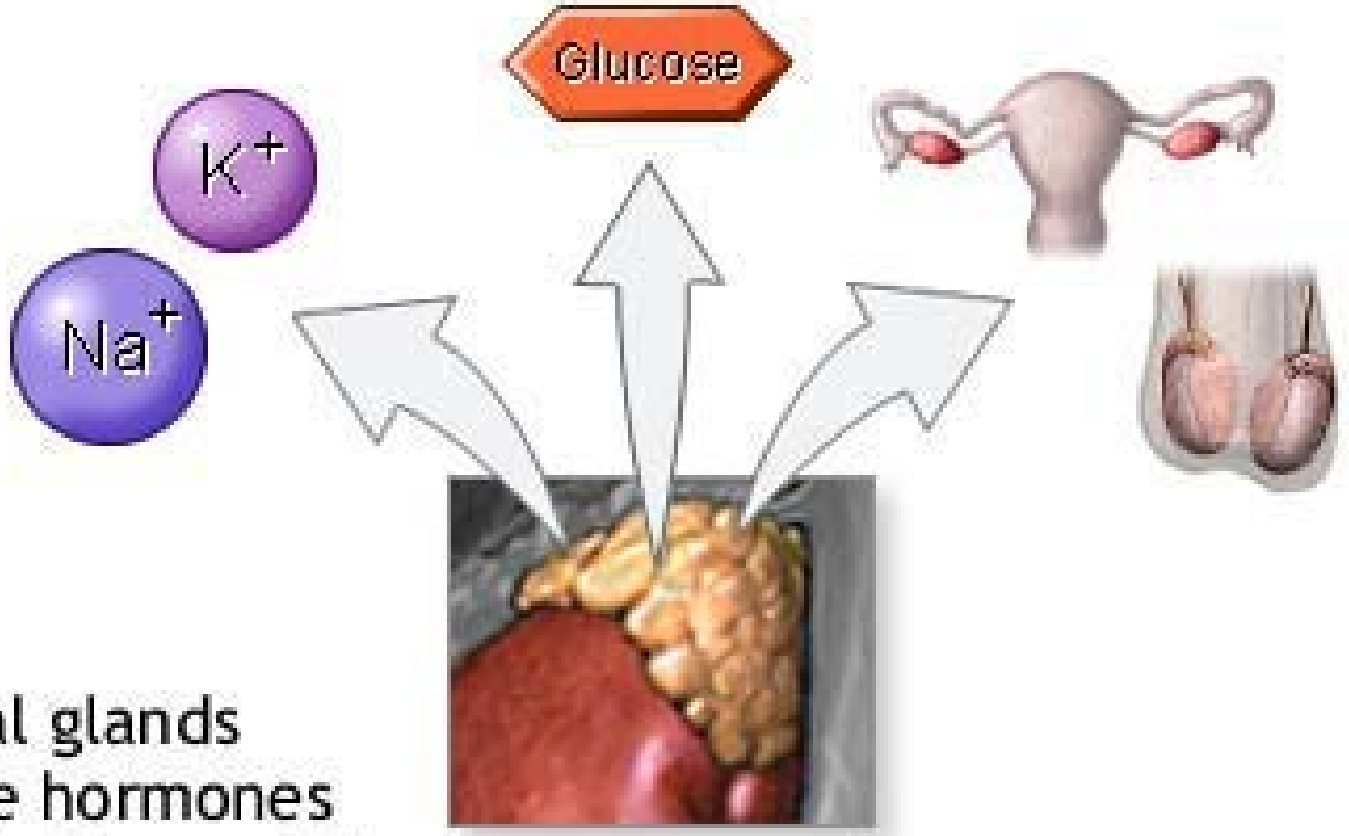
Revised: September 2007

Canadian Addison Society
September 2007

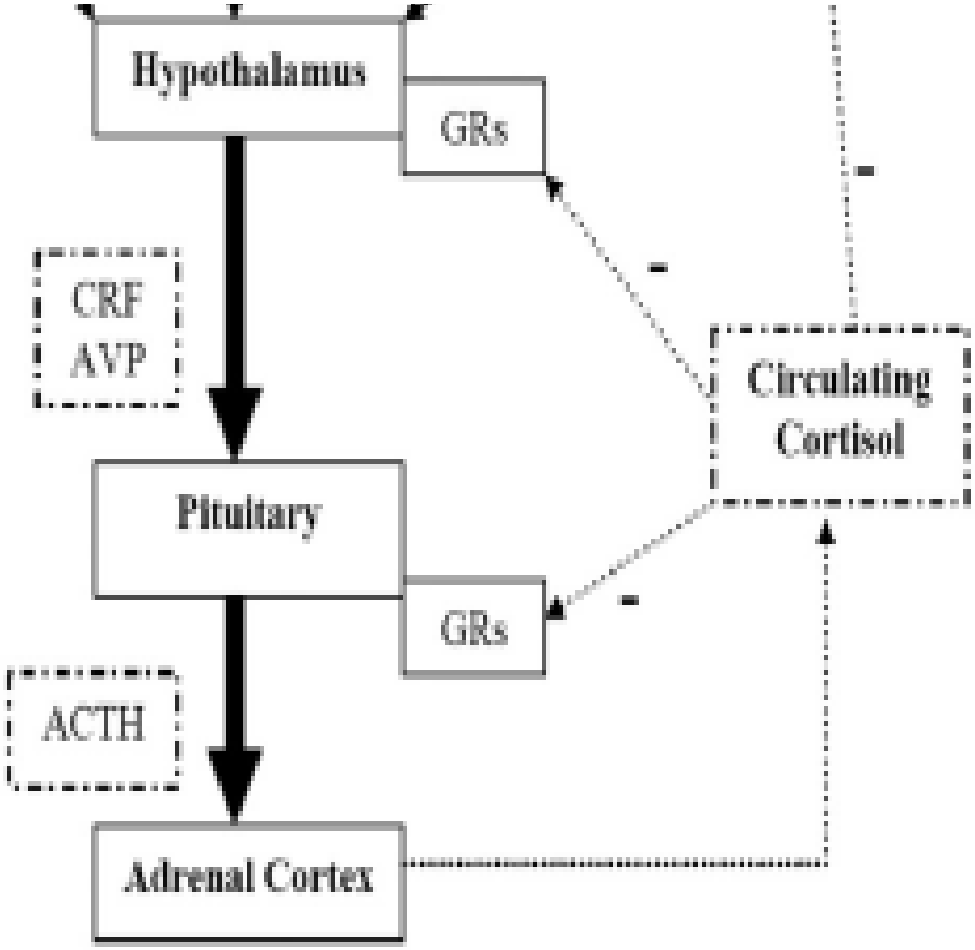
Stan Van Uum

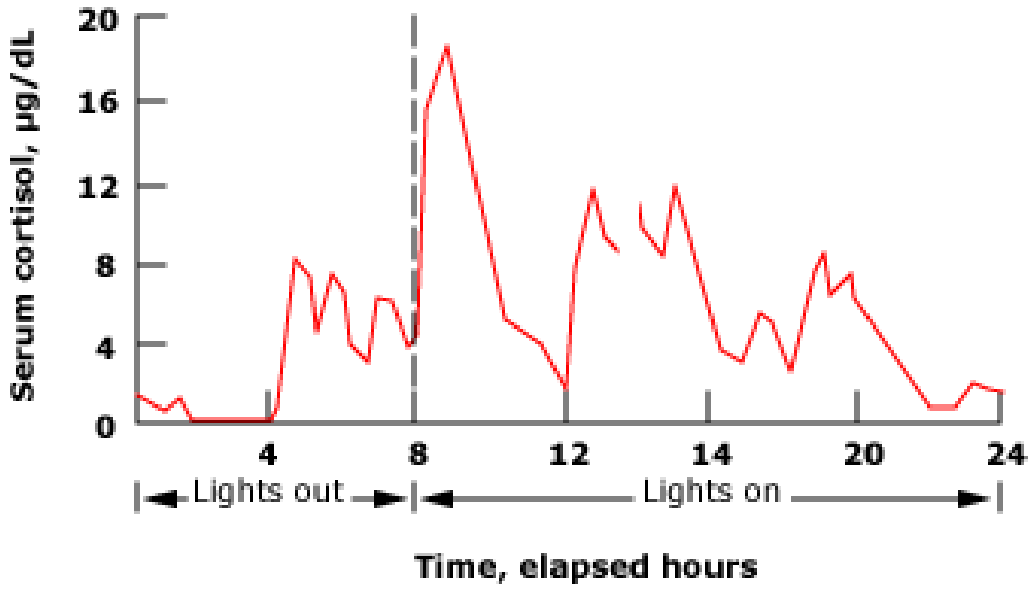

Pituitary gland
Thyroid and parathyroid glands
The endocrine glands secrete hormones which regulate various functions throughout the body
Adrenal glands
Pancreas
Testes (male)
Ovaries (female)
A.D.A.M.

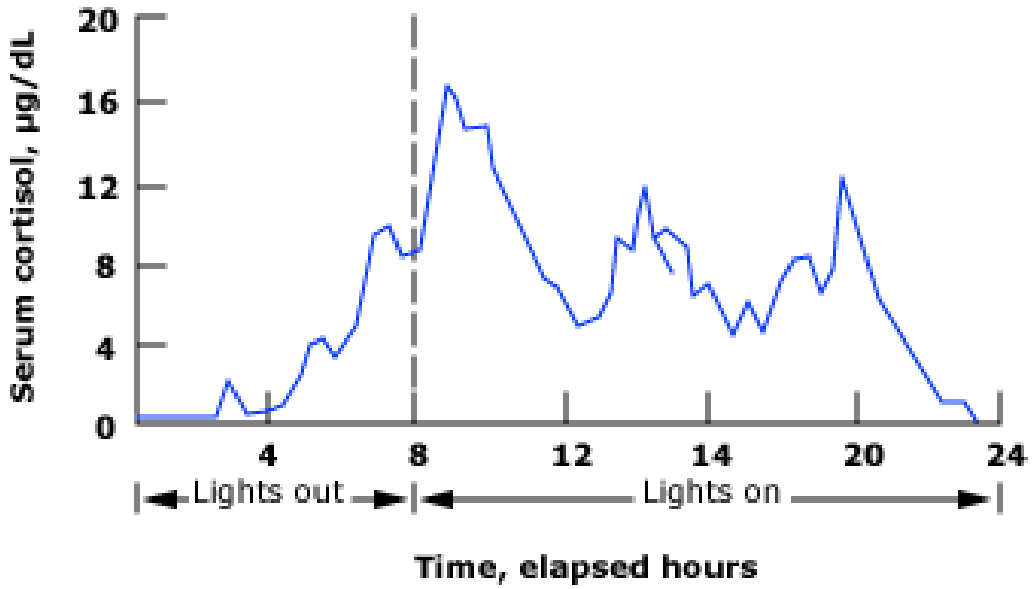




Adrenal glands secrete hormones which help regulate chemical balance, regulate metabolism and supplement other glands


Hypothalamus
GRs
CRF
AVP
Circulating
Cortisol
Pituitary
GRs
ACTH
Adrenal Cortex


Serum cortisol, µg/dL
20
16
12
8
4
0
4
8
12
14
20
24
Lights out
Lights on
Time, elapsed hours


Serum cortisol, µg/dL
20
16
12
8
4
0
4
8
12
14
20
24
Lights out
Lights on
Time, elapsed hours

Chronic Adrenal Insufficiency

Symptom	Frequency, percent
Weakness, tiredness, fatigue	100
Anorexia	100
Gastrointestinal symptoms	92
Nausea	86
Vomiting	75
Constipation	33
Abdominal pain	31
Diarrhea	16
Salt craving	16
Postural dizziness	12
Muscle or joint pains	6-13

Chronic Adrenal Insufficiency

Sign	
Weight loss	100
Hyperpigmentation	94
Hypotension (systolic BP <110 mmHg)	88-94
Vitiligo	10-20
Auricular calcification	5

Chronic Adrenal Insufficiency
Laboratory signs

Electrolyte disturbances	92
Hyponatremia	88
Hyperkalemia	64
Hypercalcemia	6
Azotemia	55
Anemia	40
Eosinophilia	17

Adrenal Crisis

Dehydration, hypotension, or shock out of proportion to severity of current illness
Nausea and vomiting with a history of weight loss and anorexia
Abdominal pain, so-called "acute abdomen"
Unexplained hypoglycemia
Unexplained fever
Hyponatremia, hyperkalemia, azotemia, hypercalcemia, or eosinophilia
Hyperpigmentation or vitiligo
Other autoimmune endocrine deficiencies, such as hypothyroidism or gonadal failure

Medications (relative strength of activity)

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

When to increase steroid dose?

- At time of surgery: injection/infusion

- Minor Febrile illness or stress
  - Increase glucocorticoid dose 2-3 fold for the few days of illness; do not increase florinef ("3 x 3 rule")
  - Contact physician if illness worsens for more than 3 days
  - No extra supplementation for most uncomplicated outpatient procedures

Emergency treatment of severe stress or trauma:

- Injection (dexamethasone 4 mg/ hydrocortisone 50-100 mg)
- Get to physician as quickly as possible

Adrenal Crisis - Treatment

In adrenal crisis, an intravenous or intramuscular injection of hydrocortisone (an injectable corticosteroid) must be given immediately. Supportive treatment of low blood pressure with intravenous fluids is usually necessary. Hospitalization is required for adequate treatment and monitoring. If infection is the cause of the crisis, antibiotic therapy may be needed.

New Developments (I)

- Hydrocortisone does not mimic normal dose; Prednisone and Dexamethasone may work for too long
- Development of Slow Release tablet, aiming to get more gradual absorption and thus better levels

New Developments (II)

- In general, the dose that is taken is higher than what healthy individuals produce.
- Uncertainty if this results in negative effects on health
- Variation between individuals.
- Try to decrease as tolerated

New Developments (III)

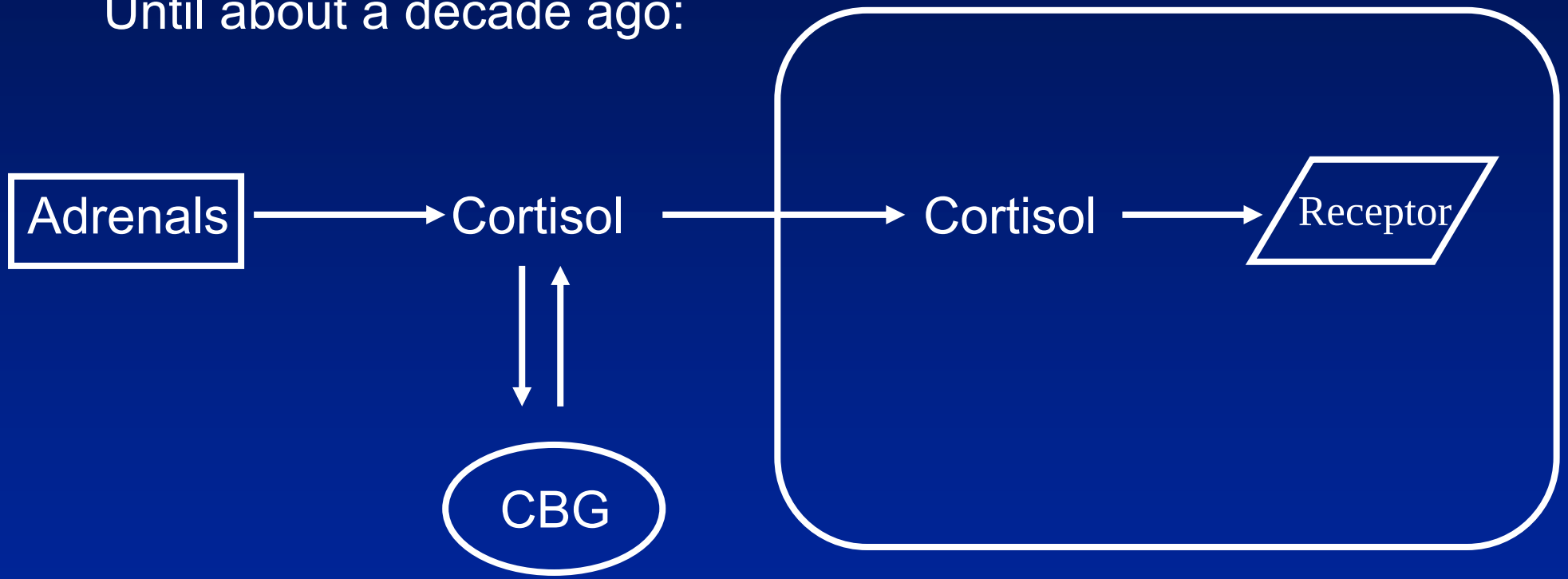
- Measurement of cortisol in hair
- Method to try to assess chronic cortisol levels.
- Will give additional information, not replace current measurements

Question 1:

- What is the difference between cortisol and cortisone, why is this ‘old-fashioned?
- Will taking licorice root extract help or hinder our immune system if we have Addison’s?

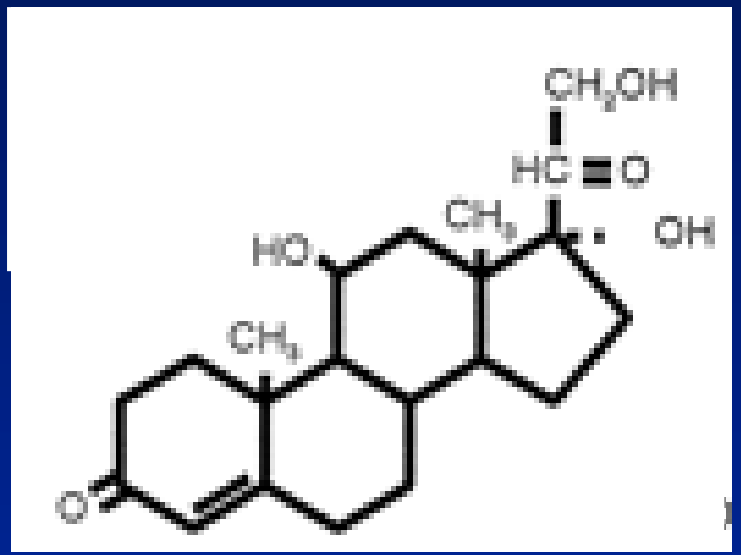
Corticosteroid action (classic view)

Until about a decade ago:

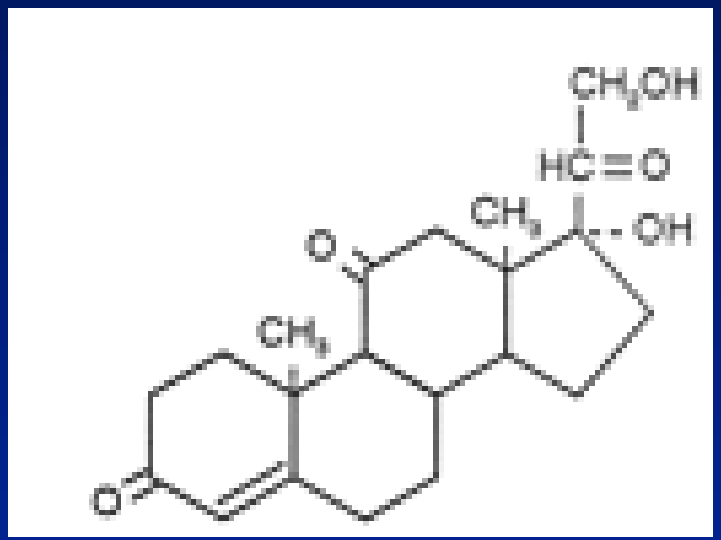


- Concentration hormone
- Receptor density
- Hormone – receptor binding specificity

11β-hydroxysteroid dehydrogenase (11β-HSD)



11β-HSD

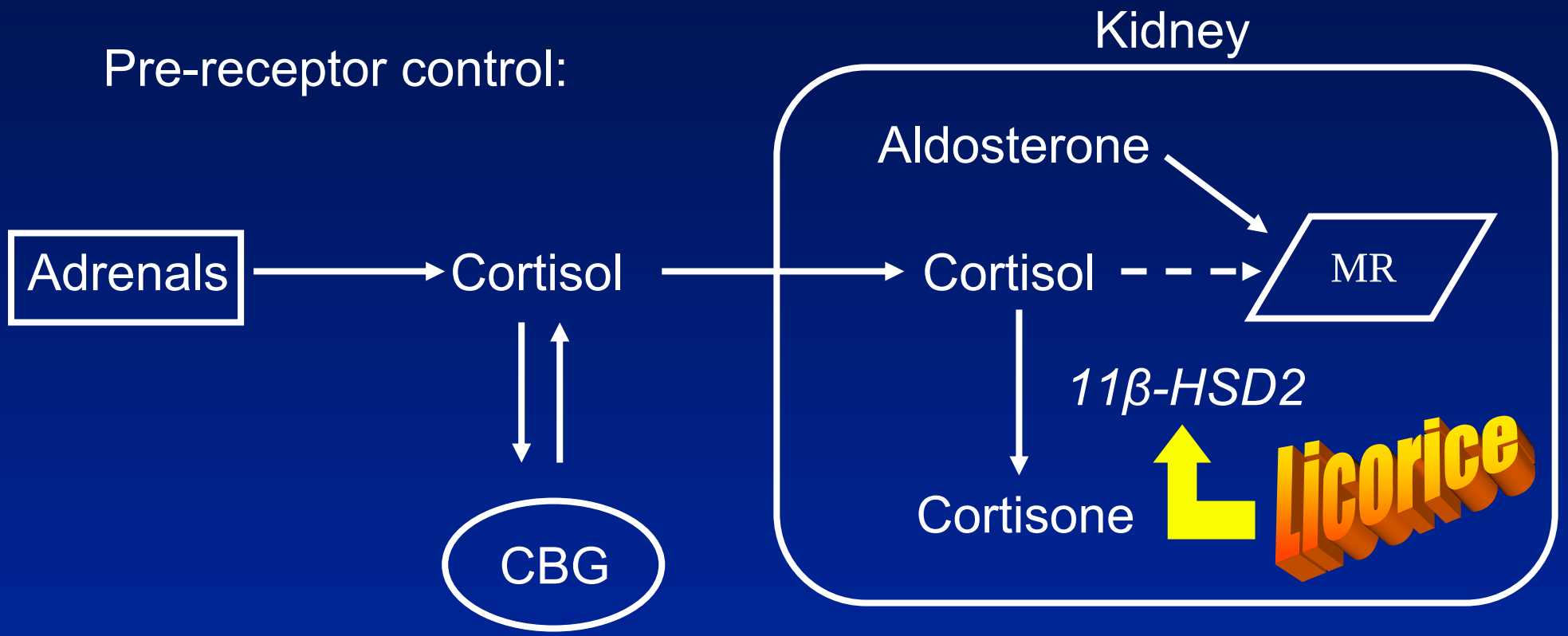


Cortisol

Cortisone

White et al,
J Hypertension
2000;18:241-8

11β-hydroxysteroid dehydrogenase



- Intracellular conversion
- Tissue specificity
- Mutations in 11β-HSD

- Glycyrrhetinic acid: inhibition
- Dexamethasone effect
- MR antagonist

Answer 1:

- Cortisone needs first to be converted to cortisol (=solucortef) before it is active. Only 80% is converted, therefore the slightly higher dose for cortisone
- Licorice will decrease the break-down of cortisol and make it more effective, causing a risk of a too high effect and high blood pressure. As the effect can vary between different amounts and types of licorice, it’s better to avoid this.

Question 2:

- What is the inheritance of Addison's / Congenital Adrenal Hyperplasia; Adrenoleukodystrophy?

Inheritance:

- Congenital Adrenal Hyperplasia -- autosomal recessive (need to receive the gene from two parents)
- Adrenoleucodystrophy ---- X linked recessive (sons may inherit from their mother, mother has no symptoms)
- Primary Addison ------ auto-immune tendency (quite a bit of variation in inheritance)

Question 3:

- What are the risks and benefits of taking extra doses when tired or stressed?

Answer 3:

- For occasional stress this is OK, very frequent extra doses can cause many side effects, including weight gain, higher blood pressure, osteoporosis and diabetes mellitus

Question 4:

- What are the benefits of timing of doses over the day?

Answer 4:

- For some patients this may help to mimic the normal cortisol rhythm over the day, but you'll have to remember to take the medication at multiple times

Question 5:

- How does cortisol interact with glucose/insulin?

Answer 5:

- Cortisol decreases the effect of insulin, less effect of insulin results in increase of blood sugars

Question 6:

- What are the possible risks involved for people with Addison's in taking echinacea, ginseng or other immune enhancing products?

Answer 6:

- Some of these products may change the metabolic breakdown of cortisol, and thus result in a change of the amount of cortisol working in your body. Some products may contain licorice and have the effects described above.

Question 7:

- One home ‘test’ for thyroid function involves taking the morning temperature immediately upon waking. If consistently below 97.6 it may indicate too low thyroid function. Can this also be because the morning cortef has not been taken?

Answer 7:

- Usually not, in fact, insufficient cortisol may sometimes results in mild increase in temperature

Question 8:

- Most Addisonians who have been treated successfully for deceased gradually develop high blood pressure. Is this a long term side-effect of Florinef? Is dietary salt intake, which is generally considered beneficial in Addison's, a probable cause? Should this be minimized?

Answer 8:

- Diet, salt and blood pressure need to be individually treated such that there are no symptoms from low blood pressure. In many people the blood pressure increases with age, and this may also happen if you have Addison

Polyglandular Auto-immune Syndrome type 1

Endocrine	
Hypoparathyroidism	89
Chronic mucocutaneous candidiasis	75
Adrenal insufficiency	60
Primary hypogonadism	45
Hypothyroidism	12
Type 1 diabetes mellitus	1
Hypopituitarism	<1
Diabetes insipidus	<1
Nonendocrine	
Malabsorption syndromes	25
Alopecia totalis or areata	20
Pernicious anemia	16
Chronic active hepatitis	9
Vitiligo	4

Polyglandular Auto-Immune Syndrome type 2

Endocrine	
Adrenal insufficiency	100
Autoimmune thyroid disease	70
Type 1 diabetes mellitus	50
Primary hypogonadism	5-50
Diabetes insipidus	<1
Nonendocrine	
Vitiligo	4
Alopecia, pernicious anemia, myasthenia gravis, immune thrombocytopenia purpura, Sjogren's syndrome, rheumatoid arthritis	1

Data from: Leshin, M, Am J Med Sci 1985; 290:77, and Neufeld, M, Maclaren, NK, Blizzard, RM, Medicine 1981; 60:355.

Adrenal Crisis – Risks if No Treatment

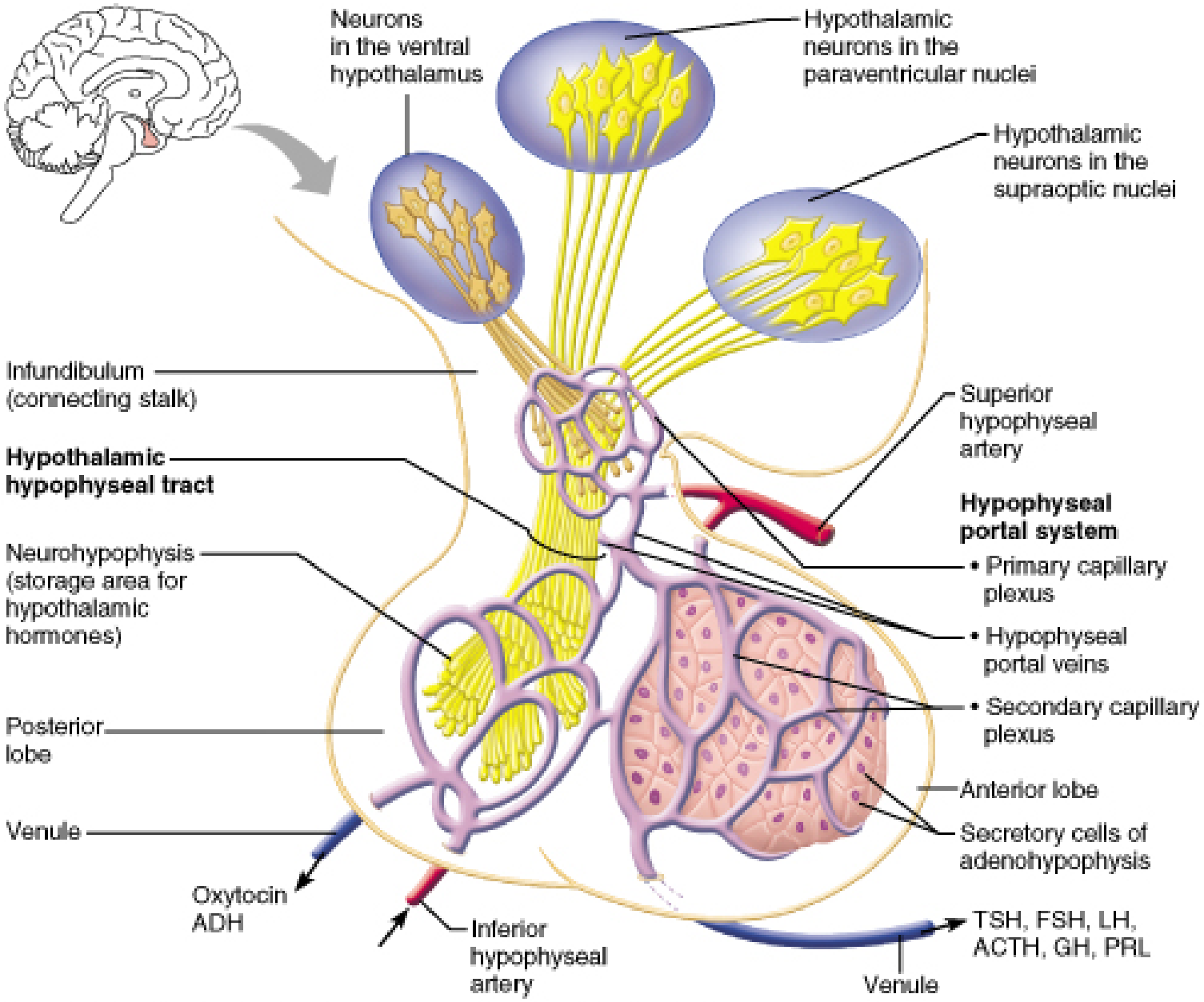
Death may occur due to overwhelming shock if early treatment is not provided.

Complications

shock

coma

seizures



Question 3 - PAIS type 1

Endocrine	
Hypoparathyroidism	89
Chronic mucocutaneous candidiasis	75
Adrenal insufficiency	60
Primary hypogonadism	45
Hypothyroidism	12
Type 1 diabetes mellitus	1
Hypopituitarism	<1
Diabetes insipidus	<1
Nonendocrine	
Malabsorption syndromes	25
Alopecia totalis or areata	20
Pernicious anemia	16
Chronic active hepatitis	9
Vitiligo	4