PUSTI

新加坡狼疮协会刊物

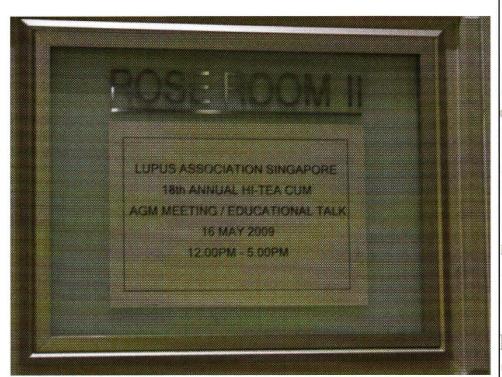
Issue 002/09

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A LUPUS ASSOCIATION (SINGAPORE) PUBLICATION

PAGE 1

LUPUS DIA



Our Annual General Meeting, Continuing Educational Talk and Anniversary Hi-Tea was held at York Hotel, Singapore on May 16th this year.

A new board of council members was successfully elected with Nancy Chin continuing to helm the board as our president and Dr Teng Gim Gee coming on board as our latest council member.

Our special thanks to Ms Ong Meng Hui, who had kindly sponsored us for the event. Your kindness and generosity is deeply appreciated.

The event started with the Educational Talk, 'Planning for a Family in Lupus' (Talk exerpts in Pages, 4-7) by our speakers, Dr Manjari Lahiri and Dr Cheng Yew Kuang.

That was followed by fun and games and even a magic performance to entertain the crowd.

All in all. It was a funfilled and enriching afternoon, with good food, good fun and good cheer. We look forward to our Anniversary Celebration next year.

CONTINUE ON PAGE 2

COUNCIL **MEMBERS**

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Nancy Chin Choy Hoong

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Dr Leong Keng Hong

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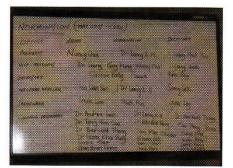
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CONTINUED FROM PAGE 1



Preparations! Volunteers helping with the door gifts.



The votes are IN!



Speakers- (From Left) Dr Manjari Lahiri & Dr Cheng Yew Kuang





Lucky Draw Winners. (From Left) Chan Suan Liang, Nancy Chin, Ms Ong Meng Hui



Entertain Us...



NEWS QUICKLY NEWS QUICKLY

TAI CHI

Tai chi chuan 太极拳 is an internal Chinese martial art often practiced for health reasons.



Come join us for Tai Chi every Wednesday, 2.00pm at Tan Tock Seng Medical Centre, Lupus Activity Room, #B2.

FUNDRAISING PROJECT



Want to share a scrumptious dish or a mouth-watering dessert with everyone? There is no better way than to contribute your secret recipes to a cookbook! Under the generous sponsorship of Ms Ong Meng Hui, the Lupus Association will be publishing a cookbook to raise funds.

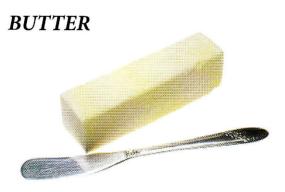
So hurry, just email your recipe to us at lupusas@ pacific.net.sg together with a photograph of your dish.

想要把美味可口的佳肴或令人垂涎三尺的甜品与大家分享吗?再好不过的方法就是献出烹饪秘方,再印刷成烹饪食谱.在王明晖女士慷慨赞助下,狼疮协会得以通出版烹饪食谱筹集基金.

故此,请大家将烹饪秘方及佳肴拍摄下来邮寄至(KIV lupusas@pacific.net.sg.

FUN FACTS FUN FACTS fun facts

For Your Information fun facts FUN FACTS



Butter is a dairy product made by churning fresh or fermented cream or milk. It is generally used as a spread and a condiment, as well as in cooking applications such as baking, sauce making, and frying. Butter consists of butterfat, water and milk proteins.

Most frequently made from cows' milk, butter can also be manufactured from the milk of other mammals, including sheep, goats, buffalo, and yaks. Salt, flavorings and preservatives are sometimes added to butter. Rendering butter produces clarified butter or ghee, which is almost entirely butterfat.

牛油

牛油属乳质品.应用新鲜,发酵奶油或牛奶搅制成. 一般用以涂搽食物或充当调味,也可用于烹煮.同时,可烘制蛋糕,制作酱料以及煎炸.牛油含有乳脂,水及牛奶的蛋白质.

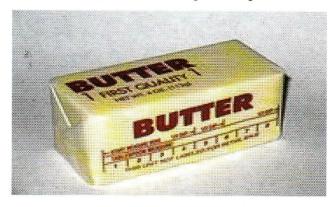
牛油通常是用牛奶制成的,但也可应用其他哺乳动物如:牛,羊,水牛,牦牛之乳.有时牛油也可加入盐,调味品和防腐剂.酥油乃属加工后的牛油.含有极高的乳脂.

牛油含有极高的饱和脂肪,同时,它也会使我们摄取高量胆固醇.故此,牛油一般上被认为会危害健康.特别是心脏病患者.过去一段时日,人们认为人造黄油不含饱和脂肪或含极低的胆固醇,甚至不含胆固醇,因而人造黄油成了牛油的替代品.近年来,人们发现人造黄油在制造过程中会形成反式脂肪.这种反式脂肪会促成大量LDL胆固醇.为此,人们研发不含反式脂肪之人造黄油.牛油只含少许乳糖,故此,对不容与乳糖者,只要有节制地摄食牛油,是不成大碍的.至于,乳糖过敏者就得避免摄食牛

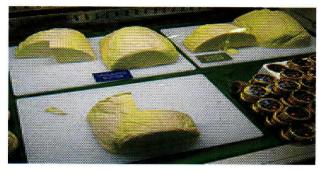
Butter consists mostly of saturated fat and is a significant source of dietary cholesterol. For these reasons, butter has been generally considered to be a contributor to health problems, especially heart disease. For many years, vegetable margarine was recommended as a substitute, since it is an unsaturated fat and contains little or no cholesterol. In recent decades, though, it has become accepted that the trans fats contained in partially hydrogenated oils used in typical margarines significantly raise undesirable LDL cholesterol levels as well. Trans-fat free margarines have since been developed.

Butter contains only traces of lactose, so moderate consumption of butter is not a problem for the lactose intolerant. People with milk allergies need to avoid butter, which contains enough of the allergy-causing proteins to cause reactions.

Butter can form a useful role in dieting by providing satiety. A small amount added to low fat foods such as vegetables may stave off feelings of hunger.



油,它会刺激过敏症.若将少许牛油加入低脂肪食物,如蔬菜类内摄食,能使你有饱和感,那么,你就不再感到饥饿.能帮助节食.



- Source: wikipedia.org

TALK IN REVIEW TALK IN REVIEW TALK REVIEW TALK

Planning for a Family

By Dr Manjari Lahiri (English) & Dr Cheng Yew Kuang (Chinese)



I have SLE? Can I have a Baby? YES, You Can!

Lupus is an autoimmune disease that affects women 9 times more than men. The most frequently affected age group is 15 to 40 years which corresponds to the child-bearing years. So obviously, a lot of questions come to mind about fertility, pregnancy and whether your child will get lupus. The following discussion aims to answer some of these questions, and hopefully clear some misconceptions.

Is Fertility Affected?

The simple answer is no. A person with lupus can conceive as easily as a healthy person. So even though you have lupus, there is no reason why you cannot have a baby! Hence it becomes even more important to understand the precautions that need to be taken to ensure a healthy outcome for both mother and baby.

Is Pregnancy outcome affected?

Yes, lupus pregnancies are considered high risk pregnancies. Becoming pregnant has implications both for how the disease affects you, and how it affects your baby. Lupus tends

to flare (get worse) in pregnancy, especially if it was not under control before you became pregnant. When the disease flares, apart from making the mother ill, it also increases the chance of the baby being born too small and weak, or born too early, or the baby may not survive.

So what can I do to prevent my lupus from flaring during pregnancy?

The most important thing is to time the pregnancy correctly. If your lupus is active in the 6 months prior to becoming pregnant, it predicts a poorer outcome. So the important thing is to time the pregnancy to happen when you feel well, and your disease has been under control for at least 6 months. This also means that your doctor plays an important role in advising you and your husband regarding the best time to conceive.

EFFECTIVE and SAFE contraception is available and should be used.

What are the effective methods of contraception that are safe?

It is important to use an effective and safe method of contraception to avoid a 'surprise' pregnancy at an inappropriate time. Barrier methods such as condoms, diaphragms and vaginal rings are safe. Some hormonal preparations which contain progesterone only (without estrogen) are also safe. These may be available as a long acting, reversible depot injection, an implant under the skin, or as a tablet (the mini pill) to be taken daily.



Effective & Safe contraception

CONTINUE ON PAGE 5

IN REVIEW REVIEW

TIMING the pregnancy to occur when the disease is not active for at least 6 months is crucial to ensuring a GOOD PREGNANCY outcome.

Common combination oral contraceptive pills which contain estrogen and progesterone ('the pill') may be safe for you if your disease is under control, and your blood does not have an abnormal tendency to clot. Use of 'the pill' should be after consultation with your doctor.

Is it safe to continue my medicines when I become pregnant?

Some medicines which you may be taking for lupus may be harmful in pregnancy. These need to be stopped at least 3 months prior to planning for pregnancy, in consultation with your doctor. Your doctor will usually substitute these medicines with those that are safe in pregnancy. Drugs which must be stopped are Methotrexate, Leflunomide (Arava®), Cyclophosphamide (Endoxan®), Mycophenolate mofetil (Cellcept® or Myfortic®), Warfarin, Enalapril and other drugs in its class, Losartan and other drugs in its class. However, some drugs are safe, and should be continued if necessary. These include Prednisolone, Hydroxychloroquine (Plaquenil®), Azathioprine (Immuran®) and Aspirin.



Drugs that need to be STOPPED

How else can I prepare for pregnancy?

Pregnancy outcomes are best with a healthy mind and a healthy body. Eat right, exercise regularly, de-stress and stop smoking. In addition, your doctor will usually start you on Folic acid supplements. If you are taking other supplements without prescription (including Traditional Chinese Medicine), you should inform your doctor, as some of these may be unsafe.

Are there any special blood tests that I must do?

Your doctor will usually test you for the presence of antiphospholipid antibodies. These antibodies pose a particular risk in pregnancy, and you may need to be monitored more carefully, or may even need to be on special medicines such as aspirin and blood thinner injections (e.g.Clexane®). You will also be tested for Anti-Ro and La antibodies. People with these antibodies need to be monitored more closely, with special ultrasound scans for the foetus.

Will my baby get lupus?

Though there is some familial tendency in lupus (e.g. you may have a relative with lupus), the risk of your baby getting it is probably less than 5%. Neonatal lupus (baby born with lupus like symptoms) occurs in 10-20% of the babies whose mothers have anti-Ro or La antibodies. This consists of temporary, self-limited skin rashes which go away after a few weeks to months. A small fraction of these babies (<1%) may have heart problems.

Patient education is key; KNOW your disease and KNOW your medicines.

What other precautions should I take while I'm pregnant?

Your best weapon against lupus is to educate yourself. Take charge of, and know

your disease, and take your medicine regularly. You know best the signs of an impending flare, so you can alert your doctor, who will then adjust your medicines. Some good educational websites to visit are www.arc.org.uk, www.rheumatology.org/public, www.lupus.org.

Is Hydroxycloroquine really safe? The package insert says otherwise.

Hydroxycloroquine (HCQ) deserves a special mention. It has been shown in several studies now that patients on HCQ flare less, and if they do, the flares are milder. These patients require less prednisolone in pregnancy. In addition there may be other beneficial effects for the mother such as protection against abnormal blood clots. The packagae insert is based on some harmful effects on animal data in the past, however harm to human pregnancies has not been shown, and HCQ is considered safe for the baby.

What happens after delivery?

The risk of a flare persists after delivery, for at least 6 months. So it is important to continue to be vigilant. In addition, your doctor may advise you not to breast feed your baby if you are on many medicines for your lupus. Low to moderate doses of Prednisolone are safe for breast feeding.



讲座回顾讲座回游客回游客

红斑狼疮病患之家庭计划

By Dr Manjari Lahiri (English) & Dr Cheng Yew Kuang (Chinese)



我是红斑狼疮患者。我可以怀孕生孩子吗?你可以!

红斑狼疮是一种自身免疫性疾病, 患病机率女性比男性超出9倍. 通常15至40岁之间的女性是高危险性的族群, 此年龄阶层之女性正处生育期. 故此, 受精机率, 能否怀与孕, 胎儿是否会有遗传等问题自然地出现在人们的脑海中. 以下之审议希望能解答出现在人们脑海中的问题, 同时也希望能纠正人们的误解.

会影响怀孕吗?

简单的答案是不会. 狼疮病患能与正常人一样容易受精, 因此, 狼疮病患没有理由不能拥有自己的孩子. 为了确保孕妇与胎儿的健康, 故此, 明白一系列的预防措施是甚重要的.

可否影响怀孕结果?

会的. 狼疮病患怀孕属高风险. 怀孕会牵连病症影响母体与胎儿. 怀孕会导致狼疮病症病情加重, 特别

是在病情未受控制时怀孕. 当病情突发时,除了会使母亲病倒以外,也会使胎儿长得小又弱,或早产或夭折.

那么我应该怎么做,才能避免怀孕期狼疮病症突发?

最重要的是怀孕要有计划,要逢时,若在狼疮病症频密发作期间之6个月内怀孕,预料将不会有好结果.故此,在身体状况较佳之时怀孕是很重要的,同时,病症要受控制至少6个月.这也意味着医生在这个生育计划中扮演重要角色,你与丈夫得向医生咨询最佳受孕期.

什么节育方法是最有效又安全的?

最重要的是要有计划,不能有

有效及安全 的避孕方法 是存在的,必须运用。 "惊喜",避免在不恰当的情况下怀孕,安全的方法就是使用安全套,子宫帽及阴道环.某些荷尔蒙药物只含黄体酮(不含estrogen)也属安全.皮下植入的药物,植入后可耐一段相当长时日,也可随时去除.或每日口服的药丸(微型片剂).当病情受控及没有血栓之下,一般含有雌激素及黄体酮之口服药丸也许是安全的.服药之前必须向医生咨询.



Effective & Safe contraception

CONTINUE ON PAGE 7

讲座图游座讲座回顾

确保有良好怀孕结果, 在紅斑狼疮病症不活跃 至少6个月后, 才计划怀孕是好时机。

怀孕期间继续服食药物是否安全? 有些药物狼疮病患得服食,但此药 物不利于身孕. 此种药物在计划生 育之前3个月就得停止服食,必须 向医生咨询. 你的医生通常会更 换适合孕妇服食的药物. 必须停止 服食类似Methotrexate, Leflunomide (Arava®), Cyclophosphamide (Endoxan®), Mycophenolate mofetil (Cellcept® or Myfortic®), Warfarin, Enalapril 之药物. Losartan之类的药物也不宜服食. 然而,有些药物是安全的,必要时 可以继续服食. 其中包括 Prednisolone, Hydroxychloroguine (Plaquenil®), Azathioprine (Immuran®) and Aspirin.

还有那一些需要为怀孕而准备的? 怀孕最佳结果是有开朗的心情及健康

的身体. 吃得健康, 定期运动, 无压力, 停止吸烟. 另外, 你的医生通常让你开始服食叶酸(Folic acid) 之补充品. 要是你服食不是医生处方上所开的补给品(包括传统中药), 你必须通知医生, 此类药物有些不能安全服食.



必须停止服用的药物

我是否得做些特别血液检验?

你的医生通常会检验你的血液, 看血液里是否含有

antiphospholipid antibodies.怀孕期间这些抗体可能会呈现风险,你必须谨慎观察,或许你需要服用特别药物如阿斯匹林和注射使血液稀薄之类的药物(例如Clexane). 你也必须接受Anti-Ro及Lo 抗体之检测. 有此抗体必须密切检测,并配合超声波扫描胚胎.

我的胎儿是否也会患上红斑狼疮之病症?

尽管红斑狼疮有家族倾向(例如,也许你有亲戚患有红斑狼疮之病症),婴孩患有红斑狼疮病症之风险低于5%. Neonatal lupus(婴孩有红斑狼疮的症状)凡是含有anti-Ro或La 抗体的母亲,其所产下的婴孩10-20%会有红斑狼疮的症状. 这种症状属暂时性,皮疹在几个星期至一个月后就会消失. 一小部分此类型的婴孩(<1%)可能会有心脏问题.

当我怀孕时还有那些预防措施 得注意的?

对付红斑狼疮最佳武器就是自 我培训,增广这方面的知识.自 律,了解自己的病态,定时服药. 当病症即将发作时,你是最先感 应到症兆的,此时就必须警示医 生,好让医生调整药物.一些能

教育病人有正确的知识, 让病人了解自己的病情, 认识所服食的药物是重要的.

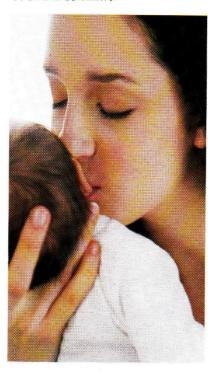
够提供良好知识的网页, 如 www.arc.org.uk, www.rheumatology.org/public, www.lupus.org

Hydroxychloroquine 是否真的安全? 包装里的说明书却是否定的.

Hydroxycloroquine (HCQ)是值得特别谈论的. 时至今日,好几起研究中显示,服用HCQ的病人病情减少发作,即使病情再度发作也有相对地减轻. 服用HCQ的这群病人在怀孕时需要服用较少的prednisolone. 除此之外,它也可能对母体还有其他的好处,诸如保护母体免遭不正常血栓的入侵. 包装内的说明书是基于过去的论据,认为此药物对动物有害,然而,对孕妇的伤害却至今未见到,HCQ对婴孩算是安全的.

生产后会有何后果?

生产后病情发作的风险会持续至少6个月.故此,继续提高警戒是很重要的.此外,倘若你得服食多种红斑狼疮之药物,医生也许会建议你别以母乳喂养婴孩.服食低分量至适度分量的Prednisolone的母亲,以母乳喂养婴孩是安全的.



Issue 002/09

FYI FYI FY FYI FYI FOR Your Information For Your Information



A LUPUS ASSOCIATION (SINGAPORE) PUBLICATION

"Tve realised that completing a race is meaningles if I am doing it only for myself."
- Salam Ismail.

Salam is dedicating his attempt at the NorthFace 100 in memory of his fiancé (Saidah,formerly Customer Service Officer at Fitness First Platinum, OUB Centre) and to raise awareness for Lupus.

For Salam, fitness and running races have been part of most of his life, having been a personal trainer for 6 years and having run many races, triathlons, marathons. This year, the NorthFace100 had a very special meaning for him as he is dedicating his run to his fiancé who succumbed to a long battle with lupus earlier this year.

Lupus is an autoimmune disease where the body's immune system develops antibodies that attack healthy tissues (auto) instead of fighting against bacteria and viruses. The immune system attacks the body's organs, failing to recognize the tissues as its own. Any organ can be affect including the skin, joints, kidneys, lungs, brain, gut, blood system and blood vessels. Patients may be severe enough to require kidney dialysis and some die if the illness is not well controlled.

Not many people know about this disease and Salam's attempt at the NorthFace 100 was to help raise awareness for lupus and get more people

interested in assisting the Lupus Association of Singapore with funding for their programs which include raising awareness of the illness, acting on patients' behalf eg. in getting lupus recognized by insurance companies, increasing physician knowledge about lupus, patient care and also promoting research about the illness and treatment.

Lupus affects an estimated 4,000 patients in Singapore, about the same number as leukemia. The cause of lupus is still unknown and treatments can be very expensive. Despite intensive research, there is no cure for lupus but there is medication that patients can take throughout their lives to help treat symptoms and suppress an "over-active" immune system to prevent it from attacking the vital organs in the body.

If you would like to support Salam's cause, please send your donation via cross Cheque payable to "LUPUS ASSOCIATION (SINGAPORE)" and mail it to: *Balestier Estate P.O. Box 460, (S)913202.* Please indicate "for Salam's NorthFace 100" behind the Cheque.

Send Salam notes of encouragement and track his progress on Facebook at Fitness First's fan page by searching for "Fitness First Singapore Community Group" on Facebook.