



Lupus Link

新加坡狼疮协会刊物



Belly Dance with Love 充满爱的肚皮舞

By Ms Irene Lim 新加坡狼疮协会主席

In February, I received a call from Ms Angelina Tay who introduced herself as a Belly Dancer and teacher. She informed me that she was organizing an event to mark International Women's Day on 8 March. As she had students and friends who had lupus, and since lupus affects mainly women, she felt it apt to use the event to support Lupus Association (Singapore). I was, of course, thrilled by the idea! LAS relies solely on donations for our activities so any contribution is welcomed with open arms. The dinner event was held at the exotic Middle Eastern restaurant ANAR, Resorts World Sentosa where Angelina performs on Saturday nights. The venue was beautiful and the food superb. The Flying Dutchman, Mark Van Cluylenburg was the perfect host for the evening. I was amazed at how enthusiastic both the belly and hula dancers were in helping our association. They danced with zeal and passion and it was really fun watching them. Cookies baked by Angelina's aunt, a diabetic who is visually impaired, sold like 'hot cakes'. Pretty flower hairclips made by Ms Namiko Chan, a hula-dance Teacher, were snapped up by the dinner guests. Belly dance costumes donated by Ms Claribel Ng, also a Belly dance teacher, and her friends were put up for auction. Numerous donations, both corporate and personal, were received. All monies collected that night went to LAS. I am heartened and impressed by Angelina and her friends for their magnanimous input towards LAS and I hope that more people with the capacity to contribute to LAS would step forward and help the association fulfil its role and goals in patient support.

在今年二月，Ms Angelina Tay 打电话给我。她说明自己是位肚皮舞舞蹈老师，也告诉我她将会举办活动庆祝三八妇女节。由于她认识患有狼疮的学生和朋友，而且狼疮也主要影响妇女，她觉得举办活动，支持狼疮协会再好不过了。我当然非常兴奋！狼疮协会主要靠慈善捐助来举办活动的，因此我们欢迎任何捐助。那晚的晚会在圣淘沙名胜世界的一间复古的中东餐厅举行。那也是Angelina在星期六表演的场所。场地非常美丽，食物也很棒。The Flying Dutchman, Mark Van Cluylenburg是当晚的主持人。我看见肚皮舞舞蹈者和呼啦舞者热烈支持狼疮协会，很惊讶。她们跳舞很投入，观看表演真的是件乐事。Angelina的阿姨，一个有视觉障碍的糖尿病人，烘烤的饼干很销。Ms Namiko Chan，一个呼啦舞者，制作的花饰发夹销量也很好。Ms Claribel Ng Chan，一个肚皮舞舞蹈老师，和她的朋友捐助的肚皮舞服饰也供大家投标。当晚，我们收到了许多私人和组织捐款。全额都将捐给狼疮协会。我很高兴并佩服 Angelina 及她的朋友对狼疮协会的付出与贡献，也希望未来有更多行有余力的人能为狼疮协会贡献一份绵力，帮助狼疮协会和病人。

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Lupus and the Eye

红斑狼疮与眼睛



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Eye symptoms in lupus are fairly common. They may be due to lupus or the drugs used to treat it, and if severe can cause problems with vision. Any part of the eye can be affected by lupus.

Dry Eyes (Keratoconjunctivitis sicca) Dry eyes are the most common symptom experienced by patients with SLE. Eyes feel tired or gritty, and there may be redness or blurring of vision especially after prolonged near work. Dry eyes may be due to Sjogren's syndrome. The diagnosis of dry eyes is made using a painless test that measures tear production (Schirmer's test). The main treatment for dry eyes is using tear substitute eye drops. In severe cases, antibiotic and anti-inflammatory eye drops may be necessary.

Other Causes of Red eyes in Lupus

- **Conjunctivitis:** inflammation of the clear layer covering the eye. It may be mistaken for "sore eyes". This is treated with topical steroids
- **Episcleritis:** inflammation of the middle layer covering the eye. It is usually not painful. This may resolve by itself or require topical steroids.
- **Scleritis:** inflammation of the deepest layer covering the eye. It causes pain and headache, eye redness and affects vision. This condition requires early medical attention. Treatment includes systemic corticosteroids.
- **Iritis:** inflammation of the anterior structures of the eye. It causes painful red eyes, blurred vision and floaters. Urgent medical consult is needed. Therapy is topical steroids in mild cases but systemic steroids may be required in severe cases.

Retinal vessel disease in SLE

Retinal vessel disease presents with varying degrees of visual loss. Severe disease is more commonly associated with antiphospholipid syndrome. The blood vessels may be inflamed or blocked and cause the cells in the retina to die. This is a severe condition reflecting active lupus and needs to be treated with immunosuppressants. Sometimes, laser treatment may be required.

SLE and the nerves of the eye

Lupus can affect the nerve of the eye known as the optic nerve and present with painless loss of vision. The nerves controlling the muscle movements of the eye may also be affected resulting in double vision with the sudden onset of squints. These are serious symptoms and require urgent treatment

Ocular manifestation secondary to therapy for lupus

Drugs that are used to treat lupus may have side effects affecting vision. Some conditions include cataracts and glaucoma (rise in pressure within the eye) with steroid use and eye infections with immunosuppressants. An important side effect of hydroxychloroquine (Plaquenil) is loss of colour vision and problems with central vision. Patients on plaquenil require regular eye screening by their ophthalmologist to pick this up early.

Take Home Message

Eye damage in lupus may occur from the disease or its treatment. Fortunately blindness is uncommon. Key symptoms to worry about include

1. very painful red eyes
2. double vision and the sudden appearance of squints
3. blurring of vision (in particular loss of central vision and when lines appear wavy)

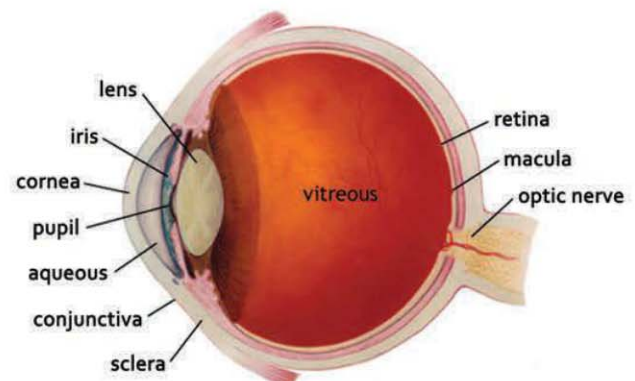
It is important to alert your rheumatologist if these occur. Your rheumatologist and ophthalmologist will work hand in hand to ensure you get the best care.

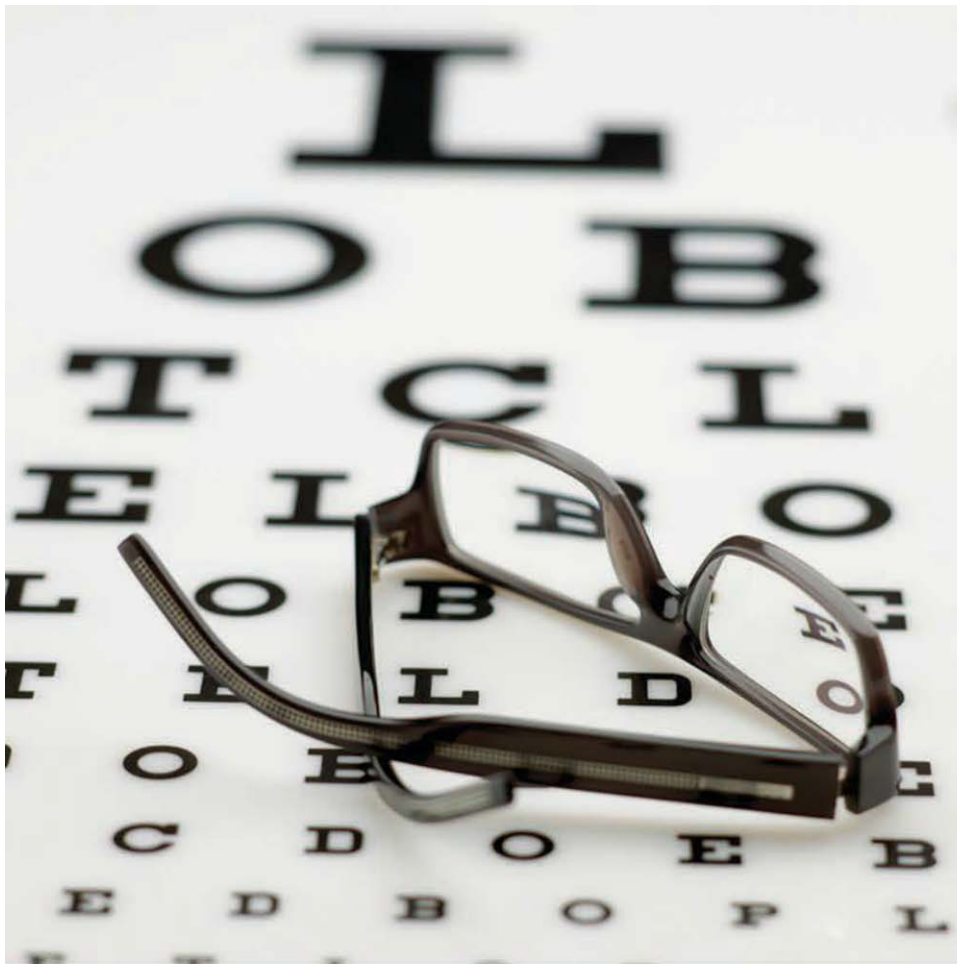
Dr Anita Chan, 顾问,
白内障和综合眼科,
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在狼疮患者中，眼睛问题极为普遍。它们可能是由狼疮或则治疗狼疮的药物所造成的。狼疮可能会影响眼睛的任何部位。

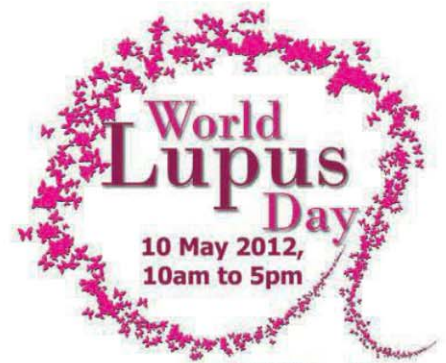
干眼症 (Keratoconjunctivitis sicca)

狼疮病患容易觉得眼部干燥，疲惫，红肿或视线模糊，尤其是长时间工作者。干眼症也可能是由干燥综合症 (Sjogren's syndrome) 所导致的。干眼症的检验过程是通过 (Schirmer's test) 测量眼泪的分泌量水平。它是个无痛的过程。干眼症的主要治疗方法是使用人工泪液眼药水。如果情况严重，或许需要使用消炎药水。





Events coming up...



Exhibition: Atrium

DVD Screening: Theatrette

Tan Tock Seng Hospital (Level 1)

1 World Lupus Day is celebrated on 10 May every year, all over the globe. In celebration of it, LAS will be screening a DVD entitled "Lupus - The Disease of a Thousand Faces" in the Theatrette, Level 1, Tan Tock Seng Hospital (TTSH). 3 SLE overcomers will be sharing their respective journey with lupus and how they have managed to brave the disease and lead life with a more positive outlook than ever. A/Prof Leong Keng Hong will also be sharing valuable advice on how to manage lupus, and that it is possible for a lupus patient to lead a healthy lifestyle just like any other. Information about SLE will be available at the booths at the Atrium, Level 1, TTSH; gifts hand made by volunteers will also be available for purchase - the funds in which will go to helping lupus patients in need of financial aid.



LAS Talk

"Skin problems and skin care in Lupus" by Dr Derrick Aw.

19th May 2012

SGH Deck on 9

12.30-4pm

Join us for an afternoon of enrichment, sharing and food!

导致红眼症的其他因素

- 结膜炎, 俗称红眼症 (Conjunctivitis): 覆盖眼睛的部分发炎。它常被人误以为是“眼肿”。它的治疗方法是使用类固醇(steroids)。
- 巩膜外层炎 (Episcleritis): 覆盖眼睛中层的部分发炎。它通常是无痛的。它的治疗方法是使用类固醇(steroids)。
- 巩膜炎 (Scleritis): 覆盖眼睛的最深层发炎。它会导致疼痛、头疼、眼红及视力模糊。这种情况需要及早治疗, 治疗包括使用皮质类固醇 (systemic corticosteroids)。
- 虹膜炎(Iritis): 眼睛的虹膜发炎。它会导致红肿眼睛、视力模糊和飞蚊症。患者必须接受紧急治疗。轻微情况使用一般类固醇 (topical steroids) 治疗, 严重的情况则需要使用内吸收的类固醇 (systemic steroids)。

视网膜疾病

视网膜疾病可能导致不同程度的视力模糊及丧失。严重的疾病通常和抗磷脂综合征 (antiphospholipid syndrome) 有关系。眼睛血管或许发炎会阻塞, 使视网膜细胞死亡。这是个严重的情况, 表示狼疮复发, 需要用免疫抑制药(immunosuppressants) 治疗。有时, 也需要用激光治疗。

眼部神经细胞

狼疮可能影响眼部神经细胞, 也称之为视神经(optic nerve)。其视力丧失的过程是无疼痛的。它也可能导致双从视线及突然的眼睛斜视。(double vision with the sudden onset of squints) 这些都是严重的症状, 需要紧急治疗。

治疗狼疮的药物导致的视网膜疾病

治疗狼疮的药物可能有副作用, 会影响视力。使用类固醇 (steroids) 和需要用免疫抑制药物(immunosuppressants) 可能导致白内障(cataracts) 和青光眼 (glaucoma: rise in pressure within the eye)。Hydroxychloroquine (Plaquenil) 可能导致色盲和视力问题。因此, 服用此药物的患者需要定期作眼睛检查, 趁早治疗。

总结

狼疮眼部问题可能是由狼疮或治疗狼疮的药物导致的。幸运的是, 失明极为罕见。

需要留意症状包括

1. 非常疼痛的红眼
2. 双从视线及突然的眼睛斜视
3. 视力模糊, 尤其是中央视力模糊和横线呈现波浪形状

如果出现以上症状, 请立刻通知医生。您的风湿部医生和眼科医生会一同合作, 确保您得到妥当的治疗。

My Lupus Story

我的狼疮经历

Mdm Anna Lim

It all began with a rash on my cheeks. Just dry skin, I thought to myself, no big deal. Then came the low-grade fevers that weren't bad enough to keep me away from work but wore me down. Some aches in my joints, but my husband could not do without the air-conditioning at night and I figured rheumatism came with age. Well, I guessed wrong.

My wake-up call came on my son's first trip to the beach. We had loads of fun in the sun but when we got home my body started itching, I had hives and my cheeks were really red. I decided to make a trip to the family clinic to grab some anti-histamine.

I saw the GP quickly but instead of sending me away with anti-histamines, he asked me "Do you have joint pains?" His next question was "How long have you had that rash on your face?" He then asked, "Have you heard of SLE?" I was tempted to tell him uh... that's one of our expressways isn't it? But somehow I felt this wasn't the time or place to joke, so I shook my head. He explained that SLE stands for systemic lupus erythematosus or lupus. A condition where the immune system goes haywire and antibodies get a go at all cells; be they good or bad. I was asked to get some blood tests done and to return a week later for my results.

It was a terrible week waiting it out. As it turned out, my ANA was positive and the doctor arranged for me to see a rheumatologist the following week. The first doctor I saw didn't think it was lupus. Perhaps the rash had gotten better by then and the hair loss could be due to stress. He gave me an appointment to return in 6 months, but my symptoms got so bad I couldn't hold a pen some days and I decided to get a second opinion. Another round of blood tests were done, and the results confirmed what I dreaded. I did indeed have lupus.

The doctor went on to explain that there wasn't a cure but with the right treatment lupus can be controlled and I could lead a normal life, albeit with a few adjustments. And so my life with lupus started. I was put on a high dose of prednisolone, which helped suppress the antibodies so that they wouldn't go "chomping" all my healthy tissues. I was given painkillers for my joint pain and an anti-malarial to reduce inflammation and control rashes. After 6 months I felt better; my joints didn't hurt as much and I wasn't as tired.

That was when I made the biggest mistake ever. I stopped taking my steroids. I went to work one morning and a colleague told me that my face was really red. I peeked in a mirror and for sure, even my ears were red! I jumped into a taxi to head to my rheumatologist's clinic, but en route I felt feverish and my eyes became bloodshot. By the time I reached the clinic my temperature was 40°C and I was so weak I had to be pushed in a wheelchair. I was diagnosed with a lupus flare and had to stay in hospital for almost a week and receive steroids by drip. That was one experience that I would never want to go through again, it took me almost 2 years to get my steroids back to the dose it was before the flare.

Fortunately, after some years I went into remission. It was then that I started considering having another child. My rheumatologist was supportive and explained that I could as long as I was closely monitored by her and an obstetrician who was experienced in dealing with high risk pregnancies. We thought we'd leave it to fate but I did get pregnant. The first few months were worrying because of the risk of miscarriages but all went well. Haeley turned out to be a huge baby by any standards. She was a month early and weighed a hefty 4.2kg! She's now 5 years old. Healthy, active and not afraid to speak her mind.

I've have been very lucky to have friends and family who have stood by me and been a pillar of strength throughout this period. My bosses and colleagues have been great (I am still working full time) and understanding. So that's my story. It's been close to 10 years since I was diagnosed with lupus. I am writing this to shout out to all those diagnosed with lupus that with proper care, treatment and support, you CAN lead a normal life. I am living proof to that.





“这就是我的故事... 希望能给大家了解狼疮患者只要有适当治疗和支持, 仍然能过常人生活。我就是活生生的证明。”

起初我的脸颊稍微敏感, 出疹。当时, 我心想这不过是干性皮肤的现象, 小事一件。之后, 我陆陆续续发烧, 虽然能继续工作, 但是体力不支。此外, 我的关节有些疼痛, 可是我的先生晚上习惯开冷气睡觉, 而且我也认为关节问题是年龄老化的问题, 所以我不怎么在意。但是, 我猜测错了。

我第一次感觉自己患上狼疮的时候是在和儿子第一次去海边。当时, 我们玩得很开心, 但是一回到家, 我全身出疹, 脸颊发红。当时, 我决定去看家庭医生, 拿一些抗组织胺药物(anti-histamine)。

我很快见到医生, 但他并没有给我拿一些抗组织胺药物(anti-histamine), 而是问我是否有关节疼痛, 接着, 他又问我脸颊出疹多久了。之后, 他问我是否听过红斑狼疮。我当下很想说“uh”。但是觉得场合不对, 便摇了摇头。医生向我解释说红斑狼疮是自体免疫性疾病, 体内的免疫系统会出问题。他也吩咐我做血液检查, 一个星期后拿检查报告。

那一周十分痛苦难熬。结果出来了, 是阳性反应。医生便安排我下周看风湿

部门的医生。我见到的第一个医生不觉得我得了狼疮。或许当时皮疹好了些, 而或许脱发是压力所致。医生吩咐我半年后再就医, 但是还没到预约时间, 我的病情恶化, 有时甚至不能握笔写字。因此, 我决定征询另一名医生。我又再次作了血液检查, 结果证实我的恐惧, 我的确患上狼疮。医生接着解释狼疮患者不能痊愈, 但是只要有适当治疗, 便能过常人生活。

就这样, 我开始了与狼疮共处的经历。我服用大量泼尼松龙(prednisolone), 它们是用来抑制抗体(antibodies), 让我的健康细胞能存活。我也服用止痛药来减轻关节疼痛和抗疟药(anti-malarial)控制皮疹和消炎。半年后, 我的情况好转, 关节没有那么疼痛, 也不如以前容易疲倦了。

就在当时, 我犯下最大的错误 - 停止服用类固醇(steriods)。隔天, 我的同事告诉我我的脸颊发红。之后, 我发现不仅仅是我的脸颊发红, 耳朵甚至也发红。因此, 我马上搭德士去风湿科。

在途中, 我开始发烧, 眼睛布满血丝。我抵达医院时, 体温已是40度。我非常

虚弱, 得坐轮椅。医生诊断我狼疮复发, 必须住院一周左右, 通过打点滴注射类固醇(steriods)。当时我花了近两年的时间才恢复到病发前的类固醇(steriods)水平, 我再也不想再经历第二次类似的经验了。

幸运的是, 过几年后, 我的病情稳定。那时, 我开始考虑生育。我的风湿部门医生非常支持我, 并解释只要定期复诊并且和熟悉高风险怀孕例子的妇产科医生商量就行了。原本, 我们打算生不生孩子就随缘, 不强求, 而最终, 我怀孕了。怀孕初期, 我还蛮担心的。因为, 流产的风险很高。但是一切顺利。Haeley是个体重较重的宝宝。她比预产期早一个月出生, 体重重达4.2公斤! 如今, 她已5岁了。她很健康, 好动, 也喜欢直接表达内心的想法。

我感到很庆幸, 在艰难时期有一群好友和家人支持, 鼓励我。我的上司和同事们也很体谅我, 如今, 我仍是全职工作者。这就是我的故事。自从被诊断患上狼疮已有10多年了, 如今我和大家分享个人经历, 希望能给大家希望狼疮患者只要有适当治疗和支持, 仍然能过常人生活。我就是活生生的证明。



International Volunteer Day

TTSH held its International Volunteer Day celebrations with an exhibition from 29th November 2011 to 1st December 2011 and a Dinner on 2nd December 2011 at the TTSH Atrium. The exhibition was held to showcase the various volunteer groups at TTSH. A dinner was held on the last day of the celebrations to honour all volunteers. Certificates and mementos were given out to them. TTSH's recognition of the volunteers' sacrifice and contribution of time and work is indeed gratifying. For LAS, the volunteers' turnout to help with the exhibition was heartening.



LAS volunteers

celebrated Christmas on the 14th December 2011 at the Activity Room located at B2, TTSH. As usual, it was a pot-luck party and there was so much delicious food. Rachel Chow contributed the turkey which everyone enjoyed. The turnout was very good. The room was buzzing and energetic and the atmosphere warm and uplifting and everyone had a great time!



Like us  on 

Get to know other members of our Association, share information about your health, and be the first to know about the latest activities and events on Facebook! Do you have a question about lupus? Simply email us so our editorial team may try answering you in the next newsletter.

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