



Lupus Link

新加坡狼疮协会刊物



Time flies and it's been 6 months since I took up the role of President. It was undoubtedly, the busiest time of my life..the day to day running, ward visits, the Peranakan Dinner, LAS Social Friday! LAS Empowerment Talk, 'Qualities of Life' exhibition, LAS Celebrates cum DVD launch and the International

Volunteers Week - all these and simultaneously, keeping up with my day job. Nevertheless, exhausting as it may be, I feel and view it as a rewarding and enriching experience. I am pleased to see needy patients get proper medications and treatments under our Medical Welfare Subsidy Scheme, glad to be able to comfort and share with fellow sufferers during our ward visits, delighted to socialize and interact with our volunteers and members at our regular gatherings and events and happy to be working with the Council in bringing the Association forward. The end of the year is the time for giving thanks and, therefore, I would like to extend my sincere appreciation to everyone who has worked with me, the Council for their precious time and invaluable contribution, Linda (Admin) and David (Accountant) for being such good help, the volunteers, both new and old, for their wonderful company and enthusiastic help and support. THANK YOU, ALL! Do look out for our events in 2012! Have a Merry Christmas and a Happy New Year!!!

By Ms Irene Lim 狼疮协会主席致词

时间总是过得很快。我担任主席一职，已经有六个月之久。无可否认的是，我的生活过得很忙碌，得参与各种活动，如病房探访、土生华人晚餐、狼疮周五聚会、狼疮教育讲座、《人生素质》展览、狼疮教育讲座兼DVD制作推行和国际志愿者周。此外，我也得兼顾工作。虽然如此，我还是觉得这是富有意义的。也从中获得许多可贵的经验。我很高兴的是，经济拮据的病患能通过医疗补贴计划获得妥善的医疗护理。此外，我也很欣慰能在病房探访时段给予同志们些许的慰藉。与志愿者和会员在聚会中交谈也令我感到十分愉快。同时，我也很高兴能与现任的执委共同合作。如今已来到年底，我先在此感谢与我合作的执委奉献宝贵的时间和贡献，行政部门的Linda，会计部门的David和新旧志愿者所给予的帮忙！谢谢大家！记得要留意2012年狼疮协会的活动哦！祝大家度过愉快的圣诞节及新年！



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Osteoporosis & SLE

红斑狼疮与骨质疏松症

By A/Prof Leong Keng Hong, 助理教授梁景康博士
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Osteoporosis is a condition where the bones become brittle. This means that the bones break easily even without much force. It affects women more than men and is more common as a person gets older. Our bones grow with us until we reach the late twenties. Then it starts to decline. We start to lose more bone than we can make. After the menopause women lose the protective effect of their female sex hormones on the bones. This explains why women are more affected. Other factors that increase bone loss are the use of steroid medication, loss of mobility, use of certain drugs to treat seizures, an overactive thyroid and low vitamin D status due to a lack of sunlight.

From this it is clear why SLE patients are at risk for osteoporosis. SLE is more common in women and because treatment is better nowadays, women with SLE can live almost as long as anyone else. Some patients have an earlier menopause due to certain medications. They need to take steroid medications. Sometimes they have overactive thyroid glands or have seizures. Depending on the condition, they may become immobile for long periods of time. Rashes in SLE tend to be worse in the sun and they need to avoid sunlight. This may bring the vitamin D levels down. Furthermore in patients with poorly functioning kidneys, they can have bone disease due to the renal failure.

So how do we know whether a patient has osteoporosis? The doctor will get the history of the illness and if it is warranted may do a bone mineral density test. This is not a radioactive bone scan and not an X ray. The X rays the patient receives is much less than even a chest X ray.

From the test and other assessments the doctor may start the patient on a medication to improve the bones and prevent fractures. Before that, the doctor will check that there is enough calcium and vitamin D being taken. Weight bearing exercise is good for the bones. This includes walking and dancing. Medications will depend on each individual patient. Possible treatments include the bisphosphonates (alendronate, risedronate, zoledronate), vitamin D analogues (alfacalcidol, calcitriol), strontium ranelate and calcitonin. Osteoporosis nowadays need not be bad news. Being aware of it leads to earlier diagnosis, earlier treatment and the patient is much less likely to suffer from fractures.

骨质疏松症指骨头易碎。即使是轻微的创伤或无外伤的情况下也容易发生骨折。该病女性多于男性，常见于老年人。我们的骨量不断地变化，直至30岁左右。在那之后，骨量就开始退化。我们也会逐渐失去更多骨量。绝经后妇女缺乏雌激素，所以造成骨质疏松。这解释为何妇女患者较多。其他因素包括使用类固醇(steroid)，行动不便，使用某些药物治疗痉挛(seizures)，过于活跃的甲状腺(thyroid)和因缺乏阳光照射而摄取不足的维生素D。

由此可见，红斑狼疮病患有较高的风险。狼疮病女性较多，而如今治疗医术发达，女性也能活到与一般人相同的岁数。由于服用某些药物，一些女性提早绝经。他们需要服用类固醇。有时候，他们的甲状腺过于活跃或者是出现痉挛情况。依据病情轻重而定，他们可能长期无法自由活动。阳光照射可能造成病患出疹。因此，患者该尽可能避免阳光照

射。但如此一来，就无法摄取充足的维生素D了。再来，肾脏功能不佳的患者因肾衰竭的因素，也容易患有骨质疏松症。

那么，我们要如何判断患者是否同时患有骨质疏松症呢？医生会依据病情而判断是否需要做骨密度检验。(bone mineral density test) 这不同于骨扫描(radioactive bone scan)或X光。进行骨密度检验的患者所摄取的X光辐射很低，甚至少于胸口X光检验。进行不同测试后，医生可能让患者服用药物，增强骨质，避免骨折。在那之前，医生会确保患者摄取充足的钙质和维生素D。走路、跳舞之类的运动有益于骨骼。依据患者病情，药物也会有所不同。患者或许会服用以下治疗药物：bisphosphonates, (alendronate, risedronate, zoledronate), vitamin D analogues (alfacalcidol, calcitriol), strontium ranelate 和 calcitonin。患有骨质疏松症不一定是坏消息。只有提早诊断及治疗，患者能减少骨折的机率。





Lupus & Pregnancy

红斑狼疮与怀孕

By Agnes Xue, Ph.D, 薛莉珊博士

Select a gynecologist for high-risk pregnancies. Lupus will always present certain risks - including pregnancy-induced hypertension and preterm birth - you will need a gynecologist who has experience with high-risk pregnancies and is at a hospital that specializes in high-risk deliveries. I know my gynecologist personally and we have both discussed about my health condition before I got pregnant. It is good that your gynecologist can be truly honest and upfront with you about your condition and actively involve your husband about your health and the developments of your foetus.

Lupus symptoms during pregnancy During pregnancy, I had to visit the clinic every month for blood and urine tests. Despite the hassle, it is very important to keep to the appointments to ensure you do not suffer from any flares, or even if they were to occur, would hopefully be mild and your doctor can treat them with low doses of prednisolone. In the very early stage of my first trimester, I had my fair share of nausea and vomiting. I was unfortunate to get an episode of food poisoning after eating some pig liver. I lost 2 kg from the incident but the baby was safe. I would advise all pregnant women not to eat pig liver or foods that are susceptible to bacteria hibernating in them. It is really not worth it if you were to suffer a miscarriage because of one careless act. My second trimester was the most enjoyable period where I could go shopping with a "compact" tummy and still wore many of my pre-pregnancy clothes. By the time I reached my last trimester, I experienced heartburn, hunger pangs and many sleepless nights because of backaches and multiple night-time trips to the washroom. My baby in the

tummy was then smaller than her average peers. But my rheumatologist and gynaecologist worked together to help ensure I faced as little complications as I could; I am so grateful for their support. I only had to take prednisolone at week 34 because the joints at my fingers were swollen and hurting and it was definitely more than trigger finger. Otherwise, my lifestyle was just like many of the mothers-to-be who do not have lupus.

Labour and birth At week 39, I had to be hospitalized to induce the delivery of my baby. According to my gynaecologist, my placenta was not as strong as it should be because of my lupus condition, and it was better for the baby to be out of the womb than inside. The birth process was a very tedious one stretching across 12 hours but my baby was born healthy at 3.2kg. I had an epidural which proved to be a blessing in disguise later on. Although I managed to deliver my baby successfully vaginally, I was bleeding profusely due to the tear in tissues during prolonged labour. My blood did not clot for the wound below and the gynaecology team had much difficulty trying to stitch me up. Without an epidural, I would probably have gone into shock and faint because of the severe pain. I had to be kept under observation in the intensive care ward (ICU) for a night and was separated from my baby. Thankfully, my baby did not require any special care hence I did not have to pay a hefty sum for my hospitalization bill. But I would advise all lupus mothers to get adequate insurance and consult hospital staff on the different packages available to cover your health care needs and those of your baby, as well as any problems that may arise.

It has been 4 years since I was diagnosed with lupus after suffering many of its symptoms for a year. There are many myths that women with lupus should not get pregnant as it seems to be such a dangerous disease, posing potential risks to both mother and child. But while every pregnancy carries its own set of risks, women with lupus can safely become pregnant and deliver healthy babies. I would like to share my personal experience in how I managed my first pregnancy at the age of 29.

Ensure your lupus is under control and review medications with your doctor I am very thankful I did not have any flare since my lupus was diagnosed in 2007. Hence in 2009, CellCept® and prednisolone were completely removed from my list of medications. As far as pregnancy is concerned, some drugs should be stopped months before one tries to become pregnant. My rheumatologist prescribed azathioprine to me instead, which is safe during pregnancy. The healthier you are when you conceive, the greater your chances of having a healthy pregnancy and baby. If possible, avoid getting pregnant until your lupus has been under control for at least six months. My husband and I are very happy that I conceived at our first attempt.

Motherhood Back home, I managed to breast-feed my baby, and expressed it to allow my husband to be involved in feeding. My baby battled breast-fed jaundice for about 8 weeks. I could stop taking prednisolone after my 2nd week out of hospital. However, I did not engage a confinement lady and I believe insufficient physical and mental rest have caused my body system to react and my episiotomy took longer than usual to heal completely, not to mention the fact I had to do the sitz bath to aid recovery. I insisted on having early hands-on training to manage everything on my own so I may know how to watch out for my baby better. But looking back, I was trying to do too much – as wife, mother, daughter-in-law, working woman. Through these years I had learnt how to deal with lupus emotionally, however, I do feel things are quite different once the baby arrives as there can be times there is so much on my mind. A word of advice for both mothers and fathers, it is important to involve the family to help out whenever possible. This period of mental and physical relief may be short but very helpful for the mother to have a breather and recharge. It is always better not to rely on medications for relieving stress. To date, my baby is healthy, happy, and active at 8 months old. I am very thankful she is growing well and my lupus condition is well controlled.

我患上红斑狼疮已有四年多了。在过去的一年多来，我的身体出现了不同症状。社会上普遍传说红斑狼疮患者不应怀孕，认为这会对母子造成一定风险。其实，怀孕本身就带有风险。虽然红斑狼疮带来一定的挑战，但患者仍然能通过一些方式，安全怀孕产子。我将分享二十九岁时首次怀孕的经验。

征询医生意见并观察病情 自从2007年被诊断患上红斑狼疮后，很庆幸的是狼疮并没有复发。因此，在2009年，我停止服用骁悉 (CellCept®) 和脱氢皮质(甾)醇 (prednisolone)。如果患者想怀孕，就得在怀孕前几个月停止服用某些药物。我的风湿科医生开了咪哇硫嘌呤 (azathioprine) 的药方给我服用。这是适合在怀孕期间服用的药物。如果想要顺利产子和确保胎儿健康成长的话，孕妇就得确保个人健康。此外，计划怀孕



的患者至少在怀孕半年前就得观察狼疮病情，这样才能断定是否适合怀孕。我与先生非常高兴能在第一番尝试就怀孕了。

高风险怀孕者得咨询经验丰富的妇产科医生 红斑狼疮为怀孕带来一定的挑战和风险。比如妊娠高血压综合征 (pregnancy-induced hypertension) 和早产。孕妇必须咨询经验丰富的妇产科医生以及寻找合适的专科医院。我私下认识我的妇产科医生。在怀孕前，我们也讨论过我的身体状况。如果妇产科医生能诚实地与你讨论你的个人状况并要求你的先生积极参与怀孕过程，告诉他你的身体状况、胎儿成长过程等话题，这是最好不过的了。

怀孕期间出现的症状 怀孕期间，我每个月都到医院作血液和尿液检验。虽然有点麻烦，定期征询医生意见等仍是必要的。唯有如此，才能确保狼疮不会复发。而即使狼疮复发，它也是轻微的，医生才能给与孕妇少量的脱氢皮质(甾)醇 (prednisolone) 作为治疗。在怀孕初期，我常常呕吐。此外，有一次，我吃了猪肝后便出现食物中毒现象。我的体重减轻2公斤，但不幸中的大幸是，腹中的胎儿没有受到影响。因此，我建议孕妇避免食用猪肝和其他细菌容易滋生的食物。假使因为一次意外而不慎的失去胎儿的话，实在太不值得了。怀孕中期是最有趣的。当时，我的腹部还没有那么明显“突起”，仍穿得下许多件怀孕前所穿的衣服。我也常常逛街。但是，到了怀孕后期时，情况大不相同了。当时，我的心口灼热，常感到饥饿，深夜因背痛难入眠又常上厕所。另一点是，我腹中的胎儿比同龄的胎儿来得小。但是，我的妇产科医生和风湿科医生都尽其所能，减少怀孕期间可能产生的问

可能产生的问题。因此，我十分感激他们。在怀孕34周，我的手指关节疼痛浮肿，因此必须服用脱氢皮质(甾)醇 (prednisolone)。除了这件事之外，我与一般没有狼疮的孕妇在生活上并没有太大的区别。

分娩期间 在怀孕39周，我必须住院。当时，风湿科医生告诉我说狼疮病情使我的胎盘不太稳固，因此在子宫外产子比较安全。分娩期间是非常艰难的。它长达12小时。庆幸的是，我的胎儿健康出生，体重为3.2公斤。我在分娩时用及硬膜外注射(epidural)。后来我才发现，用及硬膜外注射(epidural)是祸中得福的。虽然我顺利在子宫外产子，难产时我的身体组织撕裂，造成出血不止。在伤口下的血无法凝固，所以医生在缝合伤口时遇到些许困难。如果没有使用硬膜外注射(epidural)，我或许会因为剧痛而昏迷了。产子后，我留在加护病房一晚。庆幸的是，我的孩子不需要特别照料，因此住院费不太昂贵。但是，我还是建议孕妇咨询医疗人员后获取充足的健康保险，保障母子的健康以及应对突发问题。

为人母感想 产后，我给孩子喂母乳但孩子因为喂母乳而有8周的黄疸。我在家哺乳让我的先生协助我。出院后的第二个星期，我仍然得持续服用脱氢皮质(甾)醇(prednisolone)。可是，我没有聘请助产婆。因为，我认为没有充分的修养身心导致我的体质虚弱，需要更长的时间康复，更别提需使用坐浴盆(sitz bath)了。当时，我认为只要有足够休息，自己一个人就能应对万事。我凡事坚持亲力亲为，以便尽早学习照顾孩子。但如今回头想想，我发现当时自己身为为人母、为人妻、女儿、媳、独立女性等，做得太多了。那已超出我的能力所及。或许当时我该寻求更多帮助。虽然这些年来，我的心理已慢慢调适，逐渐接受狼疮病情，可是，我仍觉得一旦家中有了孩子，一切大不相同了。有时候，我必须完成很多事情，负担很重。在此，我建议准父母尽可能不时地寻求家人帮助。有了短暂的休息，我们才能喘口气继续坚持下去。如果压力太大而需要服用药物的话是不太健康的。如今，我的女儿很健康也很活泼。我很感激的是，女儿能健康地成长而本身的狼疮病情没有复发。

Qualities of life exhibition

人生素质展览2011

Report by Ms Irene Lim 狼疮协会主席

Lupus Association (Singapore) participated in this year's QUALITIES OF LIFE Exhibition from 30th September to 2nd October 2011 at Suntec Singapore International Convention & Exhibition Centre. The complimentary booth space of 6sqm was given to us by the event organizer, Ezyhealth (Singapore) Pte Ltd. Unlike previous years where we distributed LAS newsletters, leaflets, CDs and booklets on Lupus, this year we put handicrafts made by our volunteers up for sale as well. Though sales were not as brisk as we had hoped, we did receive some small donations. We had many people stop by at our booth to enquire about Lupus and to talk to us. From the public's queries, it was obvious that the awareness of Lupus is very much lacking. Nevertheless, we were proud to put up our new LAS posters designed by our very creative and innovative co-opted Council member, Dr Agnes Xue. The posters were indeed very attractive and informative. Thanks, Agnes! All in all, it was a good experience especially for our new volunteers who spontaneously offered help with the exhibition, alternating shifts and some even taking multiple days' duties. The volunteers' help was tremendous. During the exhibition, I noticed that the old and new volunteers got along really well together. I count myself very fortunate to have such a wonderful group of volunteers to help me.

狼疮协会在30/9/11到2/10/11期间在新加坡会展中心举办了人生素质展览。主办单位Ezyhealth (Singapore) Pte Ltd大方地免费提供了6平方米的展览位置。今年展览与往年相比，内容稍有不同。除了分发狼疮协会期刊、传单、CD等，我们也售卖志愿者制作的手工艺品。虽然收入不如预期理想，但不打紧。我们也获得了一些捐助。此外，有许多人与我们交谈，询问与狼疮有关课题。从大众反馈，我们察觉一般人缺乏狼疮一方的知识。此外，我们很高兴能呈现由具有创意思维的委员，薛莉珊博士，所设计的狼疮海报。这些海报确实别有一番风味，也具有教育内容。谢谢你，薛博士！总的来说，这次的展出经验是极其宝贵的。新加入的志愿者给予狼疮协会极大的协助，他们轮班，有些人甚至执行多天任务。志愿者给予的协助实在不容忽视。在展览期间，我发现新旧志愿者合作无间。我也很庆幸能有此福幸和这么棒的一群志愿者一同合作。





LAS Celebrates!

Empowerment Talk/DVD Launch/Year-end Party 2011 at La Barca Ristorante & Wine Bar

By Ms Irene Lim

WE HAD A BLAST! The venue and set-up was superb, the food was fabulous, the camaraderie was great, the crowd was delightful and the event went perfectly well. We absolutely could not have asked for more. Nothing could stop us - not even the slight inconvenience in locating the restaurant within the campus grounds and the intermittent heavy rain.

First, we were all empowered by a most informative talk on "Lupus and the Eye", courtesy of Dr Anita Chan and Dr Tan Tze Chin. Then, we launched our new DVD entitled: Lupus – The Disease of a Thousand faces. The DVD is so named because Lupus or SLE is an unpredictable disease that manifests itself in many different ways and can affect many parts of the body. This new DVD is part of our Association's efforts to increase the awareness of the disease and to highlight our support for Lupus sufferers and their caregivers. My sincere thanks to the three patients featured in the DVD. It is indeed very brave and courageous of them to speak openly of their arduous journey with Lupus. Their recollection of the ravages of the illness on them is both candid and poignant. Most Lupus patients, if not all, will be able to identify with their painful experiences. Personally, I was extremely moved. I am sure that for anyone just learning about Lupus, this video will be both touching and enlightening.

Lupus is a chronic disease with no known cure at this point in time. But, thankfully, there can be a happy ending once the disease is under control with proper medication and treatment. And, with increased awareness, we hope that the people around us: our family, friends, colleagues and even employers will not see us as sickly people but rather as over-comers with the will and capacity to function like everyone else!

My heartfelt thanks to all those who helped make the event a successful one. Deep appreciation to our Council Members, Dr Faith Chia for recommending the restaurant, Associate Prof Leong Keng Hong for sponsoring the event, Serene Mai for coordinating the DVD launch and Chan Suan Liang for overseeing the audio and visual logistics and for being a wonderful emcee.

Last but not least, my gratitude to the LAS volunteers for their committed and enthusiastic help! It was great working alongside all of them. I hope everyone had as great a time as I did and to those who did not attend the function, I look forward to seeing you at our future events. It is my sincere wish to see an even more vibrant, energetic, inclusive and cohesive association for all the members and Lupus patients.



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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