



新加坡狼疮协会刊物

LupusLink

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SINGAPORE PATIENT ADVOCATE AWARD 2017

获颁2017年新加坡激励贡献康护 奖中的‘倡导者’奖项

by Charmaine Lee



Our Heartiest Congratulations to our President, Mdm Irene Lim Suan Kim, on being awarded the "Singapore Patient Advocate Award 2017" on 20 October 2017 at the Singapore Patient Conference held at TTSH. The award was presented by the Guest-of-Honour, Mr Ng How Yue, Permanent Secretary, Ministry of Law & 2nd Permanent Secretary, Ministry of Health. The theme of the event was **"Volunteerism - Powering Change in Health and Social Care"**.

Singapore Patient Conference is an annual patient conference where patients, caregivers, volunteers, community partners and healthcare professionals came together to share their healthcare journeys and to spark new ideas in co-creating a better healthcare system for all. Singapore Patient Conference 2017 was the fifth of the annual event.

Irene joined Lupus Association (Singapore) shortly after being diagnosed with lupus in the year 2000. She had learnt of the existence of the association after her eldest sister, also a lupus patient, passed away in 1992. Meeting and receiving support from the volunteers convinced her to become a volunteer herself so that she may help other lupus patients, especially newly diagnosed ones whom she feels, need support most.

In 2009, Irene became the Honorary Treasurer in the LAS Council. With strong leadership skills and determination to help lupus patients, she was elected as the President in the year 2011. Throughout these six years, she actively led the association towards achieving its vision and goals, motivating and guiding volunteers and bringing the association to greater heights and stature.

Being a passionate active patient advocate, Irene Lim encourages and motivates other lupus patients with her tenacity, compassion and positivity. She led by example, pro-actively managing her own illness, taking charge of her own health, continuously maintaining a positive attitude and always projecting a well-groomed appearance.

Understanding the emotional stresses as a lupus patient, she empowers other patients with skills to manage their stresses and fears, boosting their morale and confidence in leading fulfilling lives.

We are indeed thankful to have Irene as our leader. She is like a lighthouse to us, especially whenever our illness relapses. Thank you, Irene, for being our role model and pillar of strength!

衷心恭喜林碹金女士获颁2017年新加坡激励贡献康护奖中的‘倡导者’奖项。颁奖典礼在2017年10月20日，位于陈笃生医院举行的‘新加坡医患与社区交流会’上进行。得奖者都从特别来宾，律政部常任秘书兼任卫生部第二常任秘书黄好游先生接过奖项。交流会的主题是“志愿服务促进医疗与社会福利的改革”。

新加坡医患与社区交流会是一年一度的交流会。病患、护理人员、义工、社区伙伴与医疗专业人士在这个平台分享心路历程，和激发灵感，共同创造更完善的医疗保健体系。2017年新加坡医患与社区交流会第五届的交流会。

2000年，林碹金女士被诊断患上红斑狼疮症。早在1992年，她最年长也是狼疮患者的姐姐去世后，她就知晓协会的存在。义工们的慰藉感动了她，令她决定当义工，帮助其他狼疮患者，尤其是刚被诊断的狼疮患者，林碹金女士觉得他们最需要支持。

林碹金女士在2009年当上新加坡狼疮协会荣誉财务长。由于她充分发挥卓越的领导才能与一心想帮助病患的毅力，林碹金女士在2011年被委任为协会会长。这6年来，她积极地引领协会实现愿景与贯彻使命，并且鼓励和领导义工们，大大提高协会的知名度。

身为一位既热忱又积极的义工，林碹金女士提倡减轻病患的不适，同时以自己的韧性、慈悲心与正能量鼓励其他患者。她以身作则，积极乐观地管理自己的病情，并时时保持整齐干净的良好形象。

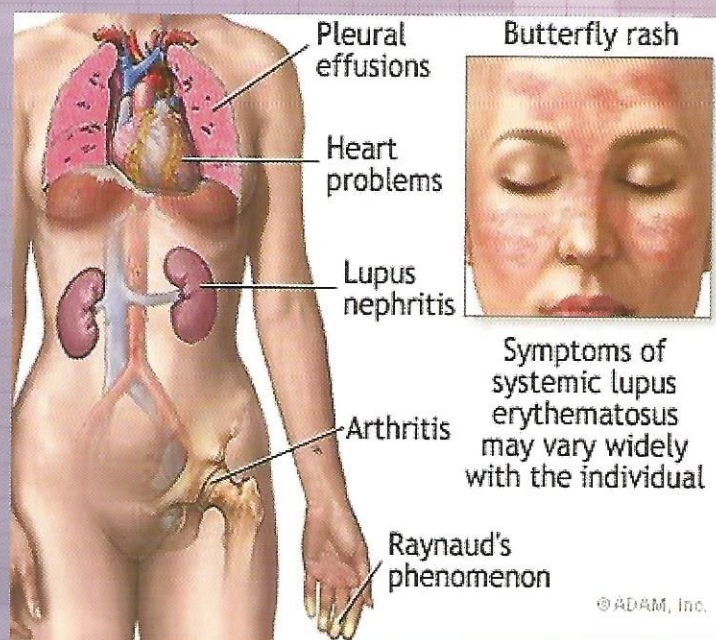
由于林碹金女士深知病患所面对的情绪压力，她教其他病患如何面对压力与恐惧的技巧，提高他们的士气与信心掌握美满的人生。

我们由衷感激有林碹金女士这样的领导。对我们而言，她就象一座灯塔，尤其当我们的疾病复发时。感谢林碹金女士一

KNOWING YOUR MEDICINE - A PRACTICAL GUIDE FOR SLE PATIENTS

Talk by Dr Stanley Angkodjojo
Singapore General Hospital

Systemic Lupus Erythematosus (SLE) is a condition caused by an immune system dysregulation, which causes the immune system to attack our own body. SLE can affect any organ, and hence present with many different symptoms. The severity of the symptoms can vary too. It is a chronic disease, and nearly all patients have periods of improvement. These periods of remission can be complete and long-lasting in some people.

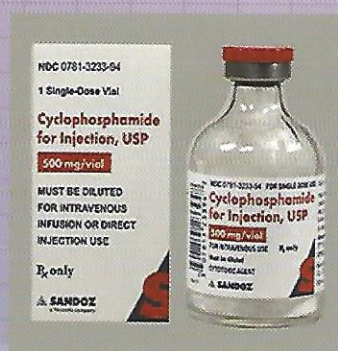


The disease course of SLE can be unpredictable with episodes of flares and remissions. This is why long term treatment and follow-up with your doctor is very important. There is no standard treatment plan for SLE. Each treatment plan can be different for each patient. Every patient's treatment program will include medications and lifestyle adjustments, and this needs careful discussion with your doctor. Medications that are started depend on the organs that are affected, and the severity of involvement.

Here are some general advice and tips that are useful for all lupus patients. First and foremost, maintain a good relationship with your lupus doctor and nurses. They are here to help you as much as they can to help you cope with this condition better. Please go for your regular check-

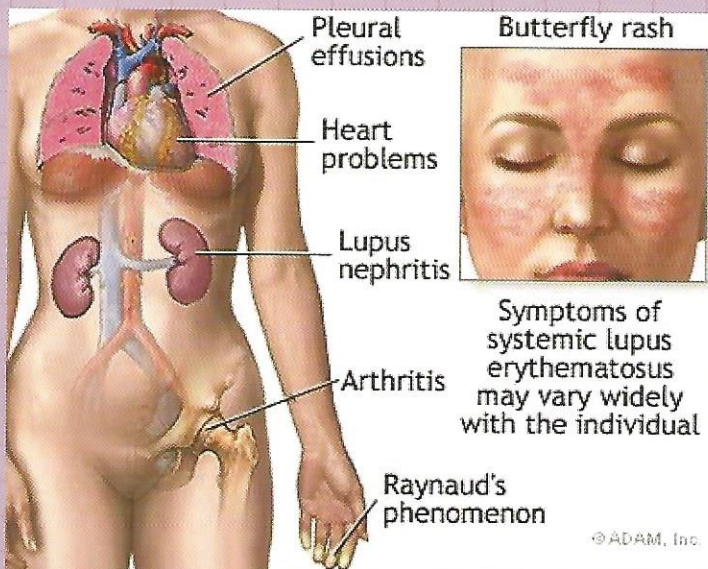


ups and blood tests, and share with them your concerns. Secondly, get adequate rest and sleep as much as possible. Thirdly, avoid the sun when it is strongest (10am to 4pm), and remember to use sunscreen if you have to. If you want to take any supplements or herbal medicines, please share this with your doctor. Do not take any raw or undercooked foods if you are on certain medications such as Azathioprine, Cyclophosphamide, Cellcept, or Calcineurin inhibitors. Always keep up-to-date with your vaccinations, in particular the flu vaccine. Avoid excessive alcohol intake and smoking. It is also good to go for regular exercises, but do not overstrain your body.



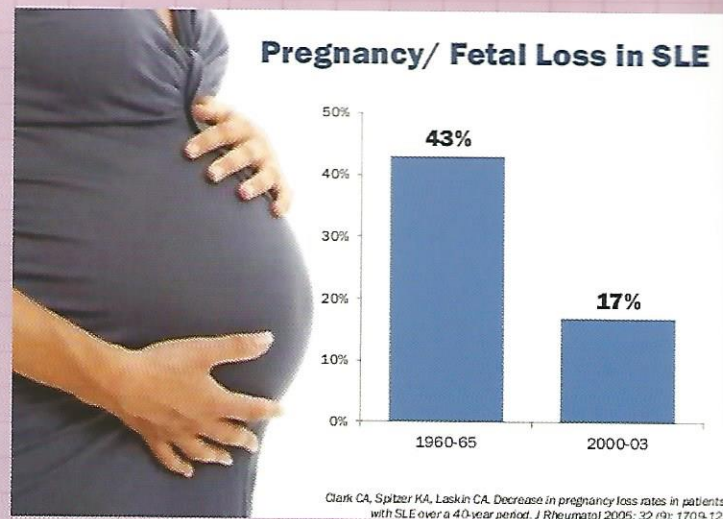
Last but not least, we want to talk to you about pregnancy in lupus patients, especially since lupus affects mainly women in their reproductive age. Many patients with SLE can have normal pregnancies. This is usually possible if their lupus is well-controlled. Pregnancy is best avoided if the disease is active. After delivery, there may be worsening of symptoms, and you will need your doctor to help you get through this. Certain medications can cause damage to the unborn fetus and are best avoided if you intend to become pregnant. It is very important to communicate closely with your doctor so that you can plan ahead for your pregnancy and ensure a good outcome for yourselves and your child. Always remember, your lupus doctor will be there for you on your journey and fight against lupus.

红斑狼疮症是一种由于自身免疫系统失调而引起的慢性系统性疾病。它可以影响身体各个器官。因此临床症状多样化，严重程度也变化无常。幸运的是绝大多数患者能进入缓解期，有些患者可成功的进入长期性的缓解期。



红斑狼疮症的治疗没有统一的标准。虽然每个病人的整体治疗方案都包括药物和生活方式的适当调整，但详细治疗方案有所不同，它取决于每个病人症状的严重程度和身体器官的受损程度。因此每个患者都需要和自己的主治医生详细讨论。

在这里与大家分享一些控制红斑狼疮症的普通常识。首先请与您的医生和护士建立良好的合作关系。他们会尽最大的努力帮助您控制病情。定期验血，复诊。如有任何疑问，请及时和医护人员沟通。其次要确保足够的睡眠和休息。最后要避免直接阳光暴晒，尤其是上午十点到下午四点之间。如有必要，一定要使用防晒霜。请不要在没有咨询医生的情况下自行服用补品，草药之类。不要吃生的或没完全煮熟的食物，尤其是在服用免疫抑制药物期间。确保定期注射疫苗，尤其是流感疫苗。避免过量饮酒，不要抽烟。定期做运动，但不要过度劳累。



由于大多数患者都属于生育年龄，所以我们很有必要来探讨一些关于狼疮患者在怀孕方面的常识。大多数病人在病情完全受到控制下是可以正常受孕。然而在病情活跃期间，一定要避免怀孕。分娩后，病情症状可能恶化。所以一定要和医生紧密配合，确保病情不会恶化。某些药物可能对胎儿照成不良影响，所以您如果打算怀孕，请尽量避免服用这类药物，提前做好准备。但这些都都需要和主治医师紧密配合，预防病情恶化，保护胎儿。我们的医护人员会和您一起对抗狼疮症。



LAS BONDING TRIP TO BATAM

新加坡狼疮协会巴淡岛联系情感之旅

by Jasmine Png



On 17 November 2017, seven of us LAS volunteers, took a ferry to Batam for our long-awaited LAS Bonding Trip. Everyone was eagerly looking forward to a relaxing and meaningful time of bonding.

Upon arrival in Batam, we proceeded to the Nagoya Hill Shopping Mall where we had a delicious lunch of local cuisines. After lunch, we immediately launched into our shopping mode, buying the local favourites like Kueh Lapis, pastries, mangoes, dried foodstuffs, etc.

Once shopping was done, we proceeded to the hotel. After checking-in to a very nice and new four-star hotel, some of us immediately headed for the Spa for massage while others went for a swim in the hotel pool. Later, after everyone had been refreshed and reinvigorated by the spa treatments, it was time to prepare for dinner time.

The night was marked by a delightful dinner provided by the hotel, with music from a live jazz band from the Philippines. The sumptuous dinner and soothing jazz music, after a day of rejuvenating spa treatments, was the epitome of a relaxing holiday.

The next day, we had a leisurely breakfast (great international breakfast buffet spread) and a short hang out by the hotel poolside before heading to the Batam Ferry Terminal for the ferry ride home. Though our Batam trip was short, we all had a relaxing happy time and all voiced the wish to have a similar trip next year, perhaps to Bintan or Bali. Why not?

我们七位狼疮协会志愿者，在2017年11月17日，乘坐渡轮踏上久违的巴淡岛联系情感之旅，每个人都向往度过轻松和有意义时光，增进友谊。

抵达巴淡岛后，我们就前往名古屋山购物中心，共享当地的美食。用完午餐后，我们即刻购物，买了当地的土产，如千层糕、糕点、芒果、干粮等。

购物完毕，我们去了下榻的四星级的新酒店。一些人前往温泉按摩，而另一些则在酒店的游泳池游泳。经过温泉水疗护理，每个人都精神抖擞，又到了准备享用晚餐的时候了。

随着来自菲律宾的爵士乐团伴奏，我们享用了愉快的晚餐。让人们恢复活力的温泉水疗护理，丰盛的晚餐与抒情的爵士音乐，是一段松懈身心旅程的亮点。

隔天，我们共进国际自助早餐，在酒店游泳池边待了一会儿就前往巴淡岛渡轮码头乘渡轮回国。虽然行程略短，但大家都觉得此行轻松又愉快，同时都希望明年能够策划类似活动，目的地可能是民丹岛或巴厘岛。何乐不为呢？

LAS EMPOWERMENT TALK AND X'MAS & YEAR-END PARTY 2017

新加坡狼疮协会激励讲座与圣诞年终派对



LAS held our annual Christmas and Year-end party together with our LAS Empowerment Talk on Saturday, 9 December 2017. The Tan Tock Seng Hospital Theatre was abuzz with fun and good cheer. Everyone, including the family and friends of some of our members, had a blast from the beginning till the end!

The festivities were kick-started with a LAS Empowerment Talk on "Diet & SLE" by Ms Goh Yi Ting, a Dietician with TTSH. It was evidently a 'hot' topic as the "Q & A" session that ensued was both spirited and engaging. Thereafter, Certificates of Appreciation were presented to our dedicated volunteers by our President, Irene Lim. The dancing team "Fine Rhythm" ("真善美"舞蹈小组) comprising Ms. Amy Koh & Ms. Wong Lai-Mun then charmed the audience with their Chinese folk dance item, titled "Butterfly Lovers" ("蝶双飞").

After a sumptuous buffet lunch, the audience was treated to a captivating and intriguing magic show by Jerry Tan & Darren Tien of JT MAGIC. Next, four of our volunteers, Josephine

Hang, Lilian Phang, Siang Gek and Han Ran, who share a passion for line-dancing, performed a lively line-dance to the popular Christmas song, "Feliz Navidad". It was truly inspiring to watch our members look past their illness, let their hair down and genuinely enjoy themselves.

As any Christmas party would not be complete without Santa's visit, our very own Emcee, Poh Jie Ying, dressed up as Santa Claus and totally thrilled the audience. She was teasingly crowned "The Prettiest Santa" by fellow volunteers. A fun photography session followed with Santa. Lady Santa was quite the highlight of the day!

A much anticipated Lucky Draw wound up the day's event. Heartiest congratulations to all the lucky winners!

Sincere thanks and appreciation to all who were involved in making the party a success. Thank you for all the hard work!

新加坡狼疮协会在2017年12月9日（星期六）举行一年一度的圣诞年终派对，与健康讲座。陈笃生医院一楼讲堂洋溢着一片欢乐与喝彩。所有的人，包括协会成员的家人与朋友都尽兴而归！

首先拉开序幕的是由在陈笃生医院任职的吴依婷营养师主讲的“饮食与红斑狼疮”。观众在问答环节时反应热烈，由此可见，这显然是个‘热门’话题。紧接着，协会会长林镛金女士颁发感谢证书给尽心尽力的义工们。由Ms. Amy Koh 与 Ms. Wong Lai-Mun组成的“真善美”舞蹈小组也为观众呈现中国民间舞蹈“蝶双飞”。

享用丰盛的自助午餐后，来自JT MAGIC的Jerry Tan 与 Darren Tien 为观众呈现既神奇又精彩绝伦的魔术表演。四位义工

Josephine Hang, Lilian Phang, Siang Gek and Han Ran也随着“我们要祝你圣诞快乐”的圣诞歌表演轻松活泼的排舞。看着成员们放下疾病，尽情地载歌载舞和观赏节目，令人非常鼓舞。

圣诞派对没有圣诞老人增辉是不圆满的。我们的司仪Poh Jie Ying打扮成圣诞老人，逗得观众非常开心。她还被誉为‘最漂亮的圣诞老人’。大家都竞相与她合照，圣诞老人成为这天的焦点。

压轴节目是让众人期待的幸运抽奖。衷心恭喜所有的幸运得奖者！

在此，真诚的感谢所有参与举办派对的功臣们。谢谢你们辛勤的奉献！





President's Message

Irene Lim

Another year has passed and, as always, I would like to thank the council members and volunteers for their significant and valuable contributions and efforts through the year.

Being presented with the SPAA Patient Advocate award this year came as a total surprise to me. Though I had been volunteering for many years, I have never considered myself to be doing anything extraordinary or deserving of recognition. Becoming a volunteer had been a natural progression for me... from the beginning, I received support and comfort from the LAS volunteers and, so, in turn, decided to give back by helping other lupus patients. Leading the association never crossed my mind at all and when I was elected, it was to me, just a role to carry on helping lupus patients, although I fully understood that I was given a job that must be done well and from my heart. Therefore, when I met with the organising team after the award was announced to me, I told them that I sincerely did not think I deserve the award as I felt that I have not done enough to merit one. To my astonishment and mild amusement, I was told that

all the recipients felt the same way and said the thing. Perhaps, it is like what Mother Teresa once said: **"Not all of us can do great things but we can do small things with great love."** And that's exactly what volunteers do best.

For 2018, we are expecting another busy year as we will likely be holding our third LAS WALK FOR LUPUS (please don't forget to support us) and we are also planning to extend ourselves to the newer hospitals, like Khoo Teck Phuat, Ng Teng Fong etc., in line with our goal of creating awareness for both lupus and our association. We are also planning to launch a new LAS Research Grant to support lupus-related research in Singapore for which we hope will be well-received. And, we are targeting the formation of a LAS Youth Group. We have a number of young patients in our membership count and I strongly urge these young or younger patients to come forward to help us, and, in the process, help one another and also help themselves.

Looking forward to 2018 and wishing you and your loved ones a Merry Christmas and a Happy New Year!

会长的信息：林瑾金女士

一年又过去了。跟以往一样，我要感谢理事会的成员与义工们在这一年里所作的重大且宝贵的贡献和努力。

今年获颁新加坡激励贡献康护奖中的‘倡导者’奖项对我来说是个惊喜。虽然我从义工活动多年，我未曾觉得我做了什么超凡或值得肯定的事。成为志愿者对我来说是很自然的进展。刚开始时，我获得新加坡狼疮协会志愿者的帮助与慰藉，所以我决定回馈，帮助其他狼疮患者。我从没想过引领协会。即使被委任为协会会长，我始终觉得这只是个帮助狼疮患者的任务，虽然我完全了解必须通过发自内心的努力，才能承担这份使命。因此，当主办单位通知我获颁奖项时，我真诚的告诉他们我受之有愧，因为我觉得我还做得不够多。令我感到惊奇又有趣的是，主办单位透露，所有的获奖者都

有此同感。或许，这就像特蕾莎修女所说：“我们当中极少数人能做伟大的事情，但是每个人都可以用崇高的爱做平凡的事。”这正是志愿者最擅长的。

2018年将是个忙碌的一年。除了举办第三届的新加坡狼疮协会义走（别忘了支持我们），我们也计划与新建的医院，如邱德拔医院与黄廷芳综合医院一起合作，让更多人了解红斑狼疮和我们的协会。我们正准备设立研究助学金，支持狼疮相关的研究，希望获得认可。此外，我们也将成立狼疮青年会。在此呼吁协会成员的年轻患者挺身而出，助己助人。

期待2018年的来临，祝您与家人圣诞节与新年快乐！

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