



新加坡狼疮协会刊物

LUPUS LINK

Team Lupus Races for Awareness 狼疮团队奔向认知



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Team Lupus Achieves New Milestones in 2023, Racing Towards Awareness and Growth

by Jean Eng

It has been a remarkable year of growth and achievement for Team Lupus. The team has reached new milestones, creating a significant impact in the lupus community and beyond, propelled by active engagement on social media and monthly paddling sessions that have increased public awareness of lupus.

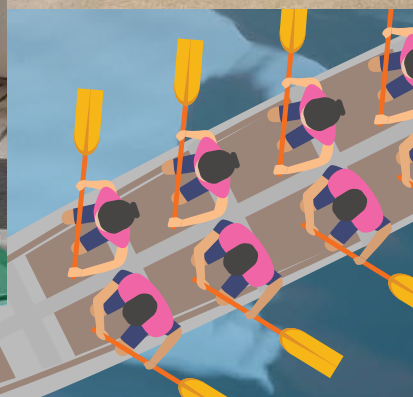
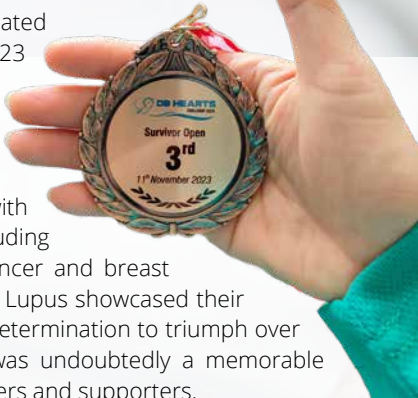
Highlights of the year include the team's participation in two notable races. The first was an invitation race in collaboration with the Cancer Society, exemplifying Team Lupus's commitment to joining forces with other organisations to address health challenges collectively. The second race, the DB Hearts Challenge held on 2 November, was a culmination of months of preparation, marked by rigorous monthly training sessions.

Eighteen teams participated in the DB Hearts 2023 race, and Team Lupus made an impressive mark clinching third place in the Survivor Open category. Competing with three other teams, including those representing cancer and breast cancer societies, Team Lupus showcased their athletic prowess and determination to triumph over health challenges. It was undoubtedly a memorable day for all team members and supporters.

A significant aspect of Team Lupus's growth is the inclusion of more individuals with lupus. Special mention to Michelle, SY Lim, Pei Shan, Jo Lee, Catherine, and Janet — these new members are not only participants but fellow lupus patients, adding a deep personal dimension to the team's mission. The team was honoured to have President of Lupus Association (Singapore) (LAS) Irene Lim, who is a symbol of leadership and inspiration for all, competing with the team.

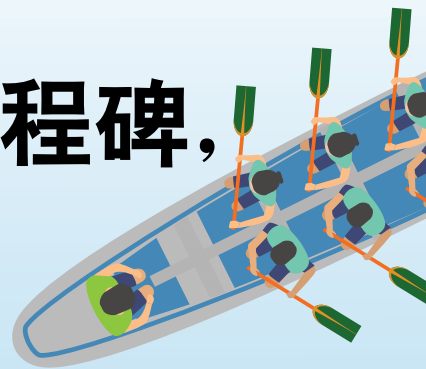
Beyond the realm of racing, Team Lupus demonstrated a commitment to making a difference by organising a fundraiser. This initiative not only supported the team's activities but also contributed to LAS, furthering the collective effort to advance lupus research and support.

As Team Lupus continues to grow, their impact goes beyond athletic achievements. The unity, dedication, and inclusivity displayed by the team make them a powerful force in advocating lupus awareness and support. With each stride and every social media engagement, Team Lupus is not just racing towards the finish line but also towards a future where lupus is better understood, supported, and ultimately conquered.



狼疮团队2023年取得新里程碑，奔向认知与成长

吴静婷女士



对于狼疮团队而言，这是成长和成就非凡的一年。在社交媒体的积极参与和每月的划桨训练推动下，团队取得了新的里程碑，在狼疮社群及更广泛的范畴中产生了显着的影响，提高了公众对狼疮的认识。

今年的亮点包括团队参与了两场显着的比赛。首先是与癌症协会合作的邀请赛，彰显了狼疮团队与其他组织携手应对健康挑战的承诺。第二场比赛是于11月2日举行的“同舟齐心” (DB Hearts Challenge)，是数月筹备的巅峰之作，其特点是每月都有严格的培训课程。

在“同舟齐心”比赛中，共有18支队伍参与，狼疮团队在幸存者类别中获得第三名，给人留下深刻的印象。与其他三支队伍竞争，包含代表癌症和乳腺癌协会的队伍，狼疮团队展示了他们的运动实力和克服健康挑战的决心。这无疑是所有团队成员和支持者们难忘的日子。

狼疮团队成长的一个重要方面是吸引更多患有狼疮的个人参与。特别感谢Michelle、SY Lim、Pei Shan、Jo Lee、Catherine和Janet - 这些新成员不仅仅是参与者，还是狼疮患者，为团队的使命增添了深刻的个人色彩。团队很荣幸能够与狼疮协会会长Irene Lim同场竞技，她是领导力和鼓舞人心的象征。

除了比赛之外，狼疮团队还通过组织募款活动，展现了与众不同的决心。这一举措不仅支持了团队的活动，还为狼疮协会做出了贡献，进一步推动了狼疮研究和支持方面的集体努力。

随着狼疮团队的不断成长，他们的影响力不仅仅体现在运动成就上。团队所展现的团结、奉献和包容性，使他们成为在提倡狼疮意识和支持方面的强大力量。每一步，每一次社交媒体的参与，狼疮团队不仅是奔向终点线，更是朝着一个更深刻理解、支持且最终战胜狼疮的未来。



Risk Factors, Flares and Remission in SLE

**Talk given on 2 September 2023
by Dr Rachel Lim**

**Senior Resident, Department of Rheumatology,
Tan Tock Seng Hospital**

We talk about the risk factors, flares and remission in SLE through the journey of Joanne (not her real name), a patient with SLE.

Case example: Joanne (not her real name) was recently diagnosed with systemic lupus erythematosus (SLE). She had joint pains, a rash on her face, and mouth ulcers. At a follow-up visit with her doctor, she raised some questions that have been bothering her.

What is SLE?

Systemic lupus erythematosus, commonly known as just lupus, or SLE for short, is an autoimmune disease, meaning that the immune system attacks healthy tissue, leading to inflammation and pain in any part of your body. The symptoms one experiences depend on the affected body system. Body systems that can be affected include the skin, joints, and internal organs like the kidneys and lungs.

SLE affects people differently. Each person's disease course is unique. SLE is characterised by periods of flares and remissions. There may be patients who enjoy long periods of remission, while some patients have chronically active disease. Some patients have mild symptoms, while others may have life-threatening symptoms and organ involvement.

It is a chronic disease which has no cure currently.

SLE is not contagious (it cannot be caught from someone or passed to others), and it is not the end — it can be well controlled, and individuals can still lead normal happy lives.

Why me? Did I do something wrong?

Anyone can develop lupus. However, certain people are at higher risk, for example, females. SLE is nine times more common in women than men. Asians and Afro-Americans are also more prone to developing the disease, and their disease tends to be more severe.

Symptoms usually start appearing between ages 15 to 45, although young children and the elderly can be affected too.

What are some risk factors for developing SLE?

There have been genes identified that are associated with lupus and are more commonly seen in people with lupus than those without the disease, although these genes have not been shown to directly cause lupus. Lupus is also more common in people with a family member with lupus or another autoimmune disease.



While a person's genes may increase the chance of developing lupus, there may also be environmental triggers that set off the illness. Common environmental risk factors include exposure to ultraviolet (UV) rays (including sunlight and other sources such as fluorescent light bulbs), certain medications, smoking, certain infections, fatigue, and physical and emotional stress.

To elaborate on some of them:

Medications:

- Certain medications make a person more sensitive to the sun, such as sulfur-containing medications
- Certain medications (e.g., hydralazine, anti-tuberculosis medications) can cause symptoms and signs of lupus, but these symptoms may go away after the medications are stopped
- Certain herbal supplements (e.g., alfalfa sprouts, echinacea (coneflower)) have also been associated with more lupus flares

Smoking:

- Lupus patients who smoke are shown to have more active disease (particularly skin)
- It also increases the risk of cardiovascular diseases such as coronary blood vessel blockage on top of lupus
- Chemicals in tobacco products also reduce the efficacy of hydroxychloroquine, a very helpful lupus medication

Stress:

- Anything that causes stress to the body, such as significant exhaustion, poor sleep, surgery, physical harm, pregnancy, birth, or severe illness, can lead to development of SLE in someone who is susceptible
- Emotional stress also counts, such as divorce, illness, death in the family, or other life complications

We go back to Joanne –

Joanne went home after that consult feeling less anxious. She tried her best to take her medications on time as prescribed by her doctor. Her symptoms got better. Two months later during a stressful period at work, she noticed her joints hurting again, and she was very tired. At her clinic consult, she asked her doctor:

Why are my symptoms back?

Lupus is a chronic disease characterised by unpredictable disease flares and remissions.

A lupus flare is when your lupus symptoms worsen, and you feel ill as a result. This should prompt a change or increase in treatment. Some flares happen without symptoms, such as deterioration of laboratory markers suggestive of disease activity, also known as “serological activity”. Some people may benefit from a change in treatment when such deterioration occurs, before symptoms kick in.

Certain predictors for a higher disease flare rate include younger age at disease onset, no use of antimalarials like hydroxychloroquine, and persistent generalised disease activity or serological activity.

What can precipitate a flare are environmental triggers, as mentioned before, or changes to physical status or level of stress, and change or cessation of treatment.

How do I know it is my lupus flaring and not something else?

Flare patterns are similar, although some patients may develop new symptoms during each flare. Knowing your own disease and symptom pattern will empower you to recognise when your disease is active. Tips on how to do so include keeping a symptom diary and monitoring how you feel in relation to the triggers you face.

The doctors taking care of you will also correlate your symptoms with laboratory tests and investigations to diagnose the cause of your symptoms. Hence, close communication with your rheumatologist and other healthcare team members is also helpful.

Remission

It has been two years since Joanne’s SLE diagnosis. She has been well without any further flares for one and a half years.

Lupus affects everyone differently. Some people with lupus eventually go into remission, while others never do. Complete remission is difficult to achieve, and most patients may need to be on lifelong medications to keep their disease quiet. The optimal target is absence of disease activity in all organ systems with the lowest possible dose of steroids and standard maintenance dose of non-steroid medications.

Other steps that patients can take to aim for disease remission:

- Smoking cessation: seeking help from professionals if necessary
- UV protection: UV protection clothing, at least SPF 50 sunblock, lamp shades
- Managing stress and work: making small changes to your work station, e.g., a more comfortable work chair, not overloading your schedule, recognising symptoms of stress such as anxiety, worry, anger, inability to focus, and then making time to relax
- Keeping active
- Partnering with healthcare team to work together towards control of disease
- Support from loved ones by explaining your diagnosis to them
- Taking time for yourself and getting sufficient sleep

AUTOIMMUNE

红斑狼疮 – 风险，复发和缓解

林玮珊医生

Senior Resident, Department of Rheumatology,
Tan Tock Seng Hospital

什么是狼疮症？

系统性红斑狼疮 (SLE), 简称为“狼疮 / 狼疮症”，是一种自身免疫性疾病。这意味着身体的免疫系统反常地攻击健康的身体部位，导致身体多个系统发生慢性发炎。

症状取决于受影响的身体系统。较常受影响的身体部位包括关节、皮肤、肾脏及血细胞。

每一个狼疮患者的症状以及疾病严重性因人而异。病症可能在数周内突然产生，也可能在几个月内逐渐出现。

至今，狼疮并无法完全治愈。不过，狼疮可以受控制，患者依然可以度过开心健康的生活。

狼疮没有传染性。一个人不能从别人感染到狼疮，或者把它传染给他人。

谁有可能得狼疮？

无论年龄，性别，种族，每个人都有可能患有狼疮。

可是某些人患有狼疮的风险会比其他人高，包括：15至44岁的女性，某些种族群体：例如亚洲人。这些风险的差别很有可能跟基因和荷尔蒙有关 – 这些都还在研究中。

有哪些因素有可能增加患上狼疮的风险呢？

这通常是本身的基因构造加上外部环境因素触发导致疾病产生。

红斑狼疮患者的基因构造和没有狼疮的人的基因构造有差别。有某些基因在狼疮的患者身上比较常见。家庭成员患有狼疮或其他自身免疫疾病的机率也比较高。这代表着基因在狼疮产生的过程中有一定的关联，但目前还没证明哪几个基因直接导致狼疮发生。

有几种环境因素可以激发红斑狼疮产生或复发：

1. 紫外线 (UV)

被认为是激发红斑狼疮的最重要的环境因素之一。

大部分的狼疮患者有光敏感性，表现为原皮损加重，或出现新皮损，且部分患者同时伴有发热、关节痛、乏力等系统性症状加重。



重。细胞受紫外线辐射后，释放多种细胞因子，随后通过一系列的自身免疫反应导致病发。室内荧光灯也会释放某种程度的紫外线。

2. 药物和草药

含有硫磺的药物，比如磺胺剂，有触发狼疮症的风险。

常服用某些降血压的药，比如hydralazine, 或治肺结核的药例如rifampicin 的病人有可能患有类似系统性红斑狼疮的症状含有苜蓿芽和紫锥菊的成分的草药也有以上的风险。

3. 抽烟

会使狼疮病症加重，也会增加患有心肌梗塞及其他心血管疾病的风险。抽烟也有可能减低羟氯喹 (hydroxychloroquine) 的功效。羟氯喹是一种对红斑狼疮症很有效的一种药。

4. 身体疲劳，生理上和心理上的压力也可能增加狼疮复发的风险。

病症复发

红斑狼疮是一种反复地复发与缓解的疾病。复发现象包括红斑、关节疼痛、身心疲劳、血液检测不寻常、尿流失蛋白质等各种症状。医生通常需要改变治疗方案。

保持写医疗日记的习惯，记录你的症状，药物和副作用，与你的医生讨论你的问题和疑虑 – 特别是如果你有副作用或不了解服药说明。

注意你的感受，并与医生分享你的身体健康上的改变。如果症状改变或恶化，立即告诉治疗团队。

病情缓解

红斑狼疮的病人大多数都需要长期吃药来控制病情，达到临床缓解。医生都会试图用最低的一类固醇分量，加上其他有效的药物来控制病情。

减少病情复发的各种贴士，包括：

- 戒烟 - 非常重要 - 如果患者遇到戒烟的困难，应向医疗人员求救
- 标准防晒方法包括使用防晒乳(至少SPF50以上)，穿保护式衣物，贴窗户防晒膜等
- 确保有充足的休息与睡眠
- 定期运动但不要过度劳累
- 低影响的活动（例如散步，游泳或骑自行车）可以帮助你的骨骼和肌肉更健康，而不会伤害到你的关节。尝试温和的瑜伽来缓解压力，并放松紧绷的肌肉
- 足够的睡眠
- 调整你的日常工作和生活作息
- 保留私人时间去做让自己开心放松的事
- 与家人沟通 - 良好的沟通对于帮助你的家人适应狼疮诊断非常重要



AUTOIMMUNE



LAS Empowerment Talk Cum Year-End Party 2023

A Joyous Celebration of Togetherness and Gratitude!

by Irene Lim



Lupus Association (Singapore) (LAS) recently held its highly anticipated LAS Empowerment Talk Cum Year-End Party on 2 December 2023 at the NUHS Tower Seminar Room. The annual event was the perfect occasion to bring together our members, dedicated volunteers, and cherished friends for an unforgettable time of celebration and camaraderie.

While our educational talks are held on a quarterly basis, the Year-End Party holds a special place in our hearts. It signifies the culmination of a meaningful year, providing a precious opportunity for everyone to personally connect, exchange warm wishes, and reflect on the past year. Moreover, it is a heartfelt gesture of gratitude towards the dedicated volunteers and members who have supported and contributed to our association throughout the year.

Thanks to our enthusiastic volunteers, Jean Ting and Cai Peishan, the room was adorned with festive decorations, such as party balloons, an inflated foil Christmas tree, reindeers, Nutcracker sculptures, and candy canes. The atmosphere was truly captivating, setting the stage for an afternoon filled with joy and merriment. A jolly Santa Claus added fun and excitement to the occasion.

We were treated to captivating live music and entertainment by talented buskers Alan and Wymo. Their melodious tunes enhanced the atmosphere.

As we bid farewell to a fulfilling year, we look forward to the exciting opportunities that lie ahead in our shared journey of empowerment, care and commitment in making a positive impact on the lives of others.

Here's to a bright and prosperous future!



新加坡狼疮协会赋权讲座暨2023 年终派对 欢欣庆典：共享团聚与感恩！

林碯金女士

新加坡狼疮协会 Lupus Association (Singapore)最近于2023年12月2日在国大医院塔楼研讨室(NUHS Tower Seminar Room)举办了备受期待的新加坡狼疮协会赋权讲座暨年终派对。一年一度的活动是一个完美的时刻，让我们的会员、热心的志愿者和珍爱的朋友们欢聚一堂，度过了一段难忘的庆祝和友情时光。

虽然我们的教育讲座每季度举办一次，但年终派对在我们的心中占据了特殊的位置。它标志着一个有意义的年度的结束，为每个人提供了一个宝贵的机会，让大家可以亲自交流、相互交换温馨的祝福，并反思过去的一年。此外，这也是对那些一年来支持并为我们协会做出贡献的热心志愿者和会员的衷心感谢的表现。

由衷感谢我们热情洋溢的志愿者Jean Ting和Cai Peishan，房间装饰着节日氛围，如派对气球、充气铝箔圣诞树、驯鹿、胡桃钳士兵雕塑和糖果拐杖。真正迷人的氛围，为一个充满欢乐和喜悦的下午奠定了基础。一位快乐的圣诞老人为活动增添了趣味和激情。

我们欣赏到由才华洋溢的街头艺人Alan和Wymo呈现的引人入胜的现场音乐和表演。他们的悠扬旋律增添了活动的气氛。

在我们告别充实的一年之际，我们期待着在共同的赋权、关怀和承诺之旅中，迎来令人振奋的机会，能为他人的生活带来积极影响而努力。

让我们为光明和繁荣的未来干杯！



LAS Volunteer Xmas Party: Reviving the Festive Spirit

by Irene Lim



After a long hiatus due to COVID-19, we were thrilled to resurrect our beloved tradition of hosting the Lupus Association (Singapore) (LAS) Volunteer Xmas Party on 20 December 2023. The much-anticipated event was a well-deserved celebration for our dedicated volunteers, who had poured their heart and soul into creating rose handicrafts, which were sold at our Year-End Party. These intricate creations not only showcased their artistic talents but also served as a means to generate funds for LAS.

We had the pleasure of welcoming Ming Hui, Charlotte, and Kenny from the Tan Tock Seng Hospital (TTSH) Volunteer Management Team. Their attendance was significant, as it showcased the strong bond and collaboration between TTSH and our association.

With delectable food and company, our volunteers had an unforgettable time.



Tribute to Kareen Chin: Dedicated Volunteer and Ex-Council Member

by Irene Lim

At Lupus Association (Singapore) (LAS), we are filled with sadness as we bid farewell to our dear friend and dedicated volunteer Kareen Chin, who passed away on 2 October 2023. Kareen has been an invaluable member of our association since 2014, and her presence will be missed.

Kareen was a remarkable individual, known for her sense of responsibility, unwavering commitment, and thoughtful approach to teamwork. As a council member, she took her role seriously, attending every council meeting and consistently contributed insightful ideas and suggestions.

Her uncle fondly remembers Kareen as “a strong lady all through her life. She was really a survivor. With each lupus relapse she had, she fought a strong battle, and came out stronger each and every time. with unwavering determination. Each battle she fought made her stronger, but it was the complexities of lupus neurotic psychosis which affected her, and took a heavy toll on her mental and physical well-being.”

Kareen's loving husband, Jun Xiang, described her as “a sweet and thoughtful girl who always put other people's well-being ahead of her own. She was so selfless that she often put on a brave front, hiding her true sufferings from others, especially her family members, so as to not worry them. She always gave 101% in everything she did, be it work or personal life. Despite facing adversity after adversity, she remained brave. She was a bright spark in everyone's life, and she will be deeply missed.”

On behalf of everyone at LAS who had the privilege of knowing Kareen personally, we want to express our heartfelt gratitude for the time we shared together. Although we mourn her loss, we are grateful for the memories she left behind.

In loving memory of Kareen Chin, may her soul rest in eternal peace.



President's Message

A Year of Dedication and Gratitude

by Irene Lim

Recently, I had the privilege of participating in a dragon boat challenge, an activity I never thought I would be able to do since I was diagnosed with lupus. It was through the inspiring efforts of Jean Eng and her team, Team Lupus, that I found the courage to take on this adventure. Jean's determination to raise awareness of lupus and her careful attention to protecting our health during the activity truly convinced me. With training sessions scheduled in the early mornings and evenings, and with the use of sunblock, long-sleeved tees, caps, and sunglasses, we were able to enjoy the experience while keeping lupus flare-ups in check.

On 11 November 2023, eight of us lupus patients participated in a Survivor Challenge as part of the annual DB Challenge event organised by PAssionWave@Marina Bay. I must admit, I was a little anxious at first. However, the spirit of friendly competition, the breathtaking view of Marina Bay, and the camaraderie among our teammates made it an unforgettable experience. It further reinforced that, with proper understanding and management of lupus, patients can lead fulfilling lives.

As we approach the end of another year, I want to take a moment to share my thoughts and express my heartfelt gratitude to all the volunteers and council members. Your tireless efforts have ensured another year of impactful work in patient welfare and support, patient and public education, and even lupus research. Your commitment and teamwork have been invaluable, and I am truly grateful for your contributions.

Additionally, I would like to extend a heartfelt thank you to members, sponsors, donors, and friends of LAS. Your continued support has helped us create a vibrant community for our members.

As we step into 2024, may it bring forth new opportunities, adventure and growth, and great blessings for each and every one of you. Wishing everybody a fantastic new year filled with joy and fulfilment!



会长的信息 奉献与感恩的一年

林瑾金女士

最近，我有幸参与了龙舟挑战，这是一项我从未想过能够参与的活动，因为我被诊断患有狼疮。正是通过吴静婷及其团队，“狼疮团队”鼓舞人心的努力，我才找到了勇气迎接这一冒险。吴静婷为提高对狼疮的认识所付出的决心，以及在活动期间对我们健康的细心关照，确实让我信服。通过在清晨和傍晚安排的培训课程，以及使用防晒霜、长袖T恤、帽子和太阳眼镜，我们能够在享受体验的同时控制狼疮的发作。

在2023年11月11日，我们八位狼疮患者参与了由PAssionWave@滨海湾组织的年度“同舟齐心” (DB Hearts Challenge) 挑战活动中的幸存者挑战。我必须承认，一开始我有点紧张。然而，友好竞争的精神，滨海湾的壮丽景色以及队友

之间的情谊使这成为一次难忘的经历。这进一步强化了，通过对狼疮的正确理解和管理，患者可以过上充实的生活。

随着又一年接近尾声，我想花一些时间分享我的感想，并向所有志愿者和理事会成员表达我衷心的感谢。你们努力不懈，确保了在病患福利和支持，病患与公众教育，甚至狼疮研究方面亦开展了一年有影响力的工作。你们的承诺和团队精神是无价之宝，我衷心感谢你们的贡献。

此外，我想衷心感谢所有的会员、赞助商、捐赠者和朋友们。你们持续的支持帮助了协会成功打造一个充满活力的社区。

随着我们迈入2024年，愿它带来新的机遇、冒险与成长，为我们每一个人带来更多的祝福。祝大家在新的一年里充满喜悦和满足！

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REACH US

Office Operating Hours
Monday to Friday, 12pm-5pm
Tel.: +65 6254 9130
Email: enquiry@lupus.sg
Website: www.lupus.sg

MAILING ADDRESS

Towner Road P.O. Box 460
Singapore 322101

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