



新加坡狼疮协会刊物

LUPUS LINK

WALK FOR LUPUS 2022



WHAT'S INSIDE

LAS Walk for Lupus 2022 ... 2 - 3

LAS Empowerment Talk Cum
Year-end Party 4 - 5

DB Hearts Challenge @
Passionwave 6 - 7

When Illness Becomes
Wellness 8 - 9

Lupus - The Wolf and the
Butterfly 10 - 11

President's Message 12

LAS WALK FOR LUPUS 2022



Sometime in mid-July, LAS received an email from Collin of Ideas Room, the event organiser whom we engaged for the LAS World Lupus Day and Lupus Awareness Month Event in May 2022. Collin, on behalf of Ideas Room, extended an invitation to us to participate in one of the segments of their SG57 Nation Walk event, the non-competitive 5-km walk. The SG57 Nation Walk event was aimed at getting true-blue Singaporeans, regardless of age or gender, to come together as "One people, One Nation" in celebrating Singapore's 57th birthday. Other nationals residing in Singapore were, of course, welcome to join in too.

The lure of the 5KM physical walk in the morning of 30 July 2022 at the Palawan Beach on Sentosa was hard to resist. The idea itself was exciting to us, to say the least. Palawan Beach, with its natural beauty and pristine shoreline, would be a great place to enjoy a breezy, scenic and idyllic walk with family and friends. The non-competitive nature of the 5-km walk would allow participants to walk or run at their own pace and, at the same time, soak up the atmosphere and enjoy the sea breeze.





Around that time, the Government had just began lifting most of the Covid-19 restrictions and LAS immediately recognised the invitation from Ideas Room as a great opportunity for our volunteers and members to get together for an in-person activity after more than two long years of suspended activities due to the Covid-19 pandemic. It would be a good time for everyone to gather and do an activity to keep fit together. Hence, it was decided that we would tag along the SG57 Nation Walk event and make it our own Walk for Lupus 2022. Afterall, our last WFL was held in 2016.

With only less than two weeks to go, the organising and planning including seeking of sponsors, printing of tee-shirts and dissemination of the event information to our members, etc. had to be executed with much haste. Very quickly, almost 50 persons registered with us and they included LAS members, and their family and friends and staff of sponsors, etc.

Other than the event organiser, Ideas Room, other sponsors for our event included:

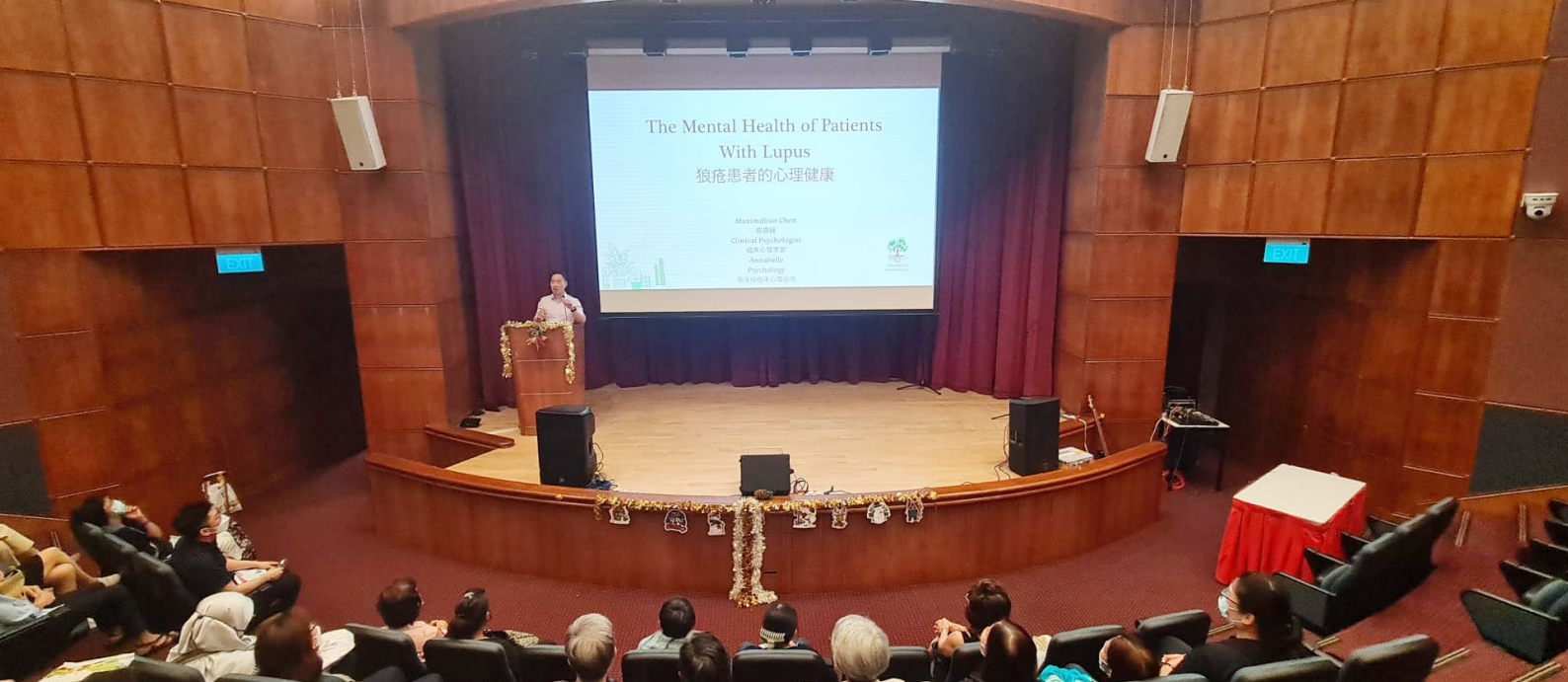
- BioMedix Pte. Ltd. who sponsored our tee-shirts
- Joo Hin Pte. Ltd. Sponsor for umbrellas
- Puro Water Pte. Ltd. Sponsor for bottled mineral water.

The day came and everyone was excited to see each other after a long time. The walk itself was fun and enjoyable. Everything went as planned and it was a beautiful day.

Our sincere thanks to all sponsors who made the event possible, the members who joined us and made our efforts worthwhile, and volunteers who helped ensure the event went smoothly.

We shall all look forward to the next LAS Walk for Lupus and other activities.





LAS EMPOWERMENT TALK CUM YEAR-END PARTY

On 10 December 2022, after almost 3 years of holding our educational talks on Zoom, we finally held our first physical LAS Empowerment Talk at the TTSH Theatrette alongside our Year-end Party.

Our members were really excited about seeing each other again after such a long time that they needed no persuasion to attend the event. There were happy and excited faces all round. The programmes included a talk entitled "Mental Health of Patients with Lupus" by Clinical Psychologist, Maximilian Chen, sharing by Lupus patient, Jean Eng, on "Against the Odds – From Illness to Wellness", music entertainment by "Afterglow" and a Lucky Draw. Bento lunch and drinks were provided as refreshments.



From the talk, we learnt that patients with SLE face significant stress and anxiety and often experience high levels of psychological burden. We were taught coping strategies and when to seek help. These are certainly important information for Lupus patients.

Getting together was not nearly as convenient and comfortable as in the old days, but nevertheless, we enjoyed each other's company and managed to have a good time.

Finally, we are heartened that our physical meetings and events are now back in full swing.



DB Hearts Challenge @ Passionwave



DB Hearts Challenge, which began in 2017, allows dragon boat paddlers from all walks of life, including those with disabilities, to participate and enjoy the activity.

Since 2019, DB Hearts Challenge, a ground-up initiative comprising volunteers from the local dragon boat community that seeks to be inclusive, has co-organised the race with PAssionWave @ Marina Bay.

The partnership between PAssion Wave and DB Hearts provides people with disabilities the opportunity to experience competitive dragon boat racing and necessary training alongside able-bodied paddlers in local community regattas.

After a two-year hiatus due to the COVID-19 pandemic, the race resumed on 5 November 2022.

This year's race involved 378 paddlers and 80 volunteers, with the paddlers competing under five main categories: Survivor Open, Corporate Open, Hearts of Passion, Adaptive Open (Intellectual) and Adaptive Open (Sensory).



Survivor Open includes cancer survivors.

Three teams of 22 paddlers competed in the Adaptive Open (Intellectual) category for paddlers with autism and Down syndrome.

Team Lupus took part in the Hearts of Passion category.

Through Ms. Jean Eng, founder of Team Lupus and a lupus patient herself, the Lupus Association (Singapore) was invited to set up a booth at the DB Hearts Challenge in 2019 and 2022. At the booth, we sold handicrafts made by our volunteers, raised funds through donations, and promoted awareness of the Lupus disease.

Lupus Association (Singapore) is proud of Ms Jean Eng, who embodies the goal of the association by way of encouraging and empowering Lupus patients to manage their condition through education, knowledge and positivity and to live their lives as normally as they can when their disease is under control.

Thank you, Jean! You are certainly an inspiration to many Lupus patients!





“同舟共济” Passion Wave 公益活动

“同舟共济”赛龙舟活动 (DB Hearts Challenge), 自2017年开始举办以来, 给各界的龙舟好手提供了一个划龙舟的大好机会, 其中也包括身心障碍者。

“同舟共济”活动原是由本地一群有善心的龙舟爱好者及志愿者发起, 自2019年以来, 成为由滨海湾Passion Wave联办。

Passion Wave 和 “同舟共济”携手合办的赛龙舟, 作为一项本地的社群活动, 给了身心障碍者一个和身体健全的划船爱好者共同竞赛, 共同训练的一个机会。

由于疫情关系, 赛龙舟活动停顿了两年, 但终于在2022年11月5日, 重新启动。

今年的竞赛共有378名划船选手和80位志愿者参与, 竞赛分为五大组别: 生存者公开赛, 集团公开赛, “热诚爱心”竞赛, 适应型 (心理障碍) 公开赛以及适应型 (身体障碍) 公开赛。

生存者公开赛主要是为癌症存活者而设。适应型 (心理障碍) 公开赛是为自闭症或唐氏综合症的选手而设, 共有22名选手。

红斑组 (Team Lupus) 则参加了“热诚爱心”竞赛。新加坡红斑狼疮协会在红斑组创立人Jean Eng 女士 (本身也是患者) 的安排下, 受邀在2019与2022年度的“同舟共济”龙舟赛设立了小棚子, 售卖志愿者制作的手工艺品, 并从中筹款, 同时向大众传达有关红斑狼疮的意识。

我们新加坡红斑狼疮协会很骄傲, 有Jean Eng 女士为大家发扬了协会的宗旨, 鼓励狼疮患者通过教育, 知识及正能量, 和狼疮共存, 在症状受控制的情况下尽可能如常生活。

感谢Jean! 你是我们许多狼疮患者的好榜样!



When Illness Becomes Wellness

Jean Eng

An Adrenaline junkie with a love for sports, I was identified as a daredevil pursuing extreme sports like motor cross, outdoor venturing and water sports.

Things changed in 2015 when I was first diagnosed with systemic lupus erythematosus (SLE). Initially, I experienced common ailments like a simple skin rash on my cheek the size of a penny and a slight swell on my wrist. I thought that it was the common athletic aches. I did not pay much attention to it until finally, I lost grip of my bike, and found that I had no strength to lift anything I once deemed easy.

The news following my blood test results was heart-breaking. Little did I know that SLE would go on to change my life thereafter. It has affected my kidneys and since it is incurable, I am taking immunosuppressive drugs and treatments to keep my immunity at bay. Throughout the years I have had SLE, I have experienced three episodes of flares that almost paralysed me. I was prescribed cyclophosphamide and I underwent episodes of increased prednisolone dosage.

The journey to control Lupus is a long and tough one. It disrupts one's emotional wellness and self-esteem to a great extent. The treatment changed my physical appearance and increased my cholesterol levels. As a result of these, I have to be mindful of my environment and my lifestyle. I have had to reduce rigorous sports and was advised to minimise sunlight exposure. I now take preventive actions like putting on coats of sunscreen and dressing up in long sleeves and hats to reduce UV exposure.

Nevertheless, I have come to terms with the condition. I have learnt to practise self-awareness, getting to know my body's reaction to the food I eat and my energy needs for the activities I participated.

Despite being a lupus patient, I figured that pursuing my passion, particularly dragon boating, has helped me physically and mentally. Dragon boating being a team sport, I have never felt any less, a part of the team. Consequently, Team Lupus was formed — to serve as an avenue to get together with like-minded people embodying perseverance and consistency. It has given me a purpose in life — to stay healthy.

To date, Team Lupus has participated in several community Dragon boat races, collaborating with the Lupus Association for the purpose of fundraising. It has developed into a purposeful sport that provides much exposure, broadening public awareness of Lupus. I hope the sport can serve as a social support for Lupus patients and their caregivers with its good vibes!

I wish all Lupus patients strength in fighting this battle gracefully and live their lives to the fullest. When "I" is replaced with "We", even "Illness" becomes "Wellness"!





排除万难，迈向健康生活

吴静婷

我向来热爱运动，也特别酷爱寻求刺激，参加过摩托车越野赛，户外探险和水上运动等极限运动，大家都认为我为视死如归的冒险家。

2015年，我被诊断患有系统性红斑狼疮(SLE)，一切突然改变。起初，我只有普通的症状，如面颊出现硬币般大的皮疹，手腕稍有肿胀。我以为不过是普通运动员都会经历的小疼痛，也就不去在意。直到后来，我骑摩托车时也无法紧握把手，最后连举起平时不觉得沉重的物件都感觉吃力。

验血报告出来时，给我很大的打击。没想到，SLE 红斑狼疮竟会彻底改变我的生活。它影响了我肾脏的操作，而且是无法治愈的，我只能服用免疫抑制剂和接受相关疗程，来应付免疫力的失调问题。受病患困扰这些年来，我经历过三次严重的症状加剧，几乎致使瘫痪。医生嘱咐我服用环磷酰胺，我也不时需要增加泼尼松龙的药量。

要抑制SLE症状，所面对是一个百般艰难的路途。以某种程度来说，它不但影响了我的心理健康，也打击了我的自尊心。治疗的过程不但改变了我的身体外观，也增加了我的胆固醇水平。

基于种种因素，我不得不特别注意自己的生活起居和日常环境。我被减少激烈的运动，也需要尽量避免晒到日光。现在的我，要就涂上一层又一层的防晒霜，不然就穿上长袖，戴上草帽，总之必须减低身体和紫外线的接触。

好在我已经接受了与病患共存的现实。我也学会了提高自我意识，多注意身体对不同食物的反应，以及参加各种活动时，自己能量所需。

虽然我是一名红斑狼疮患者，但我相信以往对于运动的喜好也给予我不少身心健康方面的锻炼，特别是划龙舟。划龙舟是一种团体的运动，我作为团队的一分子，也就无需顾虑自己是否落于人后。红斑队就是如此组成的。它提供了一个渠道，让志同道合的爱好者不屈不挠地坚持奋斗。它也给予我一个很简单的生命目标：就是要过着健康的生活。

红斑队如今已经参加过好些不同社团所主办的龙舟赛，也和红斑狼疮协会合作主办筹款活动。它已经演变成一种具有深刻意义的运动，也成为一种平台，借以提高社会人士对于红斑狼疮的意识。我希望这项运动能继续给患者带来更多各界的支持，也给患者的看护者带来更多鼓励！

我在此祝福所有红斑狼疮患者，希望大家都能以更平和的心态面对斗争，让自己的生命过得更加充实。当个别的“我”化成“我们”，“病患”也成了“共患难”，激励着我们，共同迈向健康的生活！



LUPUS - THE WOLF AND THE BUTTERFLY



Systemic Lupus Erythematosus (SLE), or Lupus for short, is an autoimmune disease where the patient's immune system attacks the organs and tissues instead of just protecting the patient against foreign invaders such as germs. It is like a soldier who attacks his own people instead of the enemy.

Lupus is a Latin word which means "wolf". The reason behind this is that some rashes in lupus attack the face and cause scars. Doctors in the old days thought they resembled wolf bites and hence the name Lupus.

The other animal associated with SLE is the butterfly. This is because some of the rashes caused by SLE are worsened when exposed to sunlight. This results in a rash on the face that is mostly on the cheeks, but not around the eyes or under the nose, resembling a butterfly. This type of rash is thus termed "butterfly rash".

Interestingly, the wolf represents all the bad things about lupus and the butterfly represents all the good things about lupus. You will notice that the logo for Lupus Association (Singapore) also resembles a butterfly.

What are some of the bad things about Lupus?

It affects women nine times more than men and the illness usually starts between the ages of 20 and 50.

Lupus is an autoimmune disease. Some other autoimmune diseases only attack one organ (e.g. autoimmune thyroid diseases). Lupus, however, can attack any organ in the body and therefore shows up in many different ways depending on which organ is affected. It can show

itself first as fever, rashes, joint pains, leg swelling, easy bruising, cough or even breathlessness. In fact, any symptom is possible. Lupus is therefore difficult to diagnose, earning itself the nickname the "Disease of a Thousand Faces".

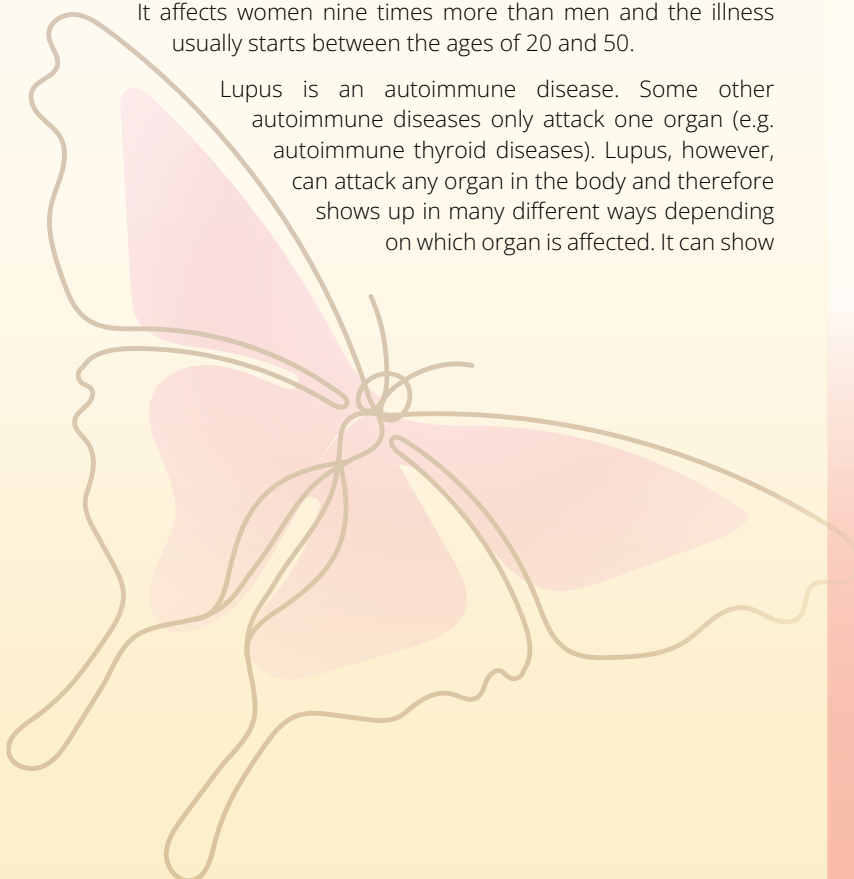
Diagnosis is not easy and treatment is no different. The Lupus doctor (rheumatologist) has to juggle between controlling the illness and avoiding side effects from the treatment. The disease arises because of an overactive immune system and medications are used to dampen the effect of the immune system. This can increase the risk of infections. For severe lupus, there is no choice but to use corticosteroids, a type of medicine that has many side effects. The rheumatologist will often add other medicines so as to lower the corticosteroid medicine to a safe maintenance dose.

For the patient, it is a challenge to understand what is going on. In the past especially, the patient may stop proper treatment, seek unproven treatments and return to the hospital in very bad shape. Uncontrolled lupus leads to organ failure (e.g. kidney failure) or even death. Not taking medicine properly to control lupus is like letting the wolf out of the cage.

What are some of the good things about Lupus?

Lupus is a relatively new disease in the world of medicine and was only properly described in 1982. Since then, there have been many changes for the better.

Firstly, although it is not a curable disease, it is definitely treatable. There is a difference between curable and treatable. An example of a curable disease is urine infection. There are germs in the urine that cause trouble. Antibiotics are given to kill the germs and that is the end of that episode of infection. A common example of a disease that is not curable but definitely treatable is diabetes. A diabetic patient needs to take medicine regularly for the long term to control his or her blood sugar levels. If the control is good, everything will be fine. However, if the blood sugars are always out of control, this can lead to blindness, kidney failure, amputated limbs or even death.



The same is true for lupus. In the 1970s, 50% of lupus patients died after five years. Nowadays, 90% of patients can survive for a decade and many survive beyond that. If the disease is well controlled, they can lead normal lives, have full-time jobs and even have children.

This improvement is because of a better understanding of the disease. This results in better strategies for treating lupus and also newer medications such as belimumab, mycophenolate mofetil and anifrolumab.

Patients also have better access to information and do not stop their own treatments so much like in the past. Much credit goes to nurses dedicated to patient education as well as groups like Lupus Association (Singapore), with their patient education and patient support activities and materials.

Conclusion

There is hope for the future. With more research and breakthroughs, treatment will continue to have better outcomes. There may come a time when lupus can be cured and not just controlled. Until that happens, things are still looking bright. Lupus today can be controlled so well that the patient can essentially lead a normal life.

The patient needs to cooperate with the doctor to make sure that they keep the wolf in the cage so that everyone can enjoy the butterflies.



**by Associate Professor
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President's Message

by Irene Lim

We have come a long way since COVID-19 changed our lives almost three years ago. For the Association, many activities were similarly disrupted and physical gatherings had to be halted, forcing us to adapt to the COVID-19 restrictions by transitioning to virtual sessions.

Over the past few years, life has not been easy for everyone as we had to make several adjustments to our daily lives. For the Association, we have not had the opportunity to gather together as much as we would have liked to. I hold several fond memories of the times spent together with members at physical gatherings, including our quarterly LAS Empowerment Talks, various volunteer and handicraft sessions and impromptu dinner meetups during the pre-pandemic days. Close friendships were built over these sessions, as everyone supported and cheered each other on, not only during the happy moments but also through the most difficult times. While there were virtual sessions after COVID-19 struck, they were not quite the same as face-to-face gatherings where we could talk, laugh, or simply offer each other a smile.

With the progressive lifting of the COVID-19 restrictions in 2022, we were able to slowly, but surely, recommence our physical activities. Earlier this year, our focus on patient education continued with the LAS Empowerment Talks, albeit held virtually. For the month of May, we organised 'Living with Lupus' in celebration of World Lupus Day on 10 May 2022. Living with Lupus saw the virtual congregation of our members, several medical experts and health professionals, including our founding member, Dr Boey Mee Leng. The event comprised several talks as well as physical and mental workouts, which not only

instilled in participants knowledge of lupus, but also how to manage it holistically. We also resumed our annual physical Walk For Lupus in July after a 6-year hiatus, and I am pleased to see members, volunteers and their families coming together like the good old days. In December, we can look forward to our yearly Christmas gathering where we can catch up with one another before the year draws to a close. The road to today was certainly not without challenges, and I would like to thank our members, volunteers and my committee for making the events happen as it is only with their dedication and commitment that they were made possible.

If there is one thing 2022 has taught me, it is that things will always get better. No matter how hard circumstances may be, they always get better with time. There is much all of us have to go through but let us keep holding on and not lose hope — there will be a rainbow waiting for us at the end. Merry Christmas and Happy New Year everyone, and I look forward to seeing everyone in 2023.



会长的信息 林瑾金女士

新冠疫情近三年来的肆虐，给大家的生活带来了莫大的冲击，如今才慢慢走出阴影。对于本协会，许多活动也无可避免地需要停顿下来，现场聚会被迫暂时取消，大家不得不适应疫情措施，改为在线上进行交流。

这几年来，由于日常生活都需要做出调整，大家都很难。本协会也难有机会像往常那样频繁地聚集在一起。我经常怀念和会员现场聚集在一块的场面，比如疫情前的LAS赋能讲座，各项志愿与手工艺活动和一些即兴的晚餐聚会。这些聚会都是大家培养感情，建立友谊的好机会，大家能够互相给予鼓励和援助，共同度过最开心或最黑暗的日子。疫情当前，大家改为在线上进行交流，但面对面的聚会总是难以相比，无法正常地聊天，欢笑，即便是给予彼此一个微笑。

随着2022年，疫情措施逐渐放松，我们终于慢慢得以恢复现场的活动。今年较早时，我们重新展开了针对患者的教育工作，得以举行LAS赋能讲座，虽说是在线上举行。到了五月，我们举行了“与狼疮共处”的活动，以配合2022年5月10日的世界狼疮日。“与狼疮

共处”的活动吸引了会员在线上的聚会，也有不少医药专家，保健专业人士等的参与，包括我们的创会成员，梅美玲医生。当天除了多场讲座之外，还有体操与心理练习的活动，不但让参与者获取关于狼疮的知识，也提供了如何面对狼疮的全面策略。七月份，我们恢复了一年一度的“为狼疮竞走”体育活动，这项活动已经停顿了六年。我很欣慰的是能够见到会员，志愿者和他们的家人共聚在一起，如同以往。到了十二月，我们又盼望到每年的圣诞聚会，大家得以在一年到头之前，欢聚一堂。这一路来的历程并不容易，我想在此感谢我们的会员，志愿工作者和我们的执委，因为唯有凭着他们的热诚和献身精神，活动才有办法成功举行。

假如有人问，2022年给了我什么启发，我想那就是：日子总有更好的一天，无论路途如何艰辛，假以时日，一切都会好。我们大家都难免要经历一些考验，但只要大家不屈不挠，坚持下去，不放弃希望，总会有一道彩虹等待着我们。在此祝大家圣诞快乐，新年进步，期待在2023年再与大家相聚！

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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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