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LUPUS LINK

COVID-19 & SLE: A NEW ERA FOR PATIENTS AND RHEUMATOLOGISTS?

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COVID-19: Evolving Healthcare

by Dr Anindita Santosa
Changi General Hospital

2020 was a year full of contradictions that marked the transition from the BC era (before COVID-19) to the AC era (after COVID-19).



COVID-19 resulted in stagnation and an apparent standstill in many facets of life, and yet 2020 was also a year in which healthcare and technology moved forward hand-in-hand at a rarely seen rapid pace. 2020 was also a year rife with social isolation, and yet it also resulted in the strengthening of bonds on a personal, professional and global level. It was a year where we experienced a lot of losses, but, at the same time, gained a lot as well. Objectively speaking, our losses appear to outweigh the gains – lives, livelihoods, regular childhood years, etc. It would, however, be ignorant to ignore the silver lining of the fallout of the pandemic: the advent of rapid drug and vaccine development, a better understanding of the immune system (albeit, this came with new mysteries and controversies), and the introduction of telemedicine and community health services.

The introduction of telemedicine in Singapore may appear excessive to some people. After all, Singapore is but a “red dot” on the globe. On top of that, it has a world-class transport infrastructure, and the restructured hospitals have a good variety of specialist medical care.

So, is there an actual need for telemedicine? As a rheumatologist, my answer to this question would be “YES”. Allow me to explain this by stating and explaining the following points:

Telemedicine prevents overcrowding of out-patient hospital facilities.

Space is a precious commodity, and more often than not, clinic waiting areas tend to be heavily populated by patients, caregivers and staff. In the AC era, measures to reduce traffic and overcrowding of public areas are likely to be the norm. Telemedicine allows doctors to continue managing patients with chronic conditions, especially if their condition is stable. The remote consult reduces unnecessary travels and potential exposures to infections.

Offloading of in-person consults would also allow specialists to spend adequate time with patients with active or severe disease. As this particular group of patients is usually on higher doses or more potent immunosuppressive drugs, the reduction of crowds also adds to their protection against exposure to infections.

Telemedicine allows ready access to healthcare for patients with mobility issues and elderly patients.

Patients with autoimmune conditions, such as lupus and other forms of inflammatory arthritis, may have difficulties travelling to see their specialists. There are also often concerns about the cost incurred by transportation, especially for patients requiring mobility aids. Telemedicine via phone consults or video consults may relieve patients of the burdens of transportation. The elderly require due care and consideration in ensuring that they have adequate support for efficient teleconsultation as digital literacy may be a limiting factor for them.



Telemedicine may also serve its role as an educational tool for the public, patients and caregivers.

Chatbots and mobile applications may provide advice on the self-management of specific symptoms, required lifestyle changes, straightforward advice on when to seek medical consultation. They may also direct patients to reliable information resources that are relevant to their conditions. More advanced functions may also direct patients on how to assess the activity of their disease, thus, prompting them to highlight issues to their managing doctors earlier.

Telemedicine may also be an educational aid for non-specialists and help streamline referrals and access to specialist clinics.

Autoimmune conditions, such as lupus, are rare and sometimes difficult to recognise in the early stages of the disease. Teleconsultations between non-specialists and rheumatologists may improve early recognition of the condition and, thus, timely referrals to specialists. As the early diagnosis and management of lupus are imperative for a better clinical outcome, we should not underestimate the value of telemedicine in facilitating early diagnosis.

Personally, I am an ardent supporter for telemedicine in rheumatology. This, however, does not mean that I would blindly adopt it for all my patients as nothing in rheumatology (and medicine) is ever a “one-size-fits-all” solution. More time and research would tell us whom telerheumatology would work best for. At the moment, I would adopt telehealth as a complementary modality to my routine medical care.

Disclaimer:

The views I have expressed in this article are my own personal views and do not necessarily reflect the views of Changi General Hospital and Lupus Association Singapore.

Telerheumatology certainly has its appeal and potential. However, given that it is still in its infancy, I would stress the need for cautious optimism at this stage and the need to continue working on developing the system to ensure that the quality of care delivered to patients remains uncompromised.

COVID-19 Vaccination in SLE Patients

Talk by Dr Chuah Tyng Yu
Sengkang General Hospital

Vaccines are one of the greatest success stories in public health. Vaccines work by simulating viral infection and train body's immune system to mount a response. Through the use of vaccines, many devastating effects of preventable infectious diseases like measles, diphtheria, and whooping cough are at an all-time low. It is the best defence we have against infectious diseases, but no vaccine is absolutely 100% safe or effective for everyone because each person's body reacts to vaccines differently. Studies show that COVID-19 vaccines are effective at keeping you from getting COVID-19. It has been shown that people with rheumatic disease (PRD) may be more susceptible to adverse outcomes from COVID-19 infection, possibly due to the increased clustering of comorbidities among these patients. With the development of vaccines, the future is becoming brighter, especially for people with lupus who might be at higher risk of complications from COVID-19 infection.

Messenger (m)RNA vaccines contain material from the COVID-19 virus that gives our cells instructions on how to make a harmless protein that is unique to the virus. After our cells make copies of the protein, they destroy the genetic material from the vaccine. Our bodies then recognise that the protein should not be there and build antibodies to fight the virus. So far, there is evidence that these approved vaccines are safe and efficacious; however, PRD on immunosuppression were excluded from the trials. However, recently there is data from observational study suggesting that the safety profile of messenger (m)RNA COVID-19 vaccines in people with rheumatic disease (PRD) is consistent with that seen in the clinical trial populations with the same expected local and systemic adverse event which is typically mild and consistent with the expected reaction from the vaccine. The study evaluated PRD who received their first dose of Pfizer/BioNTech respectively. Among all patients in the study, 28% are patients with lupus. There is also no evidence to think that people with lupus are at greater risk of vaccine allergy. Another reassuring point is that these are non-live vaccines. Hence, they cannot give you the viral disease nor can they change your genetic information.

It is ideal to vaccinate before the start of your immunosuppressant medications, but this is not always possible. A vaccination is most effective when the amount or level of immune-suppression is low; however, the risk of a flare of the disease is real when you reduce your medication, and therefore it is not advised to decrease your medication by yourself before consulting your rheumatologist.

There are case reports of disease flare or a new onset autoimmune disease following vaccination. However, there are also reports of a new onset autoimmune condition following COVID-19 infection. The risk of disease flares appears to be very low.

Increased viral transmission creates greater opportunities for the emergence of COVID-19 variants, thus increasing the likelihood of rendering resistance to vaccination. Hence it is important to have as many people vaccinated as we possibly can, reducing the chance of more transmission and mutation.

The general advice to people with lupus is to know your lupus disease activity, the treatment that you are taking and other medical conditions that you have before making the decision for vaccination. Always remember to discuss with your rheumatologist to make the decision together. People with lupus are also encouraged to continue following all public health guidelines regarding mask wearing, physical distancing and other preventive measures even after vaccination.



红斑狼疮患者 2019冠病疫苗接种须知

主讲者：蔡婷伊医生
盛港综合医院



疫苗是公共卫生方面最伟大的成功案例之一。疫苗的原理是模拟病毒感染和训练身体的免疫系统以启动免疫反应。通过使用疫苗，麻疹，白喉和百日咳等可预防传染病处于前所未有的低水平。这是我们抵御传染病的最佳防御措施，但是没有一种疫苗对每个人都是100%安全或有效的，因为每个人的身体对疫苗的反应都不同。研究表明，2019冠病疫苗能有效防止你感染2019冠病。研究显示，自身免疫性疾病患者较易受到2019冠病感染后的不良反应，可能是由于这些病人的合并症所致。随着疫苗的发展，未来正变得较好，特别是对于狼疮患者。

mRNA疫苗含有2019冠病病毒的物质，这些物质为我们细胞提供了如何制造一种病毒特有的无害蛋白质的指示。在我们的细胞复制蛋白质后，它们会破坏疫苗中的遗传物质。然后，我们的身体认识到，蛋白质不应该在那里，并建立抗体来对抗病毒。到目前为止，有证据表明这些经过批准的疫苗是安全和有效的；然而自身免疫性疾病患者没有在临床试验之内。最近有新的研究数据来自观察性研究表明，mRNA疫苗对自身免疫性疾病患者的安全状况是一致的。在临床试验人群中看到相同的预期局部和系统性副作用，通常是轻微的，与一般人口对疫苗的预期反应相同。这项研究评估了已经接受了第一剂辉瑞/BioNTech和第一剂Moderna的自身免疫性疾病患者。在研究的所有患者中，28%是狼疮患者。这项研究也没有证据表明狼疮患者对疫苗过敏的风险更大。另一个令人放心的一点是，这些通过批准的疫苗是非活疫苗。因此，它不能给你2019冠病病毒性疾病，也不能改变你的遗传信息。

在理想的情况下是当免疫抑制量或水平低时，接种疫苗最为有效。然而，当你减少你的药物时，疾病爆发的风险是真实的，因此在咨询你的风湿病学家之前，不建议自己减少你的药物。

在过去的病例报告中，接种疫苗后，有疾病复发或新的自身免疫性疾病发病，但也有报告声明感染2019冠病病毒性疾病后，触发新的自身免疫性疾病。虽然这些病例还处在研究的阶段，但疮病复发的风险总体上似乎非常低。

病毒传播为2019冠病病毒的变种创造了更大的机会，从而增加了对疫苗接种产生效果较差的可能性。因此，重要的是要尽可能让更多的人接种疫苗，以减少更多的传播和病毒变种的机会。

对狼疮患者的一般建议是：

- (一) 了解您的狼疮疾病活动
- (二) 了解您正在服用的治疗方法
- (三) 了解您的其他医疗状况

请记得和你的风湿病学家商量后一起做决定。

在这我想提醒大家，特别是对于服用免疫抑制剂的狼疮患者，在接种疫苗后，仍应继续遵守公共卫生和一般安全管理措施。

In Memoriam

Remembering Frances: Volunteering at Lupus Association

by Yeo Ngoh Kim



Frances Koh discovered she had lupus autoimmune illness in 1995. It debilitated her, causing joint pains, and inhibited her mobility. Nevertheless, she enjoyed volunteering at Tan Tock Seng Hospital on Wednesdays, visiting patients afflicted with the same disease and telling them how to bring it under control. She also continued working part-time three days a week until her retirement in 2016.

Through regular reviews and close management by her specialist doctors, Frances was able to lead her life as normally as possible. She exercised regularly and played tennis till she was too weak to do so.

In 2009, she was diagnosed with cancer but never gave up on her volunteer work at the Lupus Association. She faced her predicament with courage, continuing to work part-time and serving as a Lupus Association volunteer.

She was an avid supporter and would attend most of the talks and events organised by the association. She was equally generous not just with her time and effort but also made some personal donations to the association as she believed it had played a major role in supporting lupus patients positively.

Irene, the Lupus Association president, recalled that Frances undertook her volunteering duties very seriously. She was faithful and responsible in visiting inpatients each week until her medical condition deteriorated. Then she was relegated to manning the booth and bringing awareness about lupus to visitors of the hospital who wanted to know more, especially those with loved ones stricken with the same malaise. Her service as a volunteer was cut short by the advent of COVID-19,

which halted such activities.

Frances suffered a relapse in her cancer and was told by her oncologist that her situation was terminal and her life span was shortened. Many of her fellow volunteers regretted not being able to bid farewell to her as she passed away during the circuit breaker period.



Geok Hong, who partnered her during the inpatient visits, remembered her fondly for her dedicated and faithful service over more than 20 years. She noticed that Frances was an ardent supporter of their activities and would eagerly lend a helping hand at their meetings and talks even though, at times, she was not in the best of health. She was impressed with Frances' positive outlook and appreciated the cheerful and

helpful attitude she displayed on those occasions.

Siang Gek, who is a Christian, felt that Frances had shown patience and courage in facing her twin ailments of lupus and cancer due to her faith in God. She was optimistic and shared with lupus patients who were warded her experience and confidence

in God in being able to lead a fulfilling life. She would tell them that the disease will be under control when you take your prescribed medications regularly and not miss your appointments for reviews with your doctors. Like her, they could still lead a normal life.

Apart from the inpatient visits, the team of volunteers would support each other and often go for lunch after their visits. They also played Rummy-O, sang and did craft work together, forging close friendships and celebrating each other's birthdays.

Both Nancy and Lian Son saw in Frances a "never give up" attitude as she still joined them on Wednesdays even though her medical condition deteriorated during her last days. They felt her immunity was low, but she would still come in early to help Geok Hong set up the awareness booth.

All her fellow volunteers were sad to see her go, but they remembered the good moments they had shared together and the camaraderie experienced as a group.



永在怀念中

悼念许凤玉女士，一位为狼疮协会奉献的志工

文/杨娥



许凤玉女士在1995年发觉她患上狼疮病症。病症逐渐削弱她的免疫系统，导致关节疼痛，并且造成行动不便。尽管如此，她每个星期三还是兴致勃勃地在陈笃生医院当志工，探望与她一样，患上狼疮症的病人，与他们分享如何控制病情。她也继续每个星期做3天的兼职工，一直到2016年退休为止。

在专科医生定时为她检查身体及密切的医疗管控下，凤玉可以过正常的生活。她时常运动，及打网球，直到她的身子变得虚弱为止。

她于2009年患上癌症，但从没放弃担任狼疮协会的志工。她勇敢面对窘境，继续做兼职及当狼疮协会志工。

她是充满热忱的支持者，总会出席许多协会举办的讲座及活动。她不只奉献时间、精力，也以个人名义捐款给协会，因为她坚信协会能赋予狼疮患者正能量，让他们积极面对病情。

协会会长林瑾金女士回忆凤玉认真看待她的志工岗位。她忠实与负责任地每个星期探望住院的患者，直到她的病情恶化。后来，她被安排担任狼疮亲善大使，管理医院的一个摊子，为医院访客解释狼疮病症，尤其是已有家人朋友患上同样病症的访客们。冠病骤然降临，以及随之而来的防疫措施，结束了凤玉在这方面的志工生涯。



凤玉后来癌症复发，她的肿瘤学主治医生告诉她这是末期癌症，生命会因此缩短。凤玉在冠病阻断措施期间离世，许多志工们都后悔没有和她正式告别。

方毓凤是一位与凤玉一起搭档探访医院病人的志工。毓凤说，凤玉最让人津津乐道的，就是她那超过20年，孜孜不倦当志工的奉献精神。她观察，凤玉总是踊跃支持她们的活动，即使她不是在最佳的状况下，也在开会时帮助她们。凤玉正面的形象在毓凤的脑海里留下深刻的

的印象，也被凤玉在这些场合所体现的友善和乐于助人的态度所感动。

祥玉，一位基督教徒，觉得凤玉能有耐心及勇敢同时面对狼疮症及癌症的侵袭，得归功于她对于神的虔诚信仰。凤玉总会乐观地于住院的狼疮患者分享她的经历，及对于神坚定不移的信仰，如何帮助她过充实的生活。凤玉常说，只要定时服药，和不错过与医生的定期检查，就可以良好地控制病情。他们一样可以如她，过正常的生活。

志工团队除了探望住院患者，也会互相支持，并在探访后一起享用午餐。她们也一起玩拉密，唱歌及做手工艺，从中培养深厚的友谊，和庆祝彼此的生日。

陈彩虹和连顺亲眼见证凤玉那种“永不言败”的态度。凤玉在生命即将结束的日子里，即使病情每况愈下，还是坚持每个星期三参加她们的活动。她们觉得凤玉免疫系统较弱，但凤玉还是提早报到，帮毓凤设立让人们多了解狼疮病症的摊子。

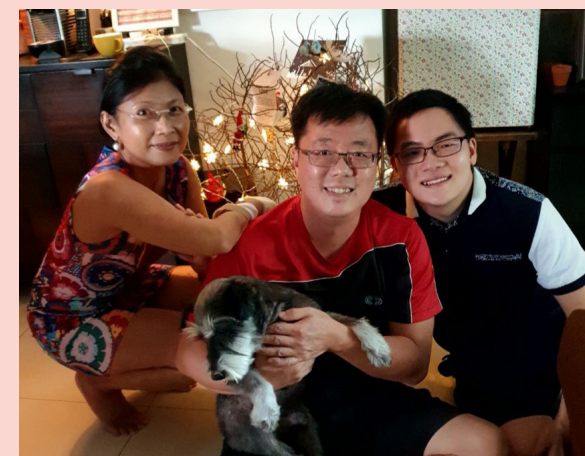
全体志工固然舍不得凤玉逝世，但她们都会记得与凤玉共同度过的美好时光，与在团队所建立细水长流般的友谊。

Patient Perspectives: How Has COVID-19 Affected Me?

Three of our members described how the pandemic has affected their daily lives, emotions and outlooks in life.

by Linda Woo

Life, as we know it, is precious and transient. Will things go back to the way they were before COVID? Maybe. But, at this point, even the smartest doctors and scientists cannot answer all the questions.



With spiralling number of cases, borders were closed, lockdowns were implemented and manufacturing slowed to almost a standstill.

Skies cleared, and the air became clean. Rivers refreshed. Some families grew closer while others, which were already breaking, broke up completely as they could not bear the lockdown together. Likewise, those who were not in good health or living in a developed country, succumbed to the disease. Yet, many others recovered. Such is life. Some people are killed by the flu virus, yet many others survive. Some survive cancer, others succumb. Disease is a great equaliser.

During the circuit breaker (CB) period, my small family of three cooked every meal at home and stayed entertained by watching Netflix. We took long morning walks, maintained a healthy weight and grew closer. The “work from home” situation made me realise how blessed my husband and I are that we could work safely from the confines of our home. It became evident that not all are as fortunate. We take so much for granted.

I am reminded how much my husband loves me because he would drive me to all my medical appointments and fetch my dad, too, because he did not want us to be unnecessarily exposed. It also led me



to appreciate that my son became more responsible and conscientious about hygiene. He would avoid going out or made sure that he used the sanitiser and washed or bathed immediately once he got home to minimise any risk of contamination as he is concerned for my compromised immune system.

With the easing of CB, we started cooking and having neighbours over for meals and neighbours reciprocated, too. In fact, because we worked from home, there were two occasions when our little old car could not start and one of our neighbours came to our aid! Both times. Embarrassing indeed but it was heartwarming, too.

Not going out also meant no shopping and no unnecessary purchases! Not entirely good for the economy but nice on our bank balance.

Our dog was the happiest as, for the entire month, he was never home alone...

The greengrocer and I became friends as we would frequent her stall twice a week for fresh greens and fruit. And, since I had time, I baked and passed her goodies. I have since neglected her because life has gone back to almost pre-CB days of eating out and I gained 2 kg!

Given that we had time on hand, I started attending an online Bible class with my hubby to enrich our faith and build my relationship with God. I hope our patience, gentleness and compassion grow along with our knowledge of the Scripture, too.

Will the vaccines work? When will air travel resume? I have many friends who cannot wait to travel again and many have families overseas. For their sake, I hope that these issues will be resolved soon.

Honestly, I am not in any hurry to be vaccinated nor am I suffering from travel withdrawal symptoms. I look back with gratitude that I spent time in Melbourne, Sydney, Moscow and St Petersburg just months before COVID descended. And should COVID or anything else claim my life one day, so be it. The journey to Heaven has to involve dying at some point.

My 20-year-old kidney transplant, my 21-year-old son, my 25 years of relationship with my hubby, the people I have come to know and appreciate, made me realise that life is about the relationships built. Everything else is a bonus.

This pandemic has helped me slow down. It made me realise, I am not Superwoman! The reason I feel alive is because of the relationships I have. If my kitchen floor is oily, it's okay.

by Haresh Buxani

**Attention Lupus Warriors!
I hope everyone is fine and safe...
Thinking about COVID-19 is a
harrowing feeling – waiting for test
day and hoping for the results to be
negative. Whatever it is, our mindset
should be positive!**



The year 2020 has been a time of reckoning. It forced us to slow down and wash our hands often with hand sanitiser. We emerged stronger, did more meaningful tasks, and achieved several breakthroughs despite needing to wear face masks whenever we go out.

The pandemic has changed the way we do things. For our survival, we stay home and go out for essential items only. We don't meet friends or go to crowded places like we used to.

The year 2020 made me realise who are the most important people in my life... my family, Sikh temple friends, lupus volunteers, and a few angels.

It was a year when I picked up good habits and learned new things. Life is challenging because of my struggle living with systemic lupus erythematosus (SLE), also known as lupus. SLE is an autoimmune disease in which the immune system attacks its tissues, causing widespread inflammation and tissue damage in the affected organs. I also suffer from antiphospholipid syndrome (APS), sometimes known as Hughes syndrome. It is a disorder of the immune system that causes an increased risk of blood clots. Besides, I suffer from muscle Inflammation. My right leg was amputated above the knee in 2008.

Thanks to God and my doctor, Associate Professor Leong Keng Hong, who gave me suitable medication to protect me from COVID-19 and other diseases. I hope and pray the pandemic ends. We have suffered a lot. I wish everyone a better 2021 and a greater 2022.

by Sylvia Sim

Everything I do is to walk well on my last journey to my eternal home... I uplift myself each day and then spread this uplifting to others.



In the year 2020, I had no volunteering duty, so I could spend all my time creating new kinds of lamps, which I sell. I donate part of the takings to the Lupus Association. During CB, I also sewed masks for the toilet cleaners at Pasir Ris Park and, thus, interacted with them. I asked our town council to remind the weekenders at the park to keep it clean. It is very fulfilling when I am able to help others.

During the pandemic and while the vaccine is so new, one has to follow the rules of social distancing, wear a mask and avoid crowded places. As I am not on medication, I have to really take care of my health.

The circuit breaker period stopped everything. All my volunteering work stopped. I also stopped seeking regular treatment to straighten my curved spinal cord. Since I have more time at home, I refocused on creating more creative lamps



and even started using wine bottles. From just decoupage work, I went on to "acrylic pour" and added paper cuttings designs. I allowed my creativity to flow and came up with different themes and moods for the lights, not leaving out various looks and options for the fastenings. Freefalling into the creative realm has allowed me to create unique, one-of-a-kind pieces worthy of being dubbed artworks. I look forward to continuing retouching completed lamps to beautify them further. This brings me lots of joy.

Everything I do is to walk well on my last journey to my eternal home.. I uplift myself each day and then spread this uplifting to others. I now have Christian, Buddhist, Hindu and Muslim friends.

My activities are all positive and, physically, I am doing well. I am not affected at all by the COVID situation. In fact, to me, COVID-19 has its positive side. It promotes cleanliness everywhere. With the government's support for the people, we are all able to live quite normally and well.

COVID-19 is a crisis, but I see it as a blessing. We all began to appreciate our government more. We appreciate help and prayers more. It's all in our mindset. To do or not to do. That's the question.

And this is living life for me, until my next lupus attack. I pray that it never recurs. I exercise my spirit, soul and body. My last lupus attack brought on mental depression, yet I overcame it. Everything is mind over matter. I cultivated my green fingers. Then God added creativity in arts. He added more wisdom and there was the joy of sharing. There is grace and love. Above all, I am learning to totally trust the timing of the Holy Spirit.

President's Message

by Irene Lim



Year 2020 was a tough year for everyone due to the COVID-19 pandemic. Compared to some countries, Singapore has generally been faring better in this dire situation. We can count ourselves lucky to have a team of capable leaders taking care of us.

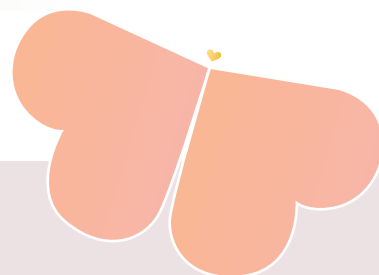
Sure, our lives have changed. COVID-19 has taught us many painful lessons, but we also learnt to appreciate life more, be grateful for what we have, and treasure relationships, friends and family.

At Lupus Association, we try our best to continue with our work. We organised our first webinar "Coronavirus (COVID-19) and Lupus" on 26 September 2020. Our annual general meeting was also held at the same time. The webinar was a success, and we had a good turnout. We will continue to organise more webinars to keep our members and lupus patients updated and engaged.

Let us look forward to the improvement of our situation soon with the vaccination rollout.

As always, stay safe and be happy!

Cheers!



会长的信息 林碯金女士

2020年对每个人而言，因为冠病19疫情的关系，是艰难的。与其他国家比较，新加坡防控冠病疫情的成绩斐然，是有目共睹的。最关键的是，我国有一群能干的领袖为民谋福祉，我们应该为此感到万幸。

当然，我们的生命因为疫情添增变数。冠病19疫情固然给予我们许多痛苦的教训，但也同时让我们更加珍惜生命，感恩当下所拥有的，珍视各种关系、朋友及家人。

狼疮协会一如既往，继续竭尽所能做好我们应

该做的事情。我们于2020年9月26日，举办首场“冠病19病毒与狼疮”在线研讨会与常年会员大会。这次的在线研讨会举办得非常成功，会员们都踊跃参与。我们会继续举办更多在线研讨会，让会员及狼疮患者获得最新的资讯，并保持联系和互动、交流。

随着冠病疫苗接种计划如火如荼地展开，让我们一起期待疫情早日好转。

请继续注意安全、保持心情愉悦！

加油！

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