



# LupusLink

新加坡狼疮协会刊物

A LUPUS ASSOCIATION (SINGAPORE) PUBLICATION

Approximately one-third of patients suffering from Systemic Lupus Erythematosus (SLE, or Lupus) will develop kidney problems that will require further examination and treatment. If the damage to the kidney is a direct result of SLE, the terms Lupus nephritis or Lupus glomerulonephritis are used. The extent of kidney involvement can range from very mild to severe.

## THE SYMPTOMS OF LUPUS NEPHRITIS

In the early stages of Lupus nephritis, there are no apparent symptoms. When the kidneys are damaged, they become 'leaky' causing protein and or blood to be leaked into the urine. If there is a large amount of protein present, the urine may appear frothy or foamy. The loss of protein into the urine can also cause swelling (Oedema) in the legs or all over the body which may be the first noticeable symptom. It is important to note that kidney problems in SLE may not always be due to Lupus nephritis. Sometimes other factors can cause kidney damage such as infections or side effects of medications.

## THE DIAGNOSIS OF LUPUS NEPHRITIS

The first assessment is usually a urine dipstick test. It is simple and can effectively detect the presence of blood and protein in the urine. Blood in the urine is called haematuria and protein in the urine is called proteinuria. If either of those conditions is detected in the urine, further examination may be required. The next assessment is usually a 24-hour urine collection. Urine is collected in a special container which provides an accurate measure of the protein loss over a day.

Blood tests, albumin or serum albumin, will help to determine how much protein has been lost by the kidneys. A renal panel will test and determine how well the kidneys are functioning by estimating the creatinine clearance or glomerular filtration rate (GFR). Some indicators of SLE activity may also be measured. Complement levels (C3 and C4) and anti-double-stranded DNA (anti-dsDNA) are gauges of how active the disease is or if it is likely to develop into Lupus nephritis.

Imaging tests such as ultrasound, intravenous pyelogram (IVP) or CT and MRI scans may be used to determine if the damage

# Lupus and the Kidney

Dr Jane Clayton, Consultant Rheumatologist  
Department of Medicine  
Alexandra Hospital, Jurong Health Services

to the kidneys is due to other causes besides SLE as well as aid in determining if it is safe to perform a biopsy. If the possibility of Lupus nephritis is detected, a biopsy will be performed. This involves inserting a needle through the back and removing a small piece of kidney tissue which is then examined under a microscope to observe the degree of inflammation or damage.

There are five classes of Lupus nephritis:

- **Class I:** the kidneys look normal, with no clear indication of Lupus nephritis
- **Class II:** a mild form which usually responds completely to treatment
- **Class III:** an early stage of the severe form of Lupus nephritis
- **Class IV:** an advanced form of Lupus nephritis – more than 50% of the kidneys affected
- **Class V:** an advanced form of Lupus nephritis – usually a large amount of protein present in the urine and it can be associated with Oedema

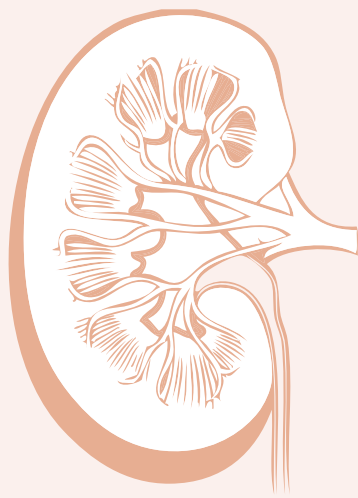
## THE TREATMENT FOR LUPUS NEPHRITIS

Treatment is dependent on several factors, including the amount of protein and or blood in the urine, how much kidney function has been lost and the pattern of damage detected on the kidney biopsy. The two major classes of drugs used to treat Lupus nephritis are corticosteroids (e.g. prednisolone and methylprednisolone) and immunosuppressive agents (e.g. cyclophosphamide and mycophenolate mofetil). Corticosteroids are given in high doses and reduced upon improvement. Immunosuppressive agents are used in more severe diseases. Rituximab, a new therapy, may also be used.

If the disease progresses despite drug therapy and the kidneys fail, dialysis may be required. Once the disease has stabilized, kidney transplantation may be an option for some patients.

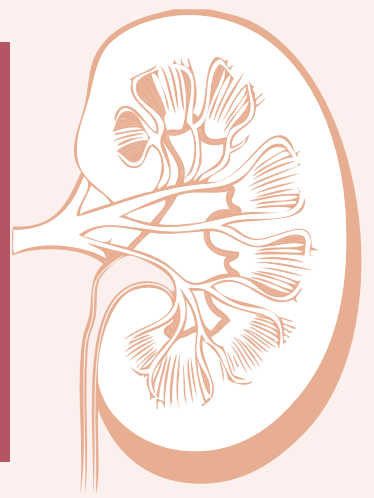
## THE GOOD NEWS

In the past few decades, there have been major advances in the diagnosis and treatment of Lupus nephritis. Over 80% of patients suffering from Lupus nephritis will not have their life spans affected.



# 红斑狼疮和肾脏

Dr Jane Clayton,  
风湿和免疫顾问  
亚历山大医院



## 简介

大约三分之一狼疮病患会患上肾脏问题而需要深入检验和治疗。如果肾脏问题是由狼疮病直接导致的，一般称为狼疮性肾炎或狼疮性肾小球肾炎。肾脏的受损程度从轻微至严重，是一种可变成很严重的重要病症。

## 狼疮性肾炎的特征

狼疮性肾炎在疾病早期没有任何症状。当狼疮损害肾脏时，蛋白质或血液将渗入尿液里。如果大量蛋白质渗入尿液，尿液会见有泡沫，也可能导致水肿，尤其是脚踝和全身。这是初期的特征。有一点该留意的是，并非所有肾脏问题都是由狼疮引发的。其他因素，如感染或由药物引发的肾脏疾病也可能导致肾脏问题。

## 如何检验是否患有狼疮性肾炎

第一个测试是尿检（尿液测试）。检验尿液中的蛋白质和血液是一种简单且普遍的测试。尿液中带有血液叫做血尿（haematuria），而尿液中带有蛋白质叫做蛋白尿（proteinuria）。如果在尿液中发觉血液或蛋白质，则可能需要进一步检验。下一个测试是进行二十四小时的尿液收集。尿液将存在一个特殊的容器内，而这将更准确测量一日所流失的蛋白质。

血液测试能确认肾脏流失的蛋白质。这个测试称为血清蛋白（albumin or serum albumin）。进行肌酐（creatinine clearance）和肾小球滤过率/肌酐清除率（glomerular filtration rate）能检验肾脏功能。这也能测量狼疮活动。补体水平（C3 和 C4）及抗ds-DNA抗体（Anti-double-stranded DNA）能测量狼疮病情，而倘若患有狼疮性肾炎，这两者将提高。

成像测试（Imaging Tests）如超声波（Ultrasound）、CT扫描（电脑断层扫描）（CT Scanning）、磁力共振扫描（MRI）或静脉肾盂造影（Intravenous Pyelogram）能用来检测肾脏受损原因，也能确认是否能进行肾脏活检（肾穿刺活

体组织检查）（Biopsy）。如果怀疑患有狼疮性肾炎，将进行肾脏活检。这检验是从腰后插入一根特殊的长针取出一小块肾组织放在显微镜下检查，以评估肾脏已有多少炎症和/或损耗。

## 狼疮性肾炎的分类：

- 1型 肾脏正常 -- 没有狼疮性肾炎象征
- 2型 最温和的形式，通常可完全治愈
- 3型 晚期肾炎的最早阶段
- 4型 晚期肾炎，超过50%肾脏蒙损
- 5型 晚期肾炎，通常有高量蛋白质流失。或可用类固醇和免疫抑制药物治疗。

## 如何治疗狼疮性肾炎：

- 1) 治疗根据以下因素，如尿中蛋白质或血液的分量、损耗的肾功能的程度和肾脏活检结果。
- 2) 药物治疗一方，共有两种类型的药物用于治疗狼疮性肾炎。
  - a) 糖皮质激素（Corticosteroids）如：泼尼松龙（Prednisolone）和甲泼尼龙（Methylprednisolone）
  - b) 免疫抑制药物（Immunosuppressive agents）：用于更严重的狼疮性肾炎。最常用的细胞毒性药物是：
    - 环磷酰胺（cyclophosphamide）
    - 吗替麦考酚酯（mycophenolate mofetil/MMF）
    - 利妥昔单抗（Rituximab）-最新的药物
- 3) 肾功能衰竭

在某些情况下，尽管已给予适当的药物治疗，也可能形成肾脏衰竭。倘若如此，就需要洗肾。除此之外，其他选择包括肾脏移植。一旦病情稳定，病人可以被安排肾脏移植。

## 好消息：

在过去的几十年来，医学界对于狼疮性肾炎的理解和治疗已经有重大进展。80%以上的狼疮性肾炎患者能有正常寿命。

# *I have been diagnosed with Lupus. What Should I Do Next?*

By Haresh Buxani

In life, we have two options: we can be miserable and ask, "Why must it happen to me?" or we can stay positive, and be thankful for the things we still have.

I make an effort to stay optimistic and remain confident in the team of doctors and nurses that tend to me. Let me share my experience in discovering and managing my condition Systemic Lupus Erythematosus (SLE, or Lupus) and Antiphospholipid Syndrome (APS).

I can vividly recall the events that occurred 5 years ago, in June 2008. I was told that in order to save my life, my right leg had to be amputated. At that point, things were beyond my control. I did not suffer from hypertension, high cholesterol, diabetes, heart or kidney problems; conditions that would have predisposed blockage of the blood vessels in my legs. However, my legs had become swollen, and over 3 months, my right leg had become cold and numb due to poor blood circulation. I was advised by my doctors to have it amputated. It was a difficult decision as time was of the essence and I did not have much of a choice as my leg was deteriorating and beginning to darken due to the lack of proper blood circulation. When I was formally diagnosed with Lupus and APS, I slipped into depression and cried a lot during that trying period.

Slowly but surely, I decided to regain control of my life using small positive steps. I made lists of the positive things in my life daily whilst warded in the hospital and steered my mind away from negative thoughts. I visualized the things that I could accomplish and convinced myself that I could achieve them. I imagined walking with the aid of my prosthetic leg and a black walking stick. This empowered me and I managed to walk again 7 months after my operation.

I began writing a book to motivate through my experience. It has taken me 4½ years to complete it and I am now looking for a publisher in hope of providing a source of aid, encouragement and comfort to patients suffering the same fate as myself.

I started the Marina Bay walking group on 4 June 2012. This walking group has approximately 1100 active members from all walks of life. We walk every Saturday morning at various parks in Singapore. A month later, I established the Walk for Lupus walking group. This group walks once a month at sunset hours. The walks are great opportunities to stay healthy and to make friends. I am also a volunteer at the Lupus Association Singapore.



On World Lupus Day 2013, the Marina Bay walking group walked 3.5 km along Marina Bay Waterfront Promenade. In my opinion, I feel that there is a need to create and increase public awareness about Lupus as few have heard of or have knowledge about it, unlike common diseases such as cancer. It is also important for patients to explore ways to cope with the stress of suffering from Lupus. I believe that frequent exercise and relaxation will make it easier for Lupus patients to battle the disease. Exercise not only reduces stress, lifts the mood, but also improves sleeping.

Stay active and positive always. May you be blessed with good health!

# 我得了红斑狼疮 接下来该怎么办？

Haresh Buxani 著

在人生当中，我们只有两种选择：

一、痛苦消沉，不断思索：“为何是我”。二、积极乐观，对我们所拥有的事物心存感激。

我尝试持有乐观的态度，积极向前看并且信赖照顾我的医生和护士们。让我分享我的故事。

我清楚地记得2008年6月，五年前的情景。那天我躺在医院，正要进行手术，将右脚截肢，保住性命。当时，我的人生不在我的掌控之内。

我没有高血压、高胆固醇、糖尿病、肾脏或心脏等毛病，不会导致脚部血管阻塞。但是，我的双脚浮肿。在三个月内，由于血液循环不良，我的右脚麻痹僵硬。于是，医生劝我截肢右脚。这不是个容易的决定，况且我得在短时间内做抉择。但是，我的右脚逐渐发黑，我别无选择。此外，我也被诊断患上红斑狼疮（Systemic Lupus Erythematosus or Lupus）和抗磷脂综合征（Antiphospholipid Syndrome）。

我不停的责问自己为何这些事发生在我的身上、为何我没有做过坏事却要历经煎熬。那段期间，我患上忧郁症，常常哭泣。

逐渐地，我决心一步一步，正面的向前走，以找回人生的掌控权。住院期间，我记录了生命中的正面事物，并且改变思维。我设想自己能够完成的事物，而且必须坚信自己能够做到。我想像有一天，装上义肢，手持黑色拐杖，重新走路。这给予我力量。手术结束的七个月后，我终于能够重新走路了。

我希望能够鼓励其他狼疮病人，因此将我的心路历程写成一本书。这花了我四年半的时间。目前，我正在寻找出版社，希望出版这本书能够给予狼疮病人一点帮助。

我在2012年6月4日发动了“滨海湾3.5公里健走兼聚会”团队。这个团队有大约一千三百名会员，他们都来自不同社会阶层。参加这个团队不需要报名费的，欢迎随时加入。每个星期六早上八点，我们会在新加坡各个公园集合。一个月后，我发动了“狼疮健走”团队。每月一次，我们在黄昏时分健走。健走是个保持身心健康和结交朋友的好机会。我也是狼疮协会的义工。

2013年世界狼疮日当天，我们在滨海湾宝龙坊进行3.5公里的健走路程。我们必须提高公众对红斑狼疮的认识。很多人都认识“癌症”，但是很少人认识“红斑狼疮”。此外，狼疮病人也应该寻找解压方式。我觉得运动和学习放轻松能帮助病人。运动能减压、改善心情和睡眠素质。

祝你们身体健康！要记得保持健康活力和持有积极乐观的态度。



## Warren Golf & Country Club

### Captain's Day 2012

*A Charity Fund-raising Event  
in aid of Lupus Association  
(Singapore)*

The Warren Golf & Country Club held their annual **Captain's Day** tournament on **Saturday 24 November 2012**. It was an afternoon game organised by their Club Captain, Mr Steve Poh, whereby each participating golfer placed a \$10 bet to challenge him. Mr Steve Poh very kindly pledged all his winnings to 2 charitable organisations. Lupus Association Singapore (LAS) was one of them.

The tournament was followed by a charity dinner in the evening. There was an auction segment during the dinner to further raise funds for the charities. I was overwhelmed and heartened by the zealous support and generosity of the club members. Many of them successfully bid for the items and then donated them for re-auction. I witnessed a spirited and robust auction that collected more than S\$100,000. The club donated S\$54,800 to LAS. It was indeed a good way to let the golfers have a fun game of golf and, at the same time, do their bit for charity. We are very grateful to Mr Steve Poh for his kindness and support of our association.

## 沃伦高尔夫乡村俱乐部 (Warren Golf & Country Club) - 高尔夫球日 2012 (Captain's Day 2012)

### 新加坡狼疮协会慈善筹款活动

2012年11月24日，沃伦高尔夫乡村俱乐部（Warren Golf & Country Club）举办了年度高尔夫球日（Captain's Day）。球赛是在下午举行，由高尔夫球队队长，Mr Steve Poh负责。参赛的高尔夫球手将下十元赌注挑战队长。

Mr Steve Poh慷慨地将所有获胜的款项捐给两家慈善机构。新加坡狼疮协会是其中之一。傍晚时分，高尔夫球赛结束后，则进行慈善筹款晚会。晚会当中的一项慈善拍卖会，则进一步为慈善筹款。

沃伦高尔夫乡村俱乐部成员们的踊跃捐助与热心支持令人鼓舞。在拍卖会上，很多成员们成功竞标后，将拍品再度捐赠供拍卖。这次的拍卖会共凑得了10万元款项。沃伦高尔夫乡村俱乐部将五万四千八百元捐给新加坡狼疮协会。这项活动让高尔夫球员进行球赛之余，为慈善尽一份绵力。我很感谢Mr Steve Poh的善心与热心支持。





# LUPUS ASSOCIATION SINGAPORE COMMEMORATES **WORLD LUPUS DAY!**

Irene Lim  
President  
Lupus Association, Singapore

**L**upus Association Singapore (LAS) honoured World Lupus Day on 10 May 2013 with a booth situated at the Singapore General Hospital (SGH). Other than an annual commemoration, the event served as an excellent platform for our association to reach out to a wide network of Lupus sufferers and to create and increase public awareness of the disease.

Preceding the event, LAS put up World Lupus Day event posters at the Rheumatology clinics in various hospitals to promote the affair. On World Lupus Day, The New Paper ran an article to notify the public of the event. The Chinese newspaper, Shin Min Daily News, published a moving story of one of our young patients, Huang Li Zhen, detailing her experiences with the disease.

During the event, we were fortunate to have our booth located at a vantage point where human traffic was high. Our volunteers were

kept busy distributing information booklets, addressing public queries, and selling handicrafts. People had started approaching our booth even before we had finished setting it up with many curious about the uncommon or otherwise, unknown disease called Lupus. There was a significant number of Lupus sufferers amongst the crowd. Even the SGH staff were eager to expand their knowledge of the disease. A number of doctors visited our booth as well. Our handicrafts were well-received and we made good sale at the event. The donation box was also generously filled up.

LAS achieved its goal in reaching out to Lupus patients as well as to the public. We would like to express our appreciation to SGH, their staff and those who rendered unreserved assistance to make the event a success. We would also like to thank the people who visited our booth. LAS is confident that these individuals have gained a greater understanding of Lupus. We look forward to organizing an event of larger scale next year!

## 新加坡狼疮协会响应世界狼疮日

林碯金  
主席  
新加坡狼疮协会

每年的5月10日是世界狼疮日。2013年5月10日，新加坡狼疮协会在新加坡中央医院举办活动。除了响应世界狼疮日，当天举办的活动也是个良好的平台，以接触更多狼疮病友，同时也提高公众对狼疮的认识。

活动进行之前，我们到各大医院的风湿部门外张贴世界狼疮日的宣传海报。当天，《新报》刊登了关于世界狼疮日的报道，《新明日报》则刊登一名年轻病患，黄丽真，与病魔抗斗的经历过程。

活动当天，我们很幸运的被安排到一个人潮众多的绝佳位置。义工们忙着分发手册、回答询问和售卖手工艺品。我们尚未摆好摊位，公众已纷至沓来。多数公众对狼疮这个较为罕见的病症感到很好奇。当中不少人是狼疮病患者，包括医院的职员也想更了解狼疮病。此外，一些医生也光临摊位。我们的手工艺品销售得很好，公众也踊跃捐款。

在众多人的支持下，狼疮协会达成了教育病患者和公众的宗旨。我衷心的感谢新加坡中央医院、所有义工朋友和公众的无私帮忙，使这项活动成功举办！我们一定会确保提高公众对狼疮的认识。我期待明年能举办更大型的活动！





# Lupus Association Singapore Annual General Meeting



Good afternoon!

I am honoured to have been re-elected for a second term and I look forward to working with the newly elected Council. I would like to thank the Vice-President, Associate Professor Leong Keng Hong, for his steadfast support throughout the last 2 years.

I would also like to express my appreciation to the Council members who have remained in the Lupus Association Singapore (LAS) Dr Bernard Thong, Dr Andrea Low, Dr Aisha Lateef, Serene Mai and Nancy Chin for their invaluable work and support. I also extend a warm welcome to Agnes Xue and David Au, our new Treasurer and Assistant Treasurer respectively. My sincere appreciation to the sponsors of this event:

Novartis Singapore  
GlaxoSmithKline Pte Ltd (or, GSK Singapore)  
Focus Network (for the chocolates in the goody bags)

As always, my heartfelt appreciation to the volunteers who selflessly contribute their precious time, efforts and support for our activities through the years I would like to thank Dr Faith Chia for her contribution in our last Council. I hope more volunteers will come forward to assist the LAS so that we can work towards a more effective and vibrant association.

The last 2 years have been a learning process for me, at times challenging but mostly, it had been gratifying helping fellow Lupus sufferers. In this term, I will continue our association's mission in providing patient care and support through our activities and subsidy scheme. I will strive to reach out to the community by creating and increasing public awareness of Lupus through education and outreach programmes. Together with my Council members, we will explore new dimensions in bringing LAS to greater heights. Thank you!

**Irene Lim,**  
*President*

## 新加坡狼疮协会常年大会 (2013年5月) 狼疮协会主席林碯金报告

下午好！

我很荣幸能连任狼疮协会主席，并且期待与新任执委一起事奉。感谢狼疮协会副主席梁景康医生这两年来支持与协助。同时也感谢 Dr Bernard Thong, Dr Andrea Low, Dr Aisha Lateef, Serene Mai 和 Nancy Chin 等连任执委。我也欢迎 Agnes Xue, 新任财务干事和 David Au, 副财务干事加入狼疮协会。我也要感谢 Dr Faith Chia 在上一任执委的付出。我们诚恳的感谢以下赞助商：

Novartis Singapore  
GlaxoSmithKline Pte Ltd (GSK Singapore)  
Focus Network (赞助礼包中的巧克力)

此外，我也很感谢所有义工朋友们，多年来奉献宝贵的时间与无私的付出。谢谢所有支持我们活动的朋友们。我希望有更多朋友们能帮助狼疮协会或是加入义工团队，一起努力打造更有效率，更活跃的狼疮协会。

过去的两年对我而言，是极具挑战性的学习历程，但是能够帮助狼疮病患是件令人欣慰的事。在新任期内，我会继续发扬狼疮协会的宗旨，也就是通过举办活动和津贴计划提供医疗治疗和精神支柱。我也会通过教育和举办活动提高公众对红斑狼疮的认识。我希望与执委们携手合作，一同将狼疮协会带上更高峰。谢谢！

### Council Members

#### President

Irene Lim

#### Vice-President

Dr Leong Keng Hong

#### Hon Secretary

Serene Mai

#### Hon Treasurer

Jennie Sokolik

#### Welfare Officer

Nancy Chin

#### Council Members

Dr Bernard Thong

Chan Suan Liang

Dr Andrea Low Hsiu Ling

Dr Aisha Lateef

Dr Agnes Xue Lishan

#### Council Members & Editorial Team

#### Editorial Team & Co-opted Member

#### Co-opted Member Text Translation

Corinne Kang

Teh Hui Ping

### Reach Us

Office Operating Hours

Monday to Friday, 12-5pm

Tel.: +65 6254 9130

Email: [enquiry@e-lupus.org](mailto:enquiry@e-lupus.org)

Website: [www.e-lupus.org](http://www.e-lupus.org)

### Mailing Address:

Towner Road P.O. Box 460  
Singapore 322101



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 to us, so our editorial team may try answering you in the next newsletter.

© All rights reserved. No portion of this publication covered by the copyright hereon may be reproduced in any form or by any means without the permission of the publisher and contributors. MICA (P) 089/12/2011 Lupus Link is published thrice annually by Lupus Association Singapore (LAS), a self-help group. This publication has no subscription or newsstand price and is supported through contributions. For information about LAS, go to [www.e-lupus.org](http://www.e-lupus.org)