



Lupus Link

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新加坡狼疮协会刊物



World Lupus Day

By Ms Irene Lim 新加坡狼疮协会主席

Lupus Association (Singapore) marked World Lupus Day on 10th May 2012 (at Tan Tock Seng Hospital Atrium and Theatre) with an exhibition cum DVD screening featuring Lupus patients and their walk with Lupus. The main aim of the event was to create awareness of the illness. Many members of the public who stopped by our booth did not know much about the condition. Some had not even heard of the disease. Our volunteers were at hand to share their knowledge of the disease. We sold handicrafts and received donations. Feedback on our new DVD was also very positive. Once again, the event went well. My sincere appreciation to our volunteers for being resourceful, spontaneous and responsive.

世界狼疮日

新加坡狼疮协会在10/5/12当天于陈篤生医院礼堂庆祝世界狼疮日。狼疮协会举办展览的同时也播放DVD，影片中狼疮病人分享了个人经验。举办展览的目的是让更多人认识狼疮。许多路过展览的大众都对狼疮一知半解。很多人甚至不知道狼疮为何事。在场的义工便积极和众人分享知识。我们也售卖手工艺品和接受捐款。众人对DVD的反馈也不错。总的来说，世界狼疮日圆满落幕。我由衷地感谢义工们的付出。

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Skin Problems & Skin Care in Lupus

红斑狼疮与眼睛

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Skin problems at different stages of Lupus A patient with Lupus is usually in one of these stages: acute, subacute, chronic, or quiescent stage. The skin signs are different at different stages, and so is the care of the skin.

In acute Lupus, the disease is not yet controlled. It is typified by a 'butterfly rash' on the face, but it can also appear as a non-descript rash on the body. Patients often suffer from recurrent mouth ulcers which impair enjoyment and intake of food. One way to manage these ulcers is to numb them by applying salicylate gel (e.g. Bonjela gel), or to simply swish and swallow a mixture of one part (2.5ml) antacid (e.g. Mylanta, an over-the-counter syrup that reduces stomach acidity) with one part (2.5ml) diphenhydramine (e.g. Benadryl, a pharmacist-only medication with anti-histamine effects). Alternatively, one can reduce the inflammation by applying a steroid gel (e.g. Oracort E or Kenalog in Orabase), which can be purchased from a pharmacy. To reduce further aggravation of pain, avoid fried, sour, spicy, crispy, caffeinated and alcoholic food and beverage.

Another common complaint in the acute stage of Lupus is hair-fall. Some people may even recognize this as a symptom of disease relapse. The good news is hair-fall that is associated with acute Lupus is

often temporary, and will reverse gradually as the disease gets under control. However, most females are very disturbed by this. To accelerate the regrowth of hair, one can purchase minoxidil 2% solution from a pharmacy, and massage it into the entire scalp twice daily. Upgrade to a 5% solution when the hair-fall fails to improve after 4 months of regular use. Alternatively, one can see a dermatologist to discuss the use of lasers and/or other medications.

A person with chronic Lupus has rashes on the body that are relatively more difficult to eradicate. These recalcitrant rashes are most often found on the ears and face, and are characterized by thick scaly dotted red-to-brownish islands. Such rashes necessitate the use of strong topical steroid creams/ointments. However, indiscriminate use of these topical steroid creams/ointments can cause side-effects such as skin thinning and the appearance of fine blood vessels and stretch marks. To avoid these problems, apply the creams sparingly without rubbing onto surrounding unaffected skins. Apply no more than twice daily, and reduce to once daily or every other day when the lesions clear. Occasionally stick a plaster onto the affected skin overnight (after applying the topical steroid) to achieve a more powerful effect. A dermatologist can inject steroids directly into very difficult-to-treat lesions. Where side-effects have developed, a dermatologist can discuss with you the use of steroid-sparing ointments.

Skin complications of medication

Many patients with Lupus are on long-term oral steroid therapy. Steroids reduce one's immunity, so a person can be more prone to developing a fungal infection on the skin. It typically manifests as circular red scaly patches ("ringworm"). One can apply an anti-fungal cream (e.g. miconazole, clotrimazole, terbinafine) twice daily. When the rash clears, it is important to continue using the cream for another 2-3 weeks to ensure that the fungus is thoroughly eradicated. Fungal infections may manifest as whitish patches on the tongue or sides of the mouth ("thrush"), or irritation and redness on the angles of the mouth. One can use miconazole oral gel twice daily to handle these infections.

Another common problem associated with long-term steroid therapy is acne. If there are few whiteheads, blackheads and red bumps, one can apply over-the-counter benzoyl peroxide cream or acne cream (or lotion) twice daily. A salicylic acid-based cleanser can help manage the whiteheads and blackheads. Anti-bacterial cleansers (containing triclosan, cetrimide or chlorhexidine) cleansers are useful where there are predominantly red bumps. When the skin starts to clear, apply a retinol or retinaldehyde-based cream onto the whole face nightly for maintenance. For those with moderate to severe acne (many more inflamed lesions - red bumps, big bumps, pus-filled bumps), it is advisable to see a dermatologist.



狼疮及皮肤护理



Prevention of Lupus flare-ups

Whatever the stage of Lupus, it is imperative that all patients with Lupus protect themselves from the sun. Ultraviolet radiation is a well-known trigger of Lupus and can cause skin flare-ups, or other Lupus organ flare-ups. Although staying indoors and actively avoiding outdoor movement between the peak periods of 10am to 4pm are helpful, one cannot totally avoid ultraviolet radiation in Singapore. It is strongly advisable to apply a good sunscreen on all sun-exposed areas of the body at least twice daily. Use a sunscreen of SPF 30 and above (ultraviolet B protection), and one with adequate ultraviolet A protection (PPD >15 or PA +++). Choose the appropriate sunscreen for one's needs and skin type. Consider whether you need a water-resistant sunscreen, whether your skin is acne-prone (select only a 'non-comedogenic' product), or whether you have a sensitive skin (select products with purely or mostly physical agents).

不同狼疮病情所造成的皮肤问题

狼疮病人的病情可分为以下阶段：急性、偏急性、慢性和轻微。不同的病情需要不同皮肤护理。急性狼疮的病情还不能受控制。通常，病人脸上会出现“蝴蝶”样皮疹的症状(butterfly rash)。但是，它也可能以一般皮疹的形式出现在身体的部位。病人常会有口疮，这多少会影响食欲。其中一个应对方式是在痔疮上涂抹药物(salicylate gel e.g. Bonjela gel)或是服用以下药物(a mixture of antacid with diphenhydramine)。另一个方式是擦抹类固醇药膏以便减轻发炎症状。(e.g. Oracort E or Kenalog in Orabase)此外，为了避免发炎，请少吃油炸、酸性、辣性、香脆、含咖啡因和酒精的食物和饮料。

另一个常见问题是脱发。有些人误以为这是狼疮复发症状。其实，狼疮所导致的脱发现象一般是短暂的，随着病情受到控制，脱发问题会渐渐改善。但是，很多女性仍关注这个问题。为了促使头发生长，您可以从药房购买药物(minoxidil 2% solution)。每天两次将它涂抹在发囊。如果使用了四个月，情况没有改善，您可以使用更强的药物(5% solution)。除此之外，您也能征询皮肤科医生的建议，讨论使用其他药物或雷射疗程。

患有慢性狼疮的患者身上出现的皮疹较难除去。这些顽固的皮疹通常在耳朵和脸部出现。它们是粗厚红色或褐色的鳞状(thick scaly dotted red-to-brownish islands)。我们必须使用效用较强的类固醇或其他药物治疗。但是，它们可能会导致

得的副作用包括皮肤表层变薄、血管浮现及橙皮。为了避免这些问题，请在受影响的地方适量地涂抹这些药物。不受影响的部位请不要涂抹药物。每天最多只能使用两次。如果情况改善，请减少涂抹药物，如每天只使用一次或者每隔一天再使用。有时候，在涂抹类固醇之后，您可以在皮疹上贴胶布，以取得更好的治疗效果。皮肤科医生可以直接将类固醇注射在顽固皮疹内。如果使用药物后产生副作用，您可以和医生商量。

使用药物而产生的皮肤问题

很多狼疮患者都长期服用口服药物-类固醇。类固醇会降低抵抗力，因此患者容易产生真菌感染(fungal infection)。它通常是圆形红色鳞状(ringworm)。您可以涂抹防真菌的药膏，一天两次。(e.g. miconazole, clotrimazole, terbinafine)当皮疹消失后，请继续涂抹两三个星期，以确保真菌彻底消除。真菌感染的现象是在舌头或口腔出现白色斑点，或则是口腔出现红肿和敏感。您可以每天两次涂抹口腔药膏(miconazole oral gel)。

另一个服用类固醇的常见问题是暗疮。如果皮肤出现少数的黑头、白头和红肿的话，您可以去药房购买消炎药膏(benzoyl peroxide cream)，一天涂抹两次。此外，含有水杨酸的洗脸霜(salicylic acid-based cleanser)能改善皮肤情况。防菌洗脸霜(Anti-bacterial cleansers containing trichosan, cetrimide or chlorhexidine)也是有效的。当皮肤改善时，您可以在晚上时将含有维生素A的药膏(retinol or retinaldehyde-based cream)涂抹在脸上。如果您的暗疮较多，情况较严重的话，您可以征询皮肤科医生的意见。

避免狼疮复发

无论您的狼疮病情处于任何阶段，请记得做好防晒准备。紫外线辐射是导致狼疮复发和其他狼疮病情复发的原因。虽然在早上十点到中午四点期间避免外出，呆在室内对狼疮病情多少有效，但是这不能完全避免紫外线辐射。请在所有阳光可及的身体部位上涂抹防晒霜，一天至少两次。请使用SPF 30以上的(ultraviolet B protection)防晒霜和(ultraviolet A protection (PPD >15 or PA +++))防晒霜。请依据个人的需要和皮肤情况选用适当的防晒霜。如果您属于敏感性皮肤，您可以考虑使用具有物理因子的防晒霜(products with purely or mostly physical agents)；如果您属于油性皮肤，您可以考虑使用水性防晒霜(water-resistant sunscreen, select only a 'non-comedogenic' product)。

Lupus has had nearly 30 years to attack Annie Ravitz's body. At age 11, it prompted her immune system to start destroying red blood cells. At age 14, the kidney became a target. A heart attack at 28 signaled clogged coronary arteries, and Annie underwent a triple coronary bypass. Despite top medical care and a sensible lifestyle, she's lost count of the number of times she's been hospitalized.

Nearly every part of Annie's body – her vital organs, joints, memory, skin—has come under assault from the disease itself or the powerful drugs she's taken to suppress her over-reactive immune system. "I've been sick more years than I've been well," the 40-year-old New Yorker says. "And I'm not some special case."

More than 1.5 million Americans have lupus, a chronic disease in which the body turns on itself in an unpredictable yet relentless pattern of flares and remissions. Existing medicines are highly toxic and can have debilitating effects.

"I've just fought hard to stay alive and to have some kind of life for myself," Annie explains. "And I have a wonderful life except the sick part." She went to college, worked in children's theater and television, and is now exploring new career options.

The file cabinets in her 12th floor Manhattan apartment are stuffed with doctors' bills—"they could fill up a room!" she exclaims—but her many friends and support group helps her get through the tedium of the bills and the inevitable highs and lows. "Growing up, there were always two friends or so who didn't care I had lupus. And I have a great family—my older brother and his wife and kids, my parents."

A Sense of Urgency

Annie's father, Robert J. Ravitz, a New York businessman, deeply admires his daughter's spirit, intellect, and attitude. "When I think of Annie, I hear Fred Astaire singing 'Take a deep breath, pick yourself up, dust yourself off, start all over again...' That's Annie. She never gives up."



Profiles of Hope: The Ravitz Family

Find inspiration and hope in these stories about people whose lives have been profoundly affected by lupus.

But along with unwavering admiration for his courageous daughter, Robert and Annie's mother, Francine, also have felt a mounting sense of urgency as the years tick by with far too little new insight into the disease. The toll on Annie's health has only grown more intense. Her kidneys started to fail and she got a transplant. Drugs to keep her immune system in check have dramatically weakened her bones. A knee replacement is scheduled for June.

"We still don't know why people get lupus, or why 90 percent are women," Robert points out. "One would think these are fabulous clues, but in fact they've long been known. We still don't have the keys to this mystery."

There has been no new major lupus treatment in over 40 years.

Getting Involved

"Lupus took over Annie's body from the time she was diagnosed as a young teenager," reflects her father. "In a way, when she was diagnosed, lupus took over our lives too."

In the first few years after Annie's diagnosis, the Ravitz's acted as many parents do, getting educated about the

disease and joining a lupus support organization. Robert went on to serve as a board member and President of the S.L.E. Lupus Foundation, a leading lupus organization headquartered in New York (and Los Angeles) that provides patient services and increases public awareness about lupus.

When the family joined the Foundation, it was itself branching out. It had started funding the work of lupus researchers in the New York metropolitan area, and in 1997 it spearheaded the nation's first research conference on lupus at the National Institutes of Health in Bethesda, Maryland.

Robert recalls it was "the first time scientists had gotten together to ask: where are we going with lupus?"

Once the word was out that the S.L.E. Lupus Foundation had money for research, grant applications from across the country started flooding in. "We were the only private sector funder for lupus research," Robert recounts. "We quickly realized, we have to try to replicate what we're doing in New York on a nationwide basis."

The Solution: Novel Research

In 1998, Robert and others at the Foundation invited nearly 30 people—top scientists, nationally recognized clinicians, families with lupus—from around the country to a meeting room in mid-town Manhattan to ask a pivotal question: “What’s the best way to accelerate progress in lupus?”

“We sat around a four-sided table with an opening in the middle and quickly boiled down the grant priorities to a short list. A consensus rapidly developed: novel research and young talent were it,” recalls Robert, who now serves as Co-Chairman of the LRI.

In the five years since the LRI was officially incorporated in 2000, it has followed this directive, raising millions to fund more than 40 groundbreaking research projects and support out-the-box thinking among brilliant lupus investigators.

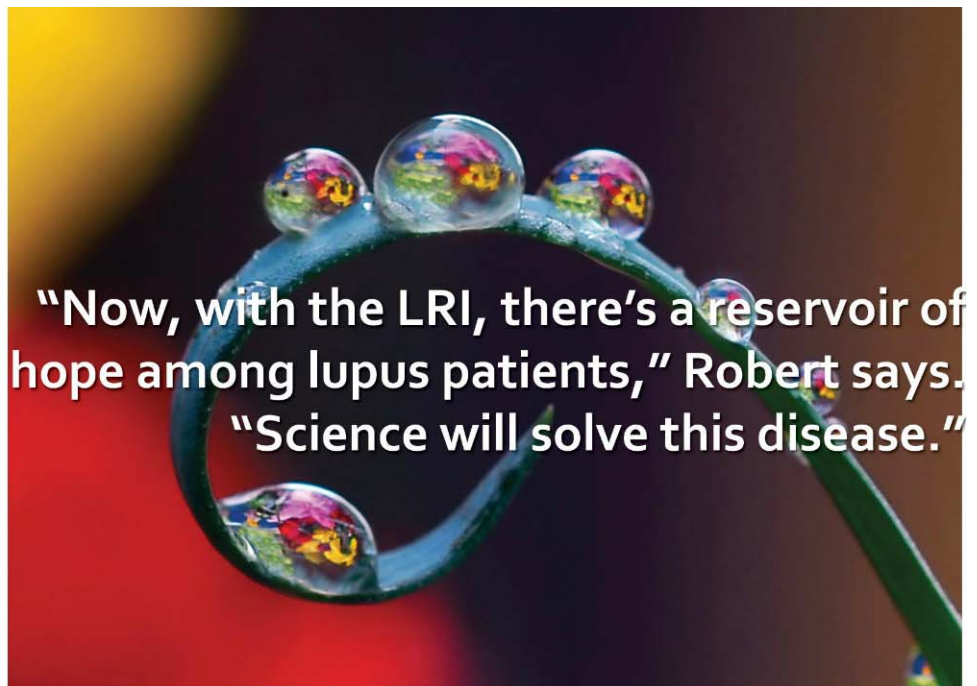
A Reservoir of Hope

Annie describes the thrill she felt when her father described the new undertaking. “I was so in awe that he was going to take this on. Over the years, my parents would mention things, but if it (the science) didn’t have a cure or new treatment attached, I found it hard to get excited.”

“But the LRI is different,” she continues. “And really for the first time, I feel hopeful and not scared to be interested and involved.”

LRI-funded investigators already have uncovered lupus disease mechanisms, potential treatments, and diagnostic techniques in central nervous system lupus, premature cardiovascular disease, kidney disease (lupus nephritis), and photosensitivity.

“There are clinical trials now,” Robert points out. “Seven or eight years ago, there were none. And word has gotten out to pharmaceuticals that lupus is an area that needs work.” In addition, nearly three-quarters of the first round of LRI-funded researchers have gone on to secure even larger grants from the NIH.



“Now, with the LRI, there’s a reservoir of hope among lupus patients,” Robert says. “Science will solve this disease.”

女儿病情—全家出动

安妮患上狼疮已经有30多年了。她从小就常常进出医院，所以已经数不清进出医院的数字了。几乎安妮的每个身体部位，如肝脏、关节、记忆力、皮肤都受到影响。四十岁的安妮说：“我生病的日子比健康的日子更多，而我不是什么特别的例子”超过1500万的美国人患有狼疮。安妮接着说：“为了活着，我努力与病魔抗斗，创造自己的人生。除了生病的日子，我过着美好的日子。”她已顺利完成学业，在儿童戏剧和电影部门工作，目前正考虑寻找新工作。

警觉性

安妮的父亲，咯伯特，纽约生意人，欣赏女儿坚韧不拔的精神。”但是，安妮的父母偶尔会沮丧，随着岁月的流逝，女儿病情日趋严重。她的肾脏衰竭，已移植新肾脏。此外，治疗药物使她的骨骼退化。“我们至今还不晓得为何人们会患上狼疮，也不知道为何90%的患者是女性。”在过去的40年以来，狼疮病情并没有突破或找到新治疗疗程。

全家出动

头几年，安妮家人参加狼疮组织等。咯伯特后来也担任位于美国纽约（和洛杉矶）狼疮组织主席。当安妮家人参加狼疮组织时，组织规模正在扩大。“我们是唯一的私人狼疮研究组织，因此很快意识到必须将在纽约做的工作研究扩大到全国。”

解决方子：新研究

1998年，咯伯特邀请全国各地的著名科学家、医生、狼疮病患家属等讨论一个问题：怎么有效治理狼疮？“经过讨论后，我们很快达成共识—必须通过新研究。”LRI组织在2000年成立，在接下来的5年，它积极筹款，并开始了40多个新研究。

希望之源

安妮说：“我知道父亲正在进行研究。过去几年，父亲会提到新事物，但是如果科学家没有找到新治疗疗程，我很难提起兴趣。但是LRI不同，我第一次觉得有希望，有兴趣，也不怕参与其中。”LRI组织的科学家已找出新狼疮症状、有潜质的治疗和诊断方子和肾衰竭等疾病。

咯伯特说：“目前正进行治疗试验，过去的7-8年都不曾进行过。药方盛产公司也察觉狼疮是个需要研究的方向。目前，LRI给予狼疮病人希望。科学一定能解决问题。”

Reprinted, with permission, from the Lupus Research Institute (LRI)

Walk for Lupus 2012 Marina Bay 3.5 km

狼疮健走2012-滨海湾3.5公里

Welcome to our Marina Bay Waterfront Promenade. Let's all come together for a casual walk or a jog on Saturday mornings at 7:15 am.

We meet every Saturday at the Marina Bay City Gallery (11 Marina Boulevard, Singapore 018940). The walk starts with a whistle at 7:30 am from the "Olympic Walk sculptures".

Who can join? Anyone can join the Marina Bay 3.5 km walk. It is open to male and female walkers, and if you're disabled and think you can't participate, think again. For safety reasons, participants who are disabled are advised to bring along their walking aids.

YOU will discover a new journey of life all over again! Walking and chatting allow new friendships to be forged and exercise keeps us healthy. Interested to join the Marina Bay 3.5 km walk? It's only an hour's walk ... Plus, it's free to join. Call LAS at Tel/Fax no: 62549130 or Email us: enquiry@e-lupus.org

欢迎大家来到滨海湾宝龙坊 (Marina Bay Waterfront Promenade), 同时也欢迎大家在星期六早晨聚集在一起健走或跑步。我们在每个星期六在滨海湾市区展览馆集合。Marina Bay City Gallery (11 Marina Boulevard, Singapore 018940). 健走在 7.30 正在奥运健走雕刻 (Olympic Walk sculptures) 一带出发。

谁适合参与? 任何人都能参加健走, 如男性、女性和残疾人上。如果您是残疾人上,

认为自己不能参与, 请再想一想, 凡事都是志在人为。为了安全起见, 残疾人士参与者请携带助步器。

你将发现崭新人生! 一边走路, 一边交谈不仅能增强健体, 还能促进友谊。你有兴趣参与滨海湾3.5公里健走吗? 健走长达一小时, 它也是免费的。

有任何疑问, 请拨打至: 62549130 或电邮: enquiry@e-lupus.org

MARINA BAY CITY GALLERY

SLE Patient Booklet

In line with our association's aim at patient support and education and the raising of public awareness, we have printed a new SLE guide for patients that provides information on symptoms, causes and diagnosis of the condition, explanation and answers to questions on lupus, updated information on outlook of the disease, new drugs and treatments available and advice on self-help and how sufferers can manage their own condition. The booklet was jointly written by the doctors on our LAS Council. We are distributing the booklets free of charge. Please call our office at 6254 9130 or email us at enquiry@e-lupus.org if you would like to get a copy.

全身性 红斑狼疮

病人手册
新加坡狼疮协会出版

Systemic Lupus Erythematosus

A guide for patients
A publication of the Lupus Association (Singapore)



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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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