

Lupus Link

新加坡狼疮协会刊物

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Page 1

From the desk of the President, Ms Nancy Chin 狼疮协会主席致词



I would like to wish all a happy and healthy New Year. Please allow me to thank my committee members, our volunteers and donors for their unfailing support for me and the Association. I am always in awe of your love and commitment to LAS over all these years, and it has been a great joy and privilege to be able to work with everyone. Please forgive me if I have taken you for granted!

Here's to a wonderful 2011.

在此,我祝大家新年快乐。此外,我也想 感谢会员、义工、捐赠朋友们给予狼疮协 会多年的支持及鼓励。

这些年来,大家积极投入狼疮协会的活动 ,我想向大家致敬。能够与大家合作给我 极大的满足及荣誉感。如果我曾将这一切 视为必然的话,请原谅我!

祝大家2011年事事顺心!



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Talk in Review

Treatment of Lupus - An update

By Dr Tan Sze Chin

Registrar

Department of Rheumatology, Allergy and Immunology Tan Tock Seng Hospital

SLE is an autoimmune disorder characterised by the formation of auto-antibodies that target various organs in the body. Most of us are familiar with conventional medications used to treat lupus such as steroids, hydroxychloroquine (Plaquenil), azathioprine and cyclophosphamide. In the recent years, new therapies have been developed that have proven to be useful for the treatment of lupus, such as Mycophenolic acid, Rituximab, Belimumab and autologous haematopoetic stem cell transplant.

Mycophenolic acid (Cellcept/Myfortic)

Mycophenolic acid is a drug that inhibits the action of immune cells called lymphocytes. It has been approved for over ten years for prevention of kidney transplant rejection and has now been proven to be effective in SLE patients who are either unresponsive to, or are unable to tolerate other immunosuppressants, particularly in cases of where lupus affects the kidneys.

An important advantage over cyclophosphamide is that there is a lower risk of fertility problems or early menopause in women. Approximately 4.5% of lupus patients in Singapore are on Mycophenolic acid.

Mycophenolic acid is taken orally in the form of tablets. Potential side effects include diarrhea, nausea, reversible blood abnormalities (low white or red blood cells; low platelets), abnormal liver function tests and risk of certain infections. Your doctor will monitor for these side effects. Mycophenolic acid cannot be used in pregnancy.



Rituximab

Rituximab is a biologic agent that targets certain immune cells that play an important part in SLE called B cells. It was a drug that was initially used to treat lymphoma and

was subsequently approved for use in rheumatoid arthritis 5 years ago. It has also been shown to be beneficial in active lupus, and is used when lupus is severe or resistant to other treatments.

Rituximab is given as a course of two intravenous infusions 2 weeks apart. The infusions need to be administered by your doctor as patients need to be monitored for infusion reactions.

Potential side effects include infusion reaction with flushing, headache, dizziness or mild fever with chills. A rare neurological disorder called progressive multifocal leukoencephalopathy has also been reported. Rituximab cannot be used in pregnancy; and you should inform your doctor if you have had TB or hepatitis in the past if you are planning to use it.

Belimumah

Belimumab (Benlysta) is another biologic agent that targets B-cells and provides a new option for the management of SLE. Specifically, it targets and inhibits the activity of B-Lymphocyte Stimulator (BLys), and hence affects the survival of these B-cells. Recent large trials involving Belimumab have shown the drug to be promising. It is currently awaiting approval by the FDA and is not yet available in Singapore.

Hematopoetic Stem Cell Transplant (HSCT)

Stem cells are 'factory cells' that originate from the bone marrow and turn into red blood cells, white blood cells and platelets. Stem cell transplant involves taking out healthy stem cells from a patient (autologous) or a healthy donor (allogenic) and using them to replace 'unhealthy' stem cells in a patient's body.

HSCT has been in use for treatment of blood cancers as well as other autoimmune diseases. It may be used for chronic and progressive SLE where many lines of established treatment have failed and the outlook is poor.

The hope is that the 'new' generation of stem cells in the patient will 'reset' the immunological clock, leading to less autoimmunity. Case reports suggest that HSCT can induce remissions and potentially cure some selected patients with therapy-refractory autoimmune diseases. However this is not yet an established treatment, and transplant-related death and potential long-term toxicity are still being studied.

Conclusion

Conventional immunosuppressants still remain effective for the treatment of SLE. Availability of new therapies in lupus provides therapeutic options for long-term remission. Your doctor tailors treatment to each individual patient. Besides medications, general measures to take include leading a healthy lifestyle, avoiding direct sunlight, practising good food hygiene (avoid raw or half-cooked food) and remember to be consistent with your medications and follow-up appointments.

狼疮治疗-更新

陈赐金医生 风湿免疫过敏部门 陈笃生医院

狼疮是种自体免疫性疾病,由活跃的免疫系统 攻击体内器官所造成的。这包括皮肤、关节、 血液、肾脏、脑部、心脏、肺、肠等。许多人 熟悉传统治疗药物如类固醇(steriods)、羟 氯喹(Hydroxychloroquine)、硫唑嘌呤 (azathioprine)和环磷酰胺 (cyclophosphamide)。近年来,也逐渐研发新 药物,如霉酚酸酯(Mycophenolic acid),美罗 华(Rituximab),Belimumab,和干细胞移植术 (autologous haematopoetic stem cell transplant).

霉酚酸酯 (Mycophenolic acid)

它是一种免疫系统抑制药物 。近十年来,霉酚酸酯已被推建在肾移植术后,用於避免移植排斥反应。如今,它被证实对传统免疫压制药物治疗没反应或无法适应的狼疮病患,尤其是在狼疮影响肾的案例中,有一定帮助。

与传统药物环磷酰胺(cyclophosphamide)相比, 霉酚酸酯 (mycophenolic acid) 有个长处,就是能减低女性不育或则过早停经的可能性。新加坡大约有4.5%的狼疮病患服用这个药物。

患者需口服药丸。另外,可能产生的副作用包括腹泻,头疼,白血球偏低 ,肝脏异常及其他感染风险。医生会观察任何可能出现的不寻常状况。此外,怀孕期间,并不能服用此药物。

霉酚酸酯 (Rituximab)

它主要针对影响狼疮病情的细胞: B免疫细胞。 霉酚酸酯(Rituximab) 是一种生物制剂,原 先是用来治疗淋巴瘤,以被批准用于治疗狼疮 病。它对活性狼疮,严重狼疮,或狼疮性肾炎 有帮助。

霉酚酸酯(Rituximab)的一次疗程包括两次静脉输液(intravenous infusions),一次静脉输液中间分隔两个星期再进行另一次。少数病人可能在注入药物时得反效果,因此药物只能在医物人员观察下服用。

另外,可能产生的副作用包括燥热,头疼,头晕,轻微发烧加寒意。较不寻常的副作用是进行性多巢性白质脑症(progressive multifocal leukoencephalopathy)。怀孕期间,并不能服用此药物。如果您曾经患有TB或肝炎(hepatitis),得先通知医生,才确定是否能使用。

Belimumab

这是另一个针对影响狼疮病情的细胞: B细胞。它主要抑制B-Lymphocyte Stimulator (BLys),因此影响B细胞的生存。最近进行大规模的医疗实验发现这个药物有一定效果。它仍待着(美国)食品及药物管理局 (FDA)的批准,目前在新加坡无法使用次药物。

干细胞移植术 (Hematopoetic Stem Cell Transplant)

干细胞是生产细胞的组细胞 ,源自于骨髓,然后再变成红血球,白血球和血小板。 干细胞移植术指从健康捐赠者(同种异基因/allogenic)或病人(自体移植式/autologous)取出健康细胞,取代患者的"坏细胞"。

干细胞移植主要用于医治血癌。它也适用于医治慢性及持续性狼疮,一种对很多疗程都没有反应的病情。大家都期望患者体内的新一代干细胞能重新调整免疫系统,减缓病情。个别案例提出干细胞移植可能彻底治疗一些患者的可能性。但是,这并不是经过具体证实的疗

程,而人们仍在研究干细胞移植与死亡和长期 毒性反应的课题。

总结

传统免疫压制药物治疗仍是最有效的疗程。新治疗药物给与长期治疗的选择。医生会根据各别患者做出医疗调整。除了服用药物,患者需要记得以下事物:过健康生活,避免阳光直接照射,良好饮食习惯(避免吃生或半熟食物)及准时服药和复诊。

Thoughts on our Christmas Celebrations

Charmaine Lee

It was with much anticipation that the yearly Lupus Association Christmas celebrations cum continuing education talk arrived on 27 November 2010. By 1pm, the registration counter was bustling with guests who were each allocated a lucky draw number. The response was overwhelming, and by 1:30pm the function rooms were filled with both members and non-members accompanied by the family and friends.

The talk started promptly with Dr Tan Sze Chin and Dr Tan Teck Choon from Department of Rheumatology, Allergy and Immunology speaking about 'Treatment of Lupus - An Update' in English and Mandarin respectively. The audience listened attentively as new treatments were discussed, and were reminded that although new drugs may have seemingly good outcomes, treatment still had to be catered towards each patient's needs. Those present also participated enthusiastically in the question and answer session with topics ranging from the use of Traditional Chinese Medicine to diet and issues with employment. Although many questions seemed to focus on problems faced, at the end of a session one lady stood up and shared her testimony on how her SLE was now in remission and she no longer required steroids. This was certainly uplifting and was a good message of hope at this festive time of the year.

We had a sumptuous spread of delicious foods like laksa, fragrant porridge, yummy tim-sum, mouth-watering fried chicken wings, topped off with desserts like cheng-teng and an assortment of cakes & fruits. More importantly than the food, it was a time to chat and mingle in the crowd, eagerly meeting old acquaintances and making new ones. After lunch, the committee members of LAS organized some games testing the audiences'

co-ordination, skill and speed. Sporting members used straws to pass a rubber band down the line, and acted out charades with much cheering from the floor. Of course, the winners were all presented with gifts.

The afternoon finished off with a heart-pouding time as the lucky draw numbers were called out. Each number called out was greeted with excitement and one by one the lucky winners delightedly went up on stage to collect their prizes, applauded by the rest of the audience who were earnestly hoping that their number would be the next to be called! Eventually, the first prize of an oven was given out, and the event finally came to an end.

The members reluctantly bid each other farewell, not forgetting to extend their wishes for a happy Christmas and New Year. Many thanks go to the committee of LAS, led by Ms Nancy Chin our President, for the relentless efforts and time towards making this event a success.

Till we meet again next year!



圣诞节庆祝会感想

Charmaine Lee

27日11月210年,大家期待的狼疮协会圣诞节庆祝会兼教育讲座终于到来了。下午1点时,登记柜台已有许多人排队领取幸运抽奖号码,反应热烈。1点半时,活动室已经有许多会员和非会员及其家属朋友。

讲座由风湿免疫部门的陈赐金医生及陈德春医生领起,准时进行。他们以英语和中文进行《狼疮治疗-更新》讲座。大家聚精回神地听讲座,了解新疗程,并获知新药物治疗虽然有一

定效果,但是疗程仍需要针对个别患者的情况 而作出调整。大家也踊跃发问,提及中药,食 物,就业等问题。大家提问的事物多数涉及当 前所面临的困难。但是,在讲座尾段有一名女 性与大家分享个人经历,提到她的病情已逐渐 稳定,不需要服用类固醇。这的确是份好消息 ,在佳期时期给予大家一份希望及鼓励。

讲座之后,大家就享用了丰盛的食物,如叻沙、粥、点心、炸鸡、清汤、糕点等。当然,食物属其次,交流在先。大家一边享用美食,一边和朋友聊天,结交新朋友。之后,狼疮协会委员会会员安排了一系列的游戏,如使用吸管

传橡皮筋等。当然, 胜利一方都获得奖品。

最后,终于到了抽奖时段。随着号码被一一念 出,大家都感到十分紧张。每个幸运者都兴奋 得上台领奖,台下的人则鼓掌并且期待着下一 个即将被公布的号码。最后,一位幸运者临走 首奖烧烤炉,活动就正式结束了。

大家都依依不舍地道别,同时不忘祝贺彼此佳节愉快。在此,我真心感谢狼疮协会执委们及主席Ms Nancy Chin。她们花费许多功夫及时间筹备节目,节目才能顺利进行。 希望明年我们能再见面!



Bobby Chinn in support of the Lupus Association Singapore Bobby Chinn 极力支持狼疮协会

The Lupus Association Singapore was proud to have Bobby Chinn supporting our charity event The Asian BBQ held on 27 January 2011 at the Grand Hyatt Singapore as part of the Asian Masters celebration of Asian cuisine. Bobby explained the origins and history of delicious dishes, whisking the participants on a whirlwind trip around Asia and the Middle East. He also came by the visit patients in our hospitals!

Here's part of his message:

"The LAS is doing an amazing job of both helping people living with Lupus in practical ways and by providing them and their families with a network of support as they cope with the condition. Simply helping sufferers of Lupus to share their experiences and realize they are not alone can offer great comfort.

Lupus is an auto-immune disease which mostly affects women. This means it is almost always someone's mother, grandmother, daughter, aunt or niece that suffers. If not that, it's a friend or a co-worker – almost everyone knows someone with Lupus, even if they may not be aware of it.

Having always held up the strong women in my family as role models, I wanted to find a way to honor their memories so supporting LAS seemed a natural fit for me.

It was a privilege to be able to visit some sufferers of Lupus with the LAS recently. What stood out for me was the strength and dignity of all of these women who were managing a difficult and and sometime debilitating condition with integrity and even humor. It was humbling"

27日1月2011年,狼疮协会荣幸邀请 Bobby Chinn 出席在新加坡君悦酒店举办的 《亚洲美食》慈善筹款会。顾名思义,《亚洲 美食》涉及亚洲美食。亚洲名厨 Bobby 也为大 家讲解亚洲及中东的来源。他也到医院探访病 人。

以下是他的感言:

-狼疮协会帮助患者以实在的方法适应狼疮病情 , 并给他们及家属支持及鼓励。简简单单的几 句话,和大家分享彼此的经验等就能让大家意 识到自己并不是孤军作战的。

狼疮是种自体免疫性疾病,主要影响妇女。很 多时候,这意味着大家认识的亲属之一可能是 患者。再不然,大家认识的朋友或同事也可能 是患者之一。每个人或多或少都会认识一些患 者。我一向来将家里坚强的女性视为典范,所 以在支持狼疮协会的同时,也想借此机会向她 们致敬。能够与患者接触是我的荣幸。最叫人 感动及谦卑的是看见女性展现坚强不息的精神 。 虽然她们面临不少困难, 但是仍然能够持有 骨气甚至以幽默度日。"



Our Upcoming Event

LAS Continuing Education Talk 2011: The ABCs of Nutrition in Lupus 新加坡狼疮协会2011年讲座:狼疮与营养

Date (日期)

: Saturday, 26th March 2011 (星期六, 26日3月2011年)

Time (时间)

: 1pm - 4pm (下午1 点- 4 点)

1.00- 1.30 Registration (报名)

1.30 - 2.30 Talk in English/Mandarin (中英讲座)

2.30 - 2.45 Question & Answer (问答时段)

2.45 - 4.00 Tea Reception (茶点)

Venue (地点)

: Singapore General Hospital (新加坡中央医院)

Block 6, Level 9 (第六栋, 九楼) Deck on 9

Speakers (演讲者): Ms Pindar Po Yee Yu (English)

Dietitian (SGH) 营养师 (新加坡中央医院)

Ms Tah Yih Shan 陈忆珊 (中文)

Nurse (SGH Rheumatology & Immunology Department)(风湿免疫部门护士)

