



LUPUS LINK

新加坡狼疮协会刊物

Issue 001/10

MICA (P) 238/10/2009

A LUPUS ASSOCIATION (SINGAPORE) PUBLICATION

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Systemic Lupus Erythematosus (SLE) In Children

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SLE is a multi-systemic autoimmune disease that can affect children as young as one year of age. About 20% of patients are diagnosed before 18 years old. The female to male ratio is less marked compared to adults. Childhood SLE is often more severe, with differing clinical course and treatment response. This is due to the effects of an immature immune system and the impact of the disease on the child's growth and development.

In children, diagnosis of SLE is usually delayed by 6-12 months. Fatigue, the most common symptom in up to 80% of children, is non-specific and may mimic many childhood illnesses. The kidney and central nervous system are more frequently affected in children than in adults. Early, and often more aggressive treatment compared to adults, is necessary to prevent poor outcomes. With this strategy, mortality from childhood SLE is now similar to that in adults, with more than 90% of patients alive at 5 years after diagnosis. Adherence to therapy and clinic visits are crucial for good long-term outcomes.

The main goals of treatment in childhood SLE are:

1. To achieve early control of disease
2. To minimise effects on the child's growth and development, both physically and mentally
3. To ensure adherence to therapy through patient and family education of the disease and treatment strategies

Prednisolone (or corticosteroids) remains the first choice of treatment because of its very rapid onset of anti-inflammatory effects, which is important in preventing damage to major organs involved. It is a well-established life-saving drug in SLE.

Appropriate use can prevent or minimize bad side effects. Many side effects are reversible once the steroid dose is decreased, and these include weight gain, a rounded face and osteoporosis. Stretch marks are by far the most devastating cosmetic complication of steroids, with the greatest risk of occurrence during the child's growth spurt. Diet control and regular exercise can effectively minimize this side effect.

Differences in organ involvement and severity dictate the choice of SLE treatment. All drugs have side effects, and so, one needs to weigh the benefits against the potential side effects. Effective communication between patients and their Rheumatologists to understand the disease, reasons behind a therapeutic approach and drug side effects, is important to achieve good adherence and treatment outcomes.

Living with children with SLE is often challenging for the care-givers. Care-givers do need to learn about SLE, the nature of the disease, how it behaves, and how it may affect various organs over time. Such knowledge is gained over time from their Rheumatologists and from useful websites (such as the Lupus Association) and from SLE information sheets provided by the doctor. Remember that children with SLE should be treated like other healthy children. There should not be any physical limitations (such as gym, P.E. class, sports), unless instructed by the Rheumatologist. When the disease is well-controlled, stress, such as from school work and examinations, will not cause the disease to flare-up. Disease flares are commonly due to non-adherence to therapy or infection.



“Play is important for children to develop normal psychosocial skills which will help them grow up to be normal and productive adults.”

Support from the family is crucial. Some ways to lend support include having a healthy diet, especially if diet modification is required with high dose steroid use. Avoiding strong sun light exposure between 10 a.m. – 3 p.m., and application of sun-block lotion, are crucial in preventing a flare of disease.

But this does not mean that children with SLE cannot participate in sports and have fun. Play is important for children to develop normal psychosocial skills which will help them grow up to be normal and productive adults. Nurturing children with SLE is not complicated, as long as care-givers know when to suspect signs of disease flares, and to contact their Rheumatologists in time.

During the adolescent years, adherence to therapy is especially poor, likely due to greater concerns about their physical appearance (which may result from side effects of certain drugs). Thus care-givers need to pay more attention to treatment adherence. Lastly, care-givers need to discuss the timing of vaccinations with their Rheumatologist, as there will be times when certain vaccines cannot be given.

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孩童之 系□性□斑狼□ (SLE)

系统性红斑狼疮(SLE) 是多元全身性感染自身免疫疾病,即使小于一岁的幼童也会患上此症,.大约有20%的患者在18岁之前被症出患上此症.与成人病患相比,他们男女病患的比例较不显著. 红斑狼疮的年幼患者一般上都会较严重. 每名儿童病患的临床疗程与治疗反应也不尽相同.这是由于孩童的免疫系统未完全发育健全,以及病症对患者成长与发育的冲击有所不同的结果.

普遍上红斑狼疮之孩童患者高达80%会有疲倦的症状,单凭疲倦不能明确显示患上系统性红斑狼疮,而它又酷似孩童的其他病状,故此,在诊断上往往会有6-12个月的延误,儿童患者的肾脏与中央神经系统较成年人更容易受到影响.得尽早医治,并在处方的比例上得较成年人加强.以避免病情恶化.运用此治疗策略,现今红斑狼疮儿童患者的死亡率与成年患者的死亡率不相上下,在被诊断出患上红斑狼疮病症后,有超过90%患者,5年后还存活着.要有长期性的好效果,就得紧附着治疗指示,并勤于复诊.



“要有长期性的好效果,就得紧附着治疗指示,并勤于复诊”

治疗红斑狼疮儿童患者的主要目标如下:

1. 朝向尽早控制病症

2. 在孩童的成长与发育中,尽量减低他们在肢体与精神上所受到的影响

3. 教育病人与其家人让他们对此疾病有更深一层的了解,以及更清楚治疗策略,同时确保他们紧附着治疗指示。

治疗系统性红斑狼疮类固醇 (Prednisolone) 或皮质类固醇 (corticosteroids) 依然为首选的药物。由于它有快速抗炎的功效,能预防相关的主要器官遭受到破坏,故此,上述药物被确立为拯救红斑狼疮病患的良药。酌量使用此药物,可以避免或降至最低限度的副作用。在服食此药物时所带来的副作用,包括体重增加,臃肿的脸及骨质疏松,但只要随着摄取剂量的降低就能逐渐减少。臃肿后所留下的痕迹,对发育期间的孩子来说,在容颜方面受到很大的破坏。要有效减低此副作用,可通过饮食的控制及有规律的运动达成。

选择治疗红斑狼疮疾病的策略,取决于其所牵涉的各种不同的器官及其严重性。所有药物都具有副作用,故此,必须衡量其得失与轻重。病人要与风湿学家有良好的沟通,才能了解疾病,以便寻找出更有效的疗程及了解药物的副作用。这对朝向依附好的疗程及治疗成果有着关键性的作用。

照顾红斑狼疮患童是一项挑战。照顾者必须学习了解红斑狼疮疾病的性质,其特殊症状及历时此症将如何影响其他各种不同的器官。此类知识可从其风湿学家及实用网站中寻获。(例如红斑狼疮协会)及从红斑狼疮医生所提供的资讯单子上。切记我们要以看待健康孩童的心态来看待红斑狼疮患童。不应该限制他们的体力活动(例如:体操,体育课,各类运动),除非风湿学家有所指示。当病情受到良好的控制时,来自学校的课业及考试的压力都不会造成疾病的发作。疾病的发作通常是由于没有紧附治疗或发炎。

“这并不表示红斑狼疮患童就不能参与各项运动以得到乐趣”

得到家人的支持是至关重要的。诸如在健康饮食上给予他们扶持,特别是在摄食强性类固醇时,更应该改变饮食习惯。上午10时至下午3时避免在阳光下曝晒,同时,搽防晒油都可预防疾病的发作。但这并不表示红斑狼疮患童就不能参与各项运动以得到乐趣。游戏活动对孩童来说是很重要的,这有助于他们正常的身心的发展,以便成长后成为正常及能从事生产的成年人。培育红斑狼疮患童是不复杂的,只要给予关爱,洞悉觉察疾病发作的征兆,并即时通知风湿学家。发育期间的青少年患者正处青春期,特别关注自己的外貌,故此,较不愿紧附治疗指示。(在接受治疗时所服食的某种药物,也许会带来影响外貌的副作用)。因此,照顾者必须加倍关注,确保他们紧附治疗指示。最后要注意的是,某些疫苗在不恰当的时候是不可注射的,故此,照顾者必须与风湿学者商讨安排注射疫苗的最佳时间。



Research In Lupus

LATEST UPDATES FROM...

The Department of Rheumatology, Allergy and Immunology at Tan Tock Seng Hospital began a study looking at systemic lupus erythematosus (SLE) in 2002. The purpose of this study was to identify factors that influence the outcome of SLE in our local patients as most information we have is from non-Asian populations. So far, more than a thousand patients have volunteered to join the study.

From this group, we can tell that most of our patients have well-controlled lupus with few irreversible complications such as hip disease. As part of this study, a tool to measure quality of life specifically in patients with lupus, called the SLEQOL, was developed and published, and is currently being validated in different countries around the world

This study also looks at proteins in the blood of lupus patients. An important finding has been that levels of interferon inducible protein -10 (IP-10) was more sensitive to changes in SLE activity compared to standard tests such as anti-dsDNA antibodies and complement levels. This raises the possibility that the measurement of IP-10 levels may enhance doctors' ability to monitor SLE disease activity.

As this study nears the 10 year mark we trust that this study will help improve our understanding and management of SLE in Singapore. We are also grateful for the participation of our patients, without whom these results would not have been possible, and hope that more patients will contribute to this study.

The Department of Rheumatology and Immunology, Singapore General Hospital

LUPUS AND YOUR CHILD

The growth and development of a child may be influenced by factors right from conception, and not just after birth. The mother's health during pregnancy may influence the health of the baby. Lupus (or SLE) is an autoimmune disease that affects women 9 times more than men. The most frequently affected age group is 15 to 40 years, corresponding to the child-bearing years. A study, currently being carried out in Singapore General Hospital, is investigating whether lupus affects the growth and development of children born to mothers with lupus.

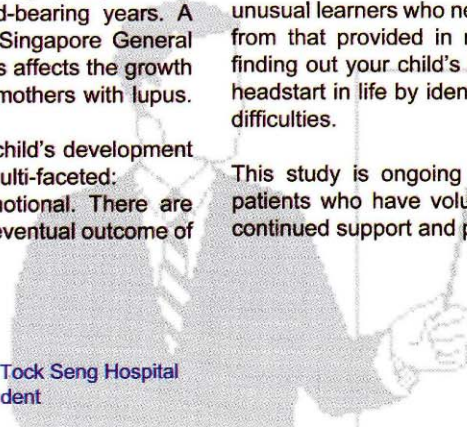
As a parent, you have watched your child's development since birth. A child's development is multi-faceted: physical, neuropsychological and emotional. There are many factors that affect the pace and eventual outcome of growth of children.

The learning capabilities of a child are correlated with the intelligence quotient (IQ) of the child. IQ tests measure problem solving skills, memory, and the ability to understand and use language, skills that are used in learning. It follows, then, that those who score unusually well or low on these tests will likely be unusual learners who need a program that is different from that provided in most classrooms. Therefore, finding out your child's IQ may help your child get a headstart in life by identifying key talents or learning difficulties.

This study is ongoing and we are grateful to the patients who have volunteered and look forward to continued support and participation.

Contributed By:

Dr Faith Chia, Associate Consultant, Tan Tock Seng Hospital
Ms Tan Tze Chin, Duke-NUS Medical Student



最新红斑狼疮科研讯息。。。

作者: Dr Faith Chia, Associate Consultant, 陈笃生医院
Ms Tan Tze Chin, 杜克-国大医学院

陈笃生医院风湿病学部门在2002年时开始了一项关于红斑狼疮的研究项目。此研究在于找出会影响本地红斑狼疮病人长久病情的导因。本地医学界目前的资料来源取自国外非亚裔族群对象的研究结论,并非完全适用于我国病人。目前,已有超过一千名病人义务参与这项研究计划。

在这群病人当中,绝大多数病人的病情稳定,鲜少有永久并发症如盆骨脆裂的例子。此研究也促成了一项调查病人生活素质的问卷的完成,并刊登在医学研究书刊上。这个问卷目前被不同国家的风湿病学医生使用在病人上。

同时,这个研究也正着手调查红斑狼疮病人血液样本内的各种细胞蛋白。研究员发现了使用一种名为Interferon inducible protein -10 (IP-10) 的蛋白能更准确的测量红斑狼疮发病时的疾病活动。IP-10或能为现有的anti-dsDNA antibodies和complement 水平作为观察红斑狼疮活动的检测起着辅助的作用。

转眼间,这项研究计划也将迈入十年的里程碑。研究人员对于志愿参加研究的病人致由衷的感谢;也相信能更好地为治疗红斑狼疮病人作出贡献。在此研究人员也希望更多的病人能参与研究,提供更多资料。

新加坡中央医院风湿病学部门 你的小孩与您

小孩的成长不止是在出生之后才受到外界的影响,宝宝的成长与发展在母体时便可能被母亲的身心健康所影响。红斑狼疮是一种系统性的免疫疾病;妇女比男性患病的几率高出了9倍。在妇女病患当中,病发高峰期是15岁至40岁,正值妇女生育年龄。新加坡中央医院已着手调查患有红斑狼疮妇女的病情是否会影响他们的小孩的身心发展。

身为家长,您或许已注意到您小孩多方面的发展:身心成长,心智与情绪的成熟。然而,仍有许多内外因素会影响小孩的健康成长。

小孩的学习能力与智商(IQ)有直接关系。智商测试是以思考能力,记忆力和运用语言的能力来评估一个人的智商。这也意味着高智商或低智商的小孩所需的学习环境与一般小孩不同。尽早测试您孩子的智商能发觉他们的优缺点,并为他们提供最适合的学习环境。

这项关于红斑狼疮妇女与她们孩子影响的研究会持续进行。研究员衷心的感谢所有参与这项计划的病人与家属,并期待更密切的合作与支持。

News Flash

Lupus Talks 2010

We've lined up a series of talks for the year
Do come and join us to learn more about lupus

Brain and Nerve Involvement in SLE
03-04-2010, 1pm
Singapore General Hospital(SGH)

红斑狼疮病症对脑及神经组织的影响
03-04-2010, 下午1点
新加坡中央医院

Dealing with Depression in Lupus
08-05-2010, 12pm
Singapore General Hospital(SGH)

如何面对红斑狼疮病症所带来的忧郁症
08-05-2010, 下午12点
新加坡中央医院

Dealing with Chronic Pain in Lupus
21-08-2010, 1pm
Singapore General Hospital(SGH)

如何面对红斑狼疮病症所带来的长期疼痛
21-08-2010, 下午1点
新加坡中央医院

Treatment Update in Lupus
27-11-2010, 1pm
Venue To Be Confirmed

治疗红斑狼疮病症之最新信息
27-11-2010, 下午1点
地点未确定



OUR NEW OFFICE HOURS:
MONDAYS TO FRIDAYS
1.00 PM - 6.00 PM