ARTHRITIS
FOUNDATION MALAYSIA

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Joint Efforts

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This Issue

PRESIDENT'S NOTE

2013 has been an election year – for the AFM amongst others – and the committee and I are grateful for the trust put in us to do right by the Foundation. I welcome new people to the committee and thank outgoing members for their service.

2013 has also seen a great World Arthritis Day celebration for the AFM, where we met many members of the public for the first time. It was good to see faces new and old on the day. It is my hope that the awareness of arthritis and related conditions continue to grow. To all those that joined as members on the day, you will receive this publication for the first time. Tell your friends, your relatives, and your loved ones. Bring them over for our 2014 events. We welcome more with open arms.

We have received feedback from those who attended our events this year and we will do our best to hold events in various languages, as well as holding events outside of the Klang Valley. Any support from outstation members will be received most gratefully.

There remain significant challenges ahead for the AFM. Whilst we do our best in looking out for the welfare of those in need of joint replacement surgery, there are many more types of arthritis treatments that are equally life changing and expensive. It is our hope that we may be able to help more sufferers in time to come.

I hope you have had a wonderful 2013 and wish all a very happy new year.

Dr Amir Azlan Zain
PRESIDENT
AFM

2013年是大马关节炎基金会新任理事会的选举年，在此我谨代表新任的理事会全体同人，为你们的信任献上至真诚的感激。我也借此良机欢迎新上任的理事会成员，为卸任的上届理事会成员们致上万二分的感感激。

大马关节炎基金会于2013年期间致力于欢庆世界关节炎日，我们也于那时首次和许多公众公开见面。能与那么多新面孔与旧相识相见是多美好的事，我也寄望有关关节炎的醒觉与知识能在各个新旧面孔中广为流传出去。为那些刚加入我们这大家庭的新成员，这将会是您第一次收到这份刊物。请将这份刊物让您的亲友们与心爱的人好好地分享，也希望您把他们一起带来参与我们2014年的节目，我们会热烈地欢迎他们。

我们获取了许多参与我们活动的与会人士们珍贵的意见，我们将会尽力举办其它不同语言的活动，也会将活动地点扩展至巴生谷以外的其它地区。如能够获得外州热心人士的支持，那么对我们来说是锦上添花。

大马关节炎基金会的前路还是充满荆棘挑战。虽然如此，我们还是会竭尽所能地为那些因罹患关节炎而被逼进手术室的的病患们的福利，他们需要一些能为他们的病情带来转机的疗程，一些费用不菲的疗程。我们希望在未来还能继续地为这些有需要的病患提供支援。

愿大家有个精彩的2013年，也祝愿大家新年进步，快乐愉快。

Dr Amir Azlan Zain
主席
大马关节炎基金会

Tahun 2013 merupakan tahun pemilihan termasuklah untuk AFM. Saya serta ahli jawatankuasa mengucapkan terima kasih atas kepercayaan yang diberikan kepada kami oleh Yayasan. Saya mengalu-alukan anggota baharu dalam jawatankuasa dan mengucapkan terima kasih kepada para ahli yang meninggalkan jawatankuasa atas perkhidmatan yang mereka sumbangkan.

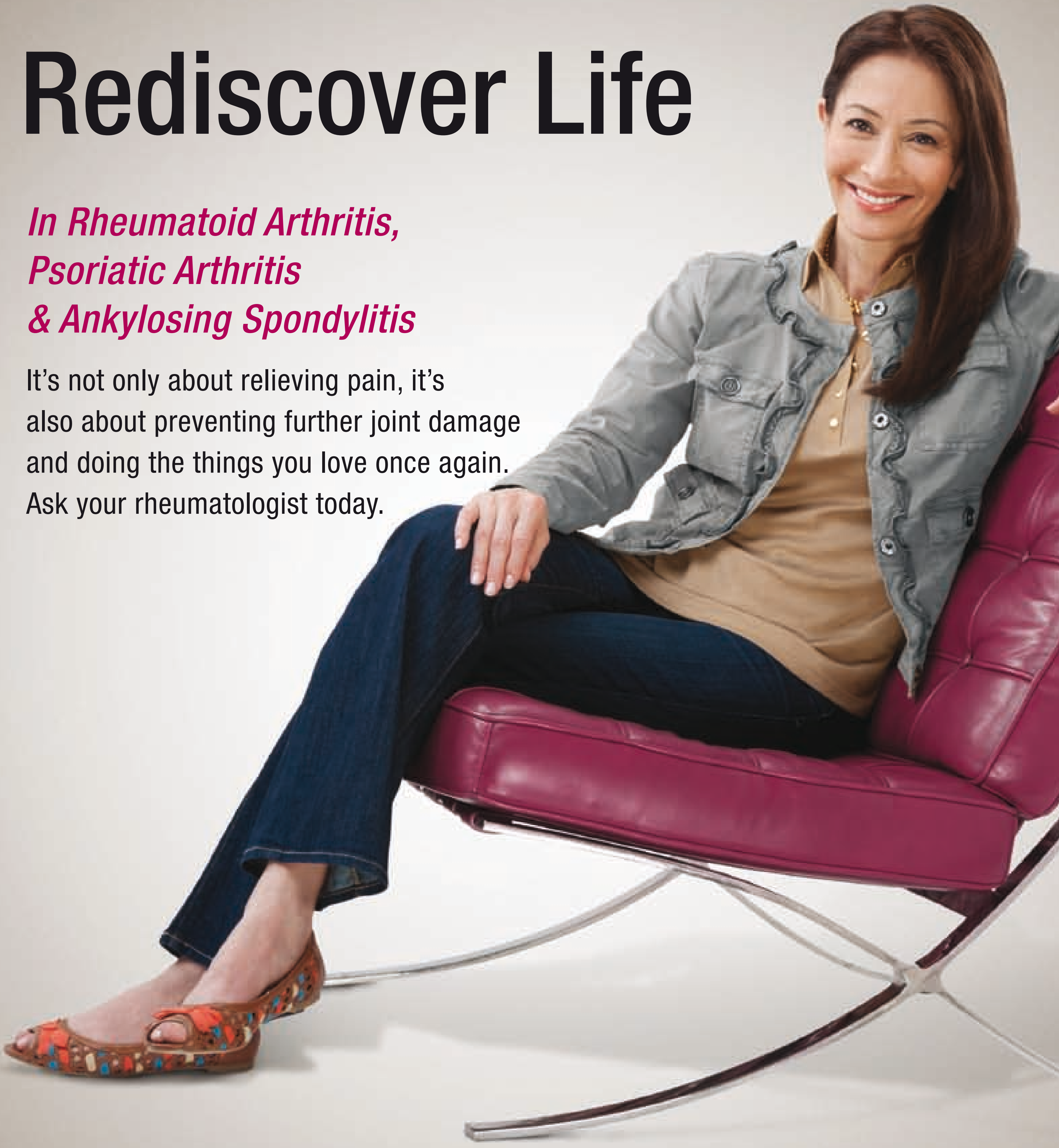
Tahun 2013 juga menyaksikan sambutan Hari Artritis Dunia yang meriah untuk AFM, di mana kita telah bertemu dengan ramai ahli awam buat julung kalinya. Harapan saya semoga kesedaran tentang artritis serta keadaan yang berkaitan dengannya akan terus berkembang. Bagi mereka yang menjadi ahli pada hari tersebut, anda akan menerima penerbitan ini buat pertama kalinya. Sila beritahu rakan-rakan, saudara mara serta orang tersayang. Bawalah mereka untuk menyertai acara kita pada tahun 2014. Kami amat mengalu-alukan mereka.

Kami telah menerima maklum balas daripada mereka yang menyertai acara yang dianjurkan pada tahun ini dan kami akan cuba untuk mengadakan acara dalam pelbagai bahasa, selain menganjurkan acara di luar kawasan Lembah Klang. Kami amat menghargai sebarang sokongan yang diberikan oleh para ahli dari luar kawasan.

Pelbagai cabaran menanti AFM. Kami akan cuba memberikan yang terbaik untuk menjaga kebajikan mereka yang memerlukan pembedahan penggantian sendi dan pada masa yang sama terdapat pelbagai jenis rawatan artritis yang mengubah kehidupan serta mahal belanjanya di luar sana. Kami harap dapat membantu lebih ramai pesakit di masa yang akan datang.

Saya mengambil peluang ini untuk mengucapkan kepada semua selamat tahun baru.

Dr Amir Azlan Zain
PENGERUSI
AFM



LUPUS ARTHRITIS

What is it, and what we can do about it, as explained by

Associate Professor Dr Sargunan Sockalingam, Physician and Rheumatologist, University Malaya Medical Centre

By now, many readers of Joint Efforts would be familiar of the causes of arthritis. There are many, with some being more common than others. Previous issues have highlighed Rheumatoid Arthritis very frequently, and rightly so. It affects one percent of the world population, and that is a large number.

Systemic Lupus Erythematosus (SLE) or simply "lupus", is also a cause of arthritis. The worldwide prevalence of SLE is around 50 to 150 per 100,000 people. Especially in Asia, whether you are in China, Thailand, India, Indonesia and the Phillipines, even Mongolia, one would come across cases of lupus more frequently than one would imagine.

In this article I will focus on the arthritis seen in lupus. But first, let me explain some basics about this disease.

Lupus is an autoimmune disease like Rheumatoid Arthritis (RA). While the effects of RA are mainly on the joints, in lupus, other systems -- such as the haematological (blood) and respiratory -- is where the disease mainly manifests. Aside from this, fever and lethargy are more commonly associated with lupus. Although in lupus skin involvement is the most common feature (in the form of a rash), musculoskeletal disease is also seen in up to 90 percent of lupus patients.

Is the arthritis of lupus different from Rheumatoid Arthritis? In the early stages it can be difficult to distinguish between the two. Both involve the small joints, cause significant early morning stiffness and can be associated with joint swellings. However, joint deformities are more common with Rheumatoid Arthritis. Having said this, there is a form of lupus arthtitis that can progress to become deforming, but this is rare. The arthritis of lupus tends to be benign and responds to treatment very rapidly. The concern is the other manifestations, such as skin lesions, protein in the urine, blood abnormalities and the fatigue that accompanies the arthritis of lupus.

Some patients report extreme lethargy and joint pains that preceed the development of other features of lupus. It is possible for the physician to incorrectly think that this is Rheumatoid Arthritis, and it does not help that the Rheumatoid Factor is positive in upto 30 percent of lupus patients, but rheumatologists are trained to tell the difference.

Most Rheumatoid Arthritis patients have almost none or very few skin lesions, they have high white cell and platelet counts. On the other hand, lupus patients are more likely to have low white cell and platelet counts, and up to 95 percent of them will have positive Anti Nuclear Factor, an antibody that is produced by the body that targets the patients' own nucleus (found in cells). The peculiar thing about the arthritis of lupus is that patients respond very well to the antimalarial drug Hydroxychloroquine, and this is one of the few instances in lupus that we use Methotrexate (a drug that is commonly used to treat Rheumatoid Arthritis).

Lupus patients require higher doses of the steroid Prednisolone, which is not the case for the Rheumatoid Arthritis patient, where we limit the steroid doses to make way for the more effective disease-modifying anti rheumatic drugs (DMARDs) such as Methotrexate, Salazopyrine and Leflunomide.

Almost all lupus patients with arthritis will be on Hydroxychloroquine. This is an important drug for lupus. Hydroxycloroquine is also the recommended treatment for Rheumatoid Arthritis, as it is especially effective in seronegative (Rheumatoid Factor negative) Rheumatoid Arthritis. Perhaps some of the disease mechanisms for the development of joint inflammation is shared among the two diseases.

Reassuringly, rheumatologists are trained to tell the difference between the two diseases. It is comforting to know that treatments in the initial stages of both the diseases are somewhat similar, and eventually even the most identical cases will show differences that point to the accurate diagnosis. Where it is difficult to differentiate the two, rheumatologists have coined the term "Rhupus" and the treatment is then tailored to capture elements of both the diseases.

红斑狼疮关节炎

它是什么？该如何处理？敬请聆听来自马大医药中心医疗与风湿科莎谷南副教授的解说。

相信《Joint Efforts》的广大读者们已对关节炎的病发因素不再感到陌生，这些因素有些还是十分普遍常见的。上一期我们已经详细剖析解说了一种纠缠世界人口中约百分之一的类风湿性关节炎，一种不可忽视的潜伏性顽疾。

系统性红斑狼疮又或简称为“红斑狼疮”也是诱发关节炎的其中一个导因，它盛行于每10万人中的50至150人。患者主要来自亚洲国家如中国、泰国、印度、印尼、菲律宾，甚至蒙古等国家皆沦为这种顽疾的天堂，它肆虐的程度肯定令您乍舌。

在这篇文章将会专注于红斑狼疮所引发的关节炎，可是在进入课题之前，让我们先探讨有关这顽疾的基本资料。

红斑狼疮是类似类风湿性关节炎的顽疾。类风湿性关节炎主要侵袭各个关节，而红斑狼疮则属另一种形式的侵害，它主要侵袭血系统（血液）和呼吸系统。此外，病患的发烧与疲累嗜睡等症状也是红斑狼疮的相关症状。即使红斑狼疮主要的特征皆显现于皮肤（以皮疹形式出现），高达九成的红斑狼疮病患亦侵害骨骼系统。

那么得如何区分红斑狼疮型的关节炎与类风湿性关节炎呢？这两类的慢性顽疾在初期时皆难以辨别区分，因两者皆侵袭小关节处、引发患处于清晨时分的僵硬和患处的肿胀。可是类风湿性关节炎则较普遍造成患处的关节移位变形。

然而，也有其中一类型的红斑狼疮型关节炎亦可使患处变形异位，可是这些皆属异数。红斑狼疮性关节炎属比较良性，也较快对治疗产生反应。另一方面，该病的其它隐忧则有皮肤溃烂、尿含蛋白质、血液出现异常和疲劳等。

一些病患亦有极度嗜睡疲劳和关节疼痛的症状，这些较极端的症状将可能掩盖了红斑狼疮性关节炎的其它症状，它们亦可能导致一些医生误判它为类风湿性关节炎。虽然类风湿性的因素的确出现在约百分之30的红斑狼疮性关节炎病患身上，可是类风湿性关节炎专科医生则可以专业的方式将它们清楚地辨别出来。

大多数的类风湿性关节炎病患几乎没有出现或只出现极少的皮肤溃烂，这些病患体内皆含高数量的白血球与血小板。红斑狼疮病患血液内的这两类物质则相较地低落，而且高达百分之95病患体内则对反细胞核因素呈阳性反应，这种病患体内产生的抗体将瞄准病患本身的细胞核（细胞内部的一部分）。红斑狼疮性关节炎病患对抗疟疾药物——硫酸羟氯喹有极佳的反应，所以对这类病列，有些医生使用了甲氨蝶呤（一种常用作治疗类风湿性关节炎的特效药）。

红斑狼疮病患需要较高剂量的类固醇——泼尼松龙；类风湿性关节炎病患则必须要它。为了更有效地控制病情，我们减少配给病患这类型药物，而选择了更佳的抗类风湿性药物（DMARD）如甲氨蝶呤、柳氮磺吡啶和来氟米特。

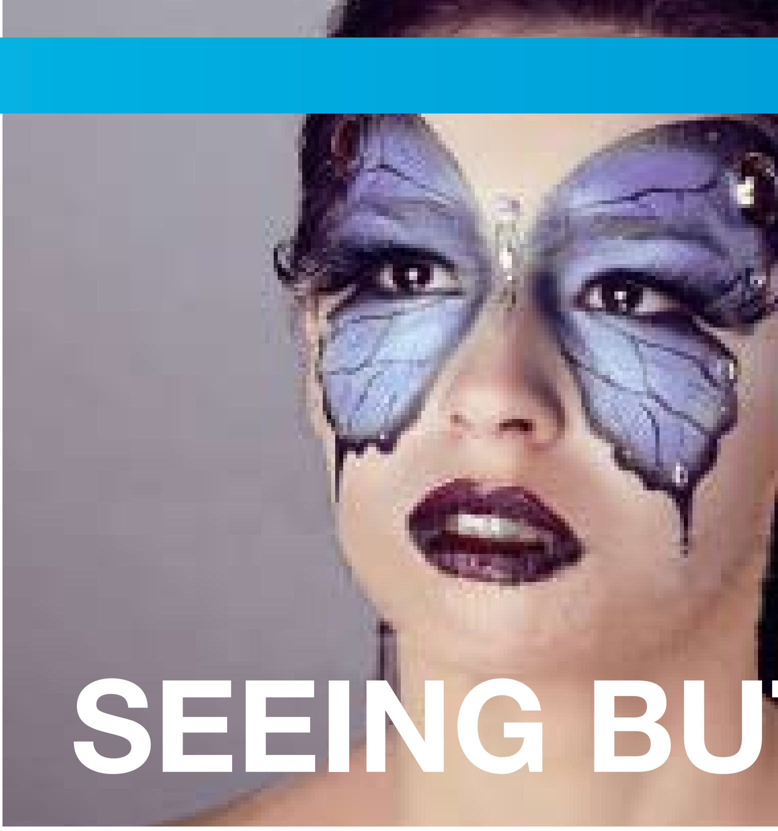
几乎所有红斑狼疮性关节炎病患会服食硫酸羟氯喹，那是一种针对该顽疾的主要特效药。这种特效药亦适合用于类风湿性关节炎患者身上，尤其是负血清型类风湿性关节炎（类风湿性关节炎因素呈阴性反应）的病患。也许是这两种顽疾皆会共同引发关节发炎的症状，才令医生采用该药物来处理。

我们得再次强调，类风湿性关节炎专科医生是受过辨识上述两种顽疾特别训练的专才。令人欣慰的是这两类关节炎的初期治疗是大致相同的，在一些极其相似的病例个案中，虽然有不同的征状，可是殊途同归，专才还是能精确地诊断它们的种类。那么辨识的难度到底在哪呢？类风湿性关节炎专科医生指出了“综合征”这个词汇，然后则需视病情而量身为病患定下治疗方案。

LUPUS ARTRITIS

Apakah itu Lupus Artritis dan apakah yang dapat kita lakukan tentangnya, seperti yang diterangkan oleh

Profesor Dr Sargunan Sockalingam, Doktor dan Pakar Reumatologi, Pusat Perubatan Universiti Malaya



Sekarang ramai pembaca Joint Efforts tahu akan sebab-sebab penyakit artritis. Sebabnya banyak dan sesetengah sebabnya adalah lebih biasa daripada yang lain. Terbitan sebelum ini juga sering mengetengahkan tentang Artritis Reumatoid dan penyakit ini dihidapi oleh satu peratus penduduk dunia, dan jumlah ini merupakan bilangan yang besar.

Systemic Lupus Erythematosus (SLE) atau hanya disebut sebagai "lupus" juga meruakan penyebab artritis. SLE dihidapi oleh anggaran 50 hingga 150 orang bagi setiap 100,000 orang. Terutamanya di Asia, sama ada di negara China, Thailand, India, Indonesia dan di Filipina, atau Mongolia sekali pun, seseorang akan berhadapan dengan lupus lebih kerap daripada yang dapat dibayangkan.

Dalam artikel ini, saya akan menumpukan kepada artritis dalam lupus. Tetapi biar saya terangkan terlebih dahulu tentang asas penyakit ini. Lupus ialah penyakit auto imun seperti Artritis Reumatoid atau RA. Kesan RA selalunya pada sendi-sendi, manakala lupus pula menjejaskan sistem-sistem lain, seperti hematologi (darah) dan pernafasan. Selain daripada itu, demam dan keletihan sering dikaitkan dengan lupus. Walaupun tanda-tanda pada kulit (dalam bentuk ruam) ialah ciri utama bagi penyakit lupus, penyakit muskuloskeletal juga terdapat pada hampir 90 peratus pesakit lupus.

Adakah artritis lupus berbeza dengan Arthritis Rheumatoid? Pada peringkat awal, ia sukar untuk membezakan antara keduanya. Kedua-dua penyakit ini melibatkan sendi-sendi kecil, menyebabkan kekakuan pada awal pagi dan boleh dikaitkan dengan pembengkakan sendi. Walau bagaimanapun, kecacatan sendi merupakan perkara biasa bagi Artritis Rheumatoid.

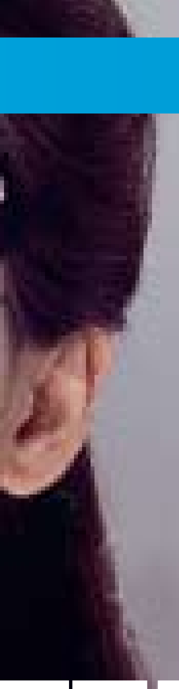
Terdapat sejenis artritis lupus yang boleh menyebabkan kecacatan, tetapi ini jarang berlaku. Artritis lupus selalunya benigna dan bertindakbalas kepada rawatan dengan cepat. Terdapat juga kebimbangan atas manifestasi lain seperti luka pada kulit, protein di dalam air kencing, darah yang tidak normal dan kelesuan akibat artritis lupus.

Sesetengah pesakit mengadu bahawa mereka rasa tersangat letih dan sakit sendi sebelum timbulnya ciri-ciri lupus yang lain. Doktor juga mungkin tersilap sangka bahawa ia adalah Arthritis Reumatoid, malah faktor-faktor Reumatoid itu positif dalam hampir 30 peratus pesakit lupus, tetapi pakar reumatologi telah dilatih untuk mengenali perbezaannya.

Kebanyakan pesakit Artritis Reumatoid tidak mempunyai atau mengalami sangat sedikit luka-luka pada kulit, mereka mempunyai kiraan sel-sel darah putih dan platelet yang tinggi. Pesakit lupus pula lebih berkemungkinan mempunyai kiraan sel-sel darah putih dan platelet yang rendah, sehingga 95 peratus daripada mereka mempunyai Faktor Anti Nuklear positif, antibodi yang dihasilkan badan menyerang nukleus (terdapat di dalam sel) pesakit sendiri. Perkara pelik tentang artritis lupus ini adalah pesakit memberi tindak balas yang baik terhadap ubat anti malaria, Hydroxychloroquine, dan dalam beberapa kes lupus, kami menggunakan Methotrexate (ubat yang biasanya digunakan untuk merawat Artritis Reumatoid).

Pesakit lupus memerlukan dos steroid Prednisolone yang tinggi, manakala bagi pesakit Arthritis Rheumatoid pula adalah sebaliknya, di mana kami mengehadkan dos steroid bagi membolehkan ubat anti-reumatik mengubah penyakit (DMARD) seperti Methotrexate, Salazopyrine dan Leflunomide supaya lebih berkesan. Hampir kesemua pesakit lupus yang mempunyai artritis akan diberikan Hydroxychloroquine. Ini merupakan ubat yang penting untuk merawat lupus. Hydroxycloroquine juga disyorkan untuk merawat Artritis Reumatoid kerana ia sangat berkesan dalam seronegatif (Faktor Reumatoid negatif) Arthritis Reumatoid. Mungkin sesetengah mekanisme penyakit yang menyebabkan pembengkakan sendi adalah sama antara kedua-dua penyakit ini.

Pakar reumatologi dilatih untuk mengenali berbezaan antara kedua-dua penyakit ini. Sebenarnya rawatan di peringkat awal kedua-dua penyakit ini agak serupa, tetapi lama kelamaan kebanyakan kes yang sama akan menunjukkan perbezaan yang akan memberi diagnosis yang tepat. Apabila ia sukar untuk membezakan antara kedua-dua penyakit ini, doktor akan menggelarnya"Rhupus"dan rawatan kemudiannya dikhususkan untuk menangani elemen kedua-dua penyakit tersebut.



One patient’s bumpy road to diagnosis of lupus

43-year-old investment Banker, Lina (not her real name), was diagnosed with Lupus three years ago, “although,” she explains, “I probably had it much earlier, but was not sensitized or aware of the symptoms to realise, before the actual diagnosis, that it was lupus.”

TTERFLIES

Although the cause for lupus in most cases is unknown, medical experts believe that lupus likely results from a combination of genetics and the environment. It appears that people with an inherited predisposition for lupus may develop the disease when they come into contact with something in the environment that can trigger lupus.

Aside from sunlight, other triggers can be certain types of anti-seizure medications, blood pressure medications and antibiotics. People who have drug-induced lupus usually see their symptoms go away when they stop taking the medication.

Lina’s lupus, she is certain, was triggered by her IVF (in-vitro fertilization) treatments. She says, “My first round of IVF was successful, but almost immediately I had severe bloating with fluid in the stomach that we thought was ovarian hyper stimulation syndrome, or OHSS, which we put down to being merely a side effect of IVF.”

For the following six to eight weeks, Lina had to have the fluid extracted at the hospital, which meant that she was also losing protein. On the ninth week, Lina took medical leave from her hectic job. That’s when she had a miscarriage because, in her own mind, “of too much movment.”

After resting for a bit, Lina returned to work, but due to the chronic fatigue she started experiencing, she had to “go on too many MCs.” It was then that she also lost alot of weight. “I felt as if I was never going to recover from the miscarriage,” she says. As it turns out, the miscarriage was a redherring that deflected the focus from the actual cause of her fatique, pallor and weight-loss, ultimately lupus.

Suspecting something more, Lina, also on the urging of her husband who is a physiotherapist, consulted a doctor of internal medicine. After running some blood tests and Lina was recommended a blood transfusion, but the actual cause of her debilitating symptoms remained ellusive.

She was then referred to the Unversity Hospital, and although she underwent a battery of tests, the SLE test was not one of them.

And so it took one more round of IVF andd Lina’s furthers adverse reactions to the procedure and the hormones administered before lupus was even suspected.

“My internal organs started to breakdown; I developed appendisitis, but of course, we didn’t know what it was at that time. I was in such pain one night, but as I seemed otherwise OK, my husband suggested that I sleep it off.”

But as the pain persisted, after a couple of days, Lina made yet another trip to the hospital where an X-Ray confirmed that the pain was caused by acute appendisitis. She was operated on imediately.

After the removal of her appendics, however, the general fatigue and “pain all over my body” persisted. It was then that Lina developed one of the most recognisable signs of lupus, a butterfly-shaped rash on her face. Her husband, being a medical professional, was the first to suspect / diagnose her condition as caused by lupus.

“My husband always proudly proclaims that he was my saviour, and that I might not be alive today if not for him. He’s so over dramatic!” Lina chuckles, rolling her eyes.

The cardiologist that Lina and her husband consulted for confirmation of his professional opinion agreed with it and proceeded to refer her to a rheumatologist. There, a chest X-Ray and SLE-specific blood tests showed Lina to have fluid retention in her chest as well as lupus. Once again, Lina was admitted immediately.

“Due to the battery of tests, I developed issues with my kidneys; there was protein in my urine,” she recounts of that extremely trying moments at diagnosis and just before recovery. She needed more blood transfusions, but was still pale, weak and listless. It was only after Lina started taking the steroids precribed that her condition started improving.

“Initially, I had monthly check-ups, but as I am much better now, I go only once every four months, and when I do, I generally have a blood test done to monitor for flare-ups,” explains Lina.

These days, she is on myfortic for her kdneys, plaquniel for lupus and prednisalone that helps prevent flare-ups. “It takes a few months to determine the correct dosage of the drugs through a process of trial-and-error. We see to have hit on the right dosages in the right combination,” Lina says, before sheepishly adding, “Sometimes, I DO forget to take my meds....”

And what impact has lupus had on her life?

“For one thing, I have had to strike the idea of having children off my wish-list, but our three dogs more than make up for it. These days I cannot be too active outdoors as too much direct sunlight weakens me. I feel bad after being in the sun,” Lina says.

Nevertheless, she makes it a point not to allow lupus to detract too much from her enjoyment of life.

“I feel that I have a fairly high tolerance for pain. I just don’t want to think about it too much; I just get on with life and not let it bother me emotionally and mentally. I know this does not sound good, but I really don’t want to read too much about it. I rely very much on my husband who is very supportive.”

Oddly enough, Lina is looking forward to menopause. She explains, “My rheumatologist told me that as my lupus seems very linked to my hormones, I may well go into a remission after menopause.”

MELIHAT RAMA RAMA

Perjalanan sukar seorang pesakit sementara menanti didiagnosis dengan lupus

Pekerja bank pelaburan berusia 43 tahun, Lina (bukan nama sebenar), telah didiagnosis menghidapi Lupus tiga tahun lalu. Katanya, "Walaupun saya mungkin telah menghidapinya lebih awal, saya kurang sedar akan simptom-simptomnya sebelum didiagnosis bahawa ia adalah lupus."

Walaupun penyebab lupus selalunya tidak diketahui, pakar perubatan percaya bahawa kemungkinan lupus adalah akibat kombinasi genetik dan persekitaran. Mereka yang mewarisi predisposisi lupus mungkin mendapat penyakit tersebut apabila mereka terkena sesuatu yang ada pada alam sekitar yang boleh mencetuskan lupus.

Selain daripada cahaya matahari, pencetus-pencetus lain mungkin merupakan sesetengah jenis ubat anti-sawan, ubat tekanan darah tinggi dan antibiotik. Mereka yang mempunyai lupus akibat ubat-ubatan selalunya tiada mengalami simptom apabila mereka berhenti makan ubat-ubatan tersebut.

Lina pasti, penyakit lupusnya tercetus akibat rawatan IVFnya (persenyawaan in-vitro). Katanya, "Rawatan IVF pertama saya berjaya tetapi tidak lama selepas itu perut saya buncit penuh dengan cecair dan kami fikir ia adalah masalah sindrom rangsangan hiper ovari atau OHSS di mana kami sangka akibat sampingan daripada IVF."

Selama enam hingga lapan minggu berikutnya, Lina terpaksa mengeluarkan cecair tersebut di hospital, di mana Lina juga kehilangan protein. Pada minggu kesembilan, Lina ambil cuti sakit daripada kerjanya yang sibuk. Ketika itulah Lina mengalami keguguran kerana, dalam fikirannya, "adalah akibat banyak bergerak."

Selepas berehat, Lina kembali bekerja tetapi mula mengalami keletihan kronik dan terpaksa mengambil banyak cuti sakit. Dia juga hilang berat badan. "Saya rasa seolah-olah saya tidak akan pulih daripada keguguran," katanya. Rupa-rupanya, keguguran tersebut telah mengalihkan tumpuannya daripada sebab sebenar kelesuan, wajah pucat dan hilang berat badan, iaitu lupus.

Lina mengesyaki perkara lain dan menggesa suaminya, seorang ahli terapi fisio, menghubungi doktor perubatan dalam. Selepas melakukan beberapa ujian darah, Lina disyorkan untuk melakukan pindahan darah tetapi sebab sebenar simptom kelesuannya tidak diketahui.

Lina kemudiannya dipindahkan ke Hospital Universiti, dan walaupun dia menjalani pelbagai ujian, ujian SLE bukanlah salah satu daripadanya. Lina menjalani sekali lagi rawatan IVF dan menambah lagi reaksi negatifnya terhadap prosedur dan hormon yang diberikan sebelum mengesyaki lupus.

"Organ dalaman saya mula rosak. Saya mempunyai masalah appendisitis, tetapi pada masa itu kita tidak tahu masalahnya yang sebenar. Saya berada dalam kesakitan yang amat sangat pada suatu malam, tetapi kemudian saya OK, maka suami saya menyuruh saya lupakannya."

Tetapi bila kesakitan tersebut berterusan selepas beberapa hari, Lina pergi ke hospital sekali lagi di mana X-Ray mengesahkan yang kesakitan tersebut disebabkan oleh appendisitis akut. Dia menjalani pembedahan serta merta. Walau bagaimanapun, selepas apendiksnya dibuang, Lina masih mengalami kelesuan dan "sakit seluruh badan". Ketika inilah Lina mempunyai tanda-tanda lupus yang mudah dikenali, iaitu ruam berbentuk kupu-kupu di mukanya, Suaminya, seorang profesional perubatan, adalah orang yang pertama mengesyaki keadaannya disebabkan oleh lupus.

"Suami saya selalu mengaku yang dia adalah penyelamat saya dan saya mungkin tidak hidup hari ini jika tidak kerana dia. Dramatik betul!" kata Lina sambil ketawa. Lina dan suaminya bertemu dengan pakar kardiologi untuk mendapatkan pengesahan dan selepas itu mereka dirujuk kepada pakar reumatologi. Di sana X-ray dada dilakukan dan ujian darah khusus SLE menunjukkan Lina mempunyai penahanan bendalir di dadanya serta lupus. Sekali lagi Lina ditahan di hospital serta merta.

"Kerana banyak sangat ujian dilakukan, saya mempunyai masalah dengan buah pinggang; dan protein di dalam air kencing saya," Lina mengimbau saat-saat sukarnya ketika didiagnosis dan sebelum pemulihan. Dia memerlukan lebih banyak pemindahan darah tetapi masih lagi kelihatan pucat, lemah dan lesu. Hanya selepas Lina mengambil steroid yang disyorkan, keadaannya bertambah baik.

"Pada mulanya saya melakukan pemeriksaan bulanan tetapi sekarang saya rasa lebih baik. Saya kini hanya pergi membuat pemeriksaan setiap empat bulan dan selalunya ujian dilakukan untuk memantau keradangan," jelas Lina. Sekarang ini, Lina mengambil myfortic untuk buah pinggang, plaquniel untuk lupus dan prednisalone yang membantu mencegah keradangan. "Ia mengambil masa selama beberapa bulan untuk menentukan dos ubat-ubatan yang betul melalui proses percubaan. Nampaknya kami mendapat dos yang betul dalam kombinasi yang betul," kata Lina sambil menambah, "Kadang-kadang saya terluap makan ubat..."

Dan apakah kesan lupus terhadap kehidupannya?
"Yang pertama, saya terpaksa membuang niat untuk mempunyai anak sendiri tetapi tiga ekor anjing kami melengkapi hidup kami. Kini saya tidak boleh terlalu aktif di luar rumah kerana sinaran matahari melemahkan saya. Saya rasa teruk selepas terdedah pada matahari," kata Lina.

Walau bagaimanapun, Lina tidak membenarkan lupus mengganggunya daripada menikmati kehidupan. "Saya rasa saya mempunyai daya ketahanan yang tinggi pada kesakitan. Saya tidak mahu terlalu memikirkannya; saya hanya mahu terus hidup dan tidak membenarkannya mengganggu saya secara emosi mahu pun mental. Saya pun tidak mahu membaca terlalu banyak tentang lupus, memang saya tahu bunyinya kurang baik. Saya bergantung kepada suami saya yang banyak memberi sokongan."

Lina teruja menanti menopaus. Katanya, "Pakar reumatologi saya memberitahu yang lupus saya ada kaitan dengan hormon saya, saya mungkin berada dalam remisi selepas menopaus."

见蝶

红斑狼疮病患的崎岖历程

年届43岁的投资银行家——丽娜（非本名）于3年前便被诊断罹患红斑狼疮症，她说：“我可能更早就已经患病了，只是我并不很留心相关的症状的出现，而是在进行精确的诊断后，方才大悟那是红斑狼疮症。”

虽然红斑狼疮的真正导因还未被真正确认，医药界普遍认为此症是由基因与环境两大因素而产生病发的综合症，红斑狼疮带因者在接触环境中的一些物质后才可能发病。

除了阳光，其它诱发因素也涵盖了某种类的抗癫痫药物、调节血压药物或抗生素。这类由药物所引发的红斑狼疮，会在病患停止服用该类药物后慢慢地消退无踪。

丽娜的情况则肯定是因她所接受的体外人工受精（IVF）治疗所诱发产生的。她说道：“我第一次的体外受精就成功了，可是我也有严重的液体腹涨问题，起初我们认为那是该受精法的其中一种副作用——子宫过度受激征状（OHSS）。

所以在接下来的6至8个周，丽娜便得上医院进行腹腔液体抽取，这使得她流失了体内的一部分蛋白质。到了第9周，她便得辞去她那份高度忙碌的工作，专心养胎。即使是在流产后，她也只是认为是自己“过动”才失去胎儿的。在调养了一阵子后，丽娜返回工作岗位。可是她开始感到极度疲劳而得“频频告假”，为此她也消瘦了许多。“我还以为我没法从流产中复原呢！”她道。最后，流产只是一个子虚乌有的幌子，让她忽略了真正让她疲劳、面色苍白、暴瘦与最终罹患红斑狼疮症的导因。

丽娜则感到她的情况并非如此简单，所以就催促身为物理治疗师的丈夫请教一些内服药物的医生。丽娜验血数次后便被劝说得进行输血，可是导致她身心疲弱的幕后黑手还是无法无天，逍遥自在。

而后，她又被转至大学医院中进行医生的一系列检测，可就是没有系统性红斑狼疮的检验。

然后，丽娜又在接受一次体外人工受精手术，她身体对手术与荷尔蒙注射的明显反应更让她怀疑红斑狼疮是否找上她了。

“我身体内的器官开始闹情绪了。而且，在毫无预警的状况下，我还患上了盲肠炎。我的肚子疼了一晚后便好像没事了，我的老公就建议我别太在意，没什么大不了的。”

可是折腾人的腹痛数日后，还是驱之不散。在无计可施之下，丽娜又得挂号照X光了。检验结果证实了对她痴痴缠的腹痛其实是急性盲肠炎，她得立即入院切除。

还以为切除盲肠便天下太平了，怎知，疲劳与“周身酸痛”还是对丽娜“不离不弃”。然后，丽娜的脸上便出现了红斑狼疮症最明显的征状——蝴蝶形的面部红斑。丽娜的医药专科老公是第一个根据这个最明显的红斑狼疮征状而怀疑她患病的人。

“我的老公时常开玩笑的说他是我的大恩人，如果不是他，我可能无法活到今时今日，他就是那么戏剧性的！”丽娜一边转动着她的眼珠子，一边自嘲的开玩笑道。

丽娜与先生双双前往咨询他们的心脏科专家，对方也认同丽娜是罹患了红斑狼疮症，也将丽娜转介到类风湿性关节炎专科医生那处再作定夺。丽娜接受了胸腔X光片与系统性红斑狼疮指定性验血检验，检验结果指出她胸腔内积水兼确认罹患红斑狼疮症。所以，她又得马上入院了。

“因接受了一系列的检验与检测，我的肾脏开始出现问题了，我的尿液里含有蛋白质。”她悉数着确诊与康复之前所承受的那些极端检测。她在进行数次输血后还是面色苍白，身体虚弱无力，而后再接受类固醇口服治疗后才逐渐有起色。

“一开始，我得每个月去做检查。可现在我的情况已经略有改善了，现在我每4个月复诊一次，每次只验血来观察病情。”丽娜解释到。那时，她得为肾脏机能而食用麦考酚酸片、抗红斑狼疮的硫酸羟氯喹和阻止病发的泼尼松龙。“我是历经了好几个月的尝试后才鉴定每种药物的剂量，看来我这番苦工并没有白费，剂量的确适合我。”她说道。她还不好意思的悄悄告诉道：“有时，我也是会忘记吃药哦......”

那么红斑狼疮症对 有什么影响呢?
“有，生儿育女得就此离我而去，可是我却有3条可爱的狗狗弥补这项不足。还有，我不能在户外活动的太久，因为阳光会令我虚弱，身体不适。”丽娜补充道。

然而，她亦表示她将不会让这顽疾欺凌她愉快地享受生活。

“我认为我能忍受偏高的痛楚，这难不倒我。我不要想得太多；我只想尽量享受，力求思域和心理的宁静。我知道这对我的病情没有好处，可是我真的不想去想太多。我寄望一直都无时无刻支持协助我的老公。”

丽娜还有另一个令人惊奇的希望，那便是更年期的来临。她解释道：“类风湿性关节炎专科医生告诉我，红斑狼疮症与人体的荷尔蒙有着千丝万缕的关系，所以我的病情可能在更年期来临后便能有所改善呢！”

On the Move against Arthritis

Caring Malaysians put their best foot forward at Kordel's Charity Walk 2013

On the eighth of September in Kuala Lumpur, looking at the approximately 1100 strong crowd all raring to walk at six in the morning, you would have been forgiven for thinking that there was some large sum of money to be won. However, there was no prize money, or fancy trophies or medals to be had. Yet, none of the participants from all walks of life and of all shapes and sizes seemed fazed by this puzzling fact. On the contrary, they seemed a highly motivated bunch whose moral was not to be dampened by such trivialities as prize money or the public recognition of their physical prowess.

This was only beacause the event was none other than the 2013 edition of Kordel's Charity Walk (KCW 2013) where the sole pupose of every participant was to walk in unison, on a mission to raise awareness and funds for the Arthritis Foundation Malaysia (AFM).

Even as this fifth edition of the walk was the inaugural one for some, for the multitude of others on the other hand, the KCW 2013 was a familiar event to which they look forward keenly to each year. Perhaps one of the more unique features of this year's KCW was that, for the first time ever, a group of arthritis patients -- with hopes of making a difference in the lives of their fellow patients -- participated in the walk.

Mr. Ho Swee Lin, General Manager for Cambert (M) Sdn Bhd explained the Kordel's ethos at flag-off by saying, "For a lifetime of good health, Kordel's emphasis is on delivering quality nutritional products while simultaneously advocating an active lifestyle. "What better way to realise our commitment than by creating an opportunity for family and friends to have some fun by enjoying the health benefits of exercise and contributing to a worthy cause through the Kordel's Charity Walk!"He added, "As we enter our fifth year of improving the lives of arthritis patients, we must thank our ever supportive participants and sponsors for this milestone. Their passion towards helping the arthritis community is commendable and helps ensure that the Kordel's Charity Walk is an annual event!"

This year, RM33,000 was donated to the AFM, fully obtained from participants' entry fees and the sales of Kordel's charity packs. The money will go towards supporting the AFM in its continuous efforts to improve the living quality of people with arthritis, particularly in helping underprivileged arthritis patients undergo joint replacement surgery. Contextualising the significance of this, Dr. Amir Azlan Zain, President of thr AFM, in his address, said, "To date, the foundation has reached out to nearly 80 patients suffering from advanced arthritis who were sponsored for much-needed joint replacement surgeries. It is with the help of corporations like Kordel's, its sponsors and caring Malaysians, that we are able to keep the Arthritis Fund up and running and reach out to more p atients. For that, we are truly grateful."

The tremendous support of numerous sponsors inspired even more excitement for the walk. On top of an exclusive Kordel's Charity Walk T-shirt and a Certificate of Participation, all participants received goodie bags with products sponsored by 100 Plus, BIC, Bio-Oil, ForsLean PLUS, Holiday Inn KL Glenmarie, Jack'n Jill, Juvanex, May, Mirinda, Nutra-Life, Nuvafemme, Orex Travel, Perskindol, Salonpas, Shallop, Sweet Sweat, Vaseline Men, Watsons. Winners from the lucky draw also took home attractive prizes including Kordel's products worth RM3,000 and a trip to Phuket and Langkawi.

As Kong Kang Chye, 63, one of the returning supporters of the Kordel's Charity Walk who has participated for the past four years shared, "Living with arthritis pain and movement limitations on a daily basis can be draining. Knowing that every step I take during the walk helps patients living with arthritis, I feel a wave of hope and pride along the way. I must say that it was a fulfilling 7km journey with my brother and I am looking forward to next year's event."

For more details on the Arthritis Foundation Malaysia and Kordel's, please visit www.afm.org.my and www.kordels.com.my

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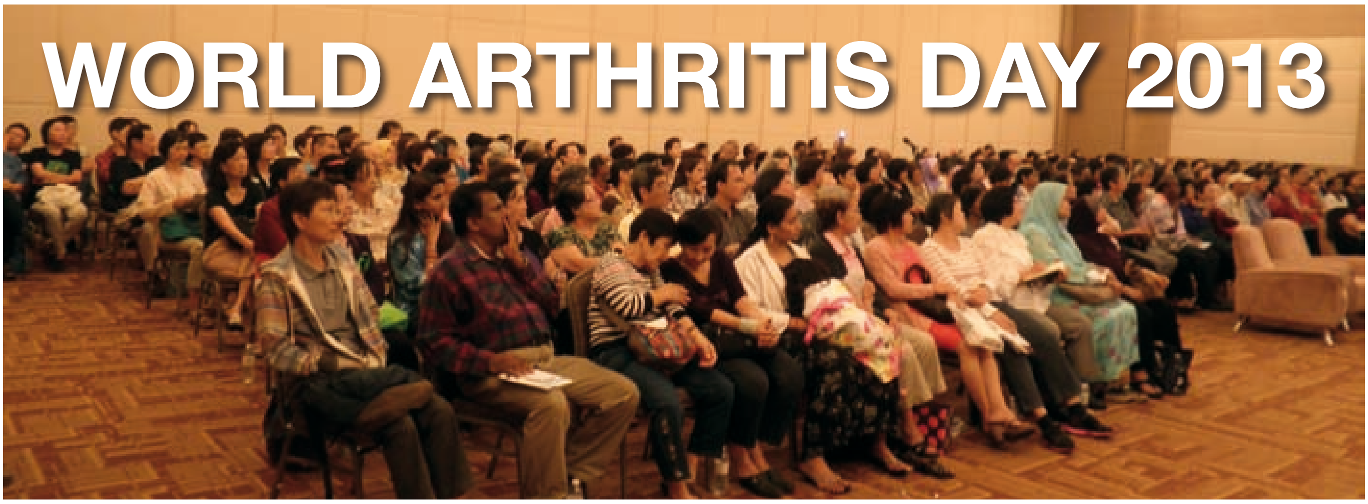
WORLD ARTHRITIS DAY 2013



This year, World Arthritis Day was celebrated with resounding success on the 12th of October at the Swan Convention Medical Centre from 9am to about 5pm. It was opened with an address by Dr Amir Azlan Zain, President of the Arthritis Foundation Malaysia (AFM).

This was followed by a speech from the guest of honour and the launching of a booklet with accompanying CD on exercise by Farmasia. Then from about 10.40am right through to five in the evening, the day was filled with a rich series of informative talks on the various aspects of the management of arthritis.

Dr Ozlan Izma Muhamad Kamil, Consultant Orthopaedic Surgeon, Prince Court Medical Centre kicked off the talks with 'Journey to the Joint'. During his session, Dr Ozlan spoke of treatment of osteoarthritis, first explaining how a joint deteriorates and then examining the role of pain as protection.

He then went on to say how the drugs used to manage pain work by attacking the nerve that causes pain, can do more damage than good as pain makes you protect the deteriorating joint. Using such drugs might well encourage bone necrosis, or the further wearing down of the bone and, subsequently, the affected joint.

Dr Ozlan also fielded questions from the participants, the most outstanding one being how one is to exercise with total knee replacements (TKR). He answered that the real reasons behind TKRs are generally to remove pain and to regain the mobility. Ideally, one should resume the physical activities one enjoyed before the onset of osteoarthritis, with the caveat that as TKRs have a lifespan, one should not overload the joint with too much activity. In other words, Dr Ozlan encouraged participants to exercise, but not to overdo it.

A coffee break followed and by 11.45am, the hall was once again packed to the brim for the next speaker, Dr Sargunan Sockalingam, Physician & Rheumatologist, Universiti Malaya Medical Centre who delivered his presentation on 'Understanding the basis of arthritis' with humour and panache.

He had the crowd laughing even as he eased into his subject matter from the very basics such as explaining the origins of the Greek stem ("rheuma") in the word "rheumatoid". Dr Sargunan then went on to explain the definition and diagnosis of arthritis, its causes, the various forms of arthritis, treatments, the role of the patient and, last but not least, the role of the rheumatologist.

Statements such as "watching exercise is certainly not the same as exercising" that Dr Sargunan delivered in a deadpan manner had the crowd in stitches. For sure, by the end of his talk, his audience were convinced that apart from rheumatology, Dr Sargunan would also excel as a stand-up comedian. Like Dr Ozlan before him, Dr Sargunan also fielded questions from the audience.

The next session by Dr Siva Poobalasingam, Director, Amrita Integrative Health Centre, Putrajaya was on 'Yoga intervention for arthritis'. After a brief introduction on the two most common types of arthritis, namely osteoarthritis and rheumatoid arthritis, he narrowed in on the pivotal role stress plays "in the aetiology and progression of rheumatoid arthritis".

Dr Siva explained how chronic stress keeps the hormones elevated consistently, reading the body for the 'fight/flight' response, and how, in the long run, this expresses as diseases such as hypertension, coronary artery disease, auto-immune diseases and anxiety. Yoga, he explained, is one of the most popular forms of Complementary Alternative Medicine (CAM) for arthritis because it is one of the most effective ways of switching on the relaxation response, a physical state of deep rest that changes the physical and emotional response to stress. And to demonstrate this, the audience was treated to a 15-minute session on yoga exercises that do so.

After this, lunch was served before Dr Suhail Suresh, Consultant Orthopaedic & Trauma Surgeon, Sunway Medical Centre took centre stage with his presentation entitled Total Joint Replacement: A Practical Approach.

During this session, Dr Suhail explained in great detail the causes as well as the process and complications associated with Total Joint Replcement (TJR) procdures.Some of the non-pharmacological treatments for joint deterioration he suggested was "Reduce weight, modify activity, use walking aids, regular exercise, and to use braces and splints if or when necessary. Walk rather than run; sit rather than stand."

Dr Suhail's session was then followed by the arthritis patients' support group, of which there is a separate report in this edition of Joint Efforts.

The last session of the day was that of Dr Chow Sook Khuan, Consultant Rheumatologist, Sunway Medical Centre, who presented on New Frontiers in Rheumatoid Arthritis.

Overall, World Arthritis Day 2014 was a huge success with a record turnout. Dr Amir has this to say, "It was such a pleasure to see so many participants, old and new faces, at WAD 2013. It made all our efforts worthwhile. It is my hope that the public continue to attend our events to spread the awareness of the conditions."

WORLD ARTHRITIS DAY 2013 SUPPORT SESSION

Go Grease Lightning!

This year's World Arthritis Day, held on the 12th of October at the Swan Convention Centre, headquarters of the Arthritis Foundation of Malaysia was a resounding success, and so was the Rheumatoid Arthritis Support Group (RASG) session, conducted by the group's Chairperson, Annie Hay that was slotted after all the doctors' presentations, at 3.30pm.

As Hay had promised, after an intensely informative day, the session was light-hearted, entertaining and fun. Without even wanting to skip a heartbeat, Hay quicky introduced the invited guests, a dance group called CH4RMS, made up of four young ladies who had been dancing together for four months before participating in their very first dance competition, MYKTQ 2013, infront of a live audience.

The girls performed a lively hip-hop (street dance style) routine that had the audience in awe. They bopped to hip-hop music that was freestyle in nature. Members marvelled at all that "breaking", "locking", and "popping".

After the dance performance, Hay invited Ding Mee Hong (former chairman of the Rheumatoid Arthritis Support Group) to present the four members a well-deserved token of appreciatIon.

Hay then gleefully announced that it was time for the participants to showcase their very own dance styles. After so much fun and laughter, the judges had to make some really tough decisions in selecting three lucky but thoroughly deserving participants from the 280 strutting their stuff with abandon.

Hay duly invited then on stage for the clincher to showcase their own renditions of the 1978 hit musical, Grease. First, however, the three were shown a music video clip of one of the hit numbers from that musical, Grease Lightning, before the three, namely, Elaine, Veloo and Tang had to "do their thing" along the lines of the music video clip.

It was arguably one of the most side-splittingly memorable sessions of WAD 2013. As the three took their respective turns to showcase their "lightning" talent, the ballroom almost shook with the raucous laughter of the crowd. The electrifying joy and laughter even inspired many to jump off their seats to boogie along in support of the contestants.

All in all, the main objective of the RASG of getting the audience to participate was achieved. With the crowd awash with feel-good endorphins that all that laughter and exercise must have surely produced, the RASG was happy to have been able to use the time alloted to them at WAD 2013 to boost, physiologically, the number of antibody-producing cells that enhance the effectiveness of T-cells, leading to stronger immune systems in their members.

The session ended on a high note -- and on time -- with Dr Chow Sook Khuan giving away three beautiful hampers, courtesy of our sponsor, Basic Health & Beauty, to the three lucky and sporting participants.

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WHAT IS GLUCOSAMINE?

For sure, "glucosamine" is a long word. It also sounds a little scary and perhaps too "medical". So this would be a great place to help demystify this substance, most commonly recognized, these days, as gel capsules in bottles arranged in neat rows on the shelves of your favourite pharmacy.

An educated guess would have you wondering if glucosamine had anything to do with glucose, and you'd be spot on! As technical as the word might appear to the untrained ear and mind, you might be surprised to discover that glucosamine is actually a natural compound that is found in healthy cartilage. It is made from glucose and the amino acid glutamine, and is needed to produce glycosaminoglycan and sinovial fluids (fluids that surround a joint), a molecule used in the formation and repair of cartilage and other body tissues.

The bad news is that the production of glucosamine slows with age.

As such, glucosamine is available as a nutritional supplement in health food stores and pharmacies, and is made in a laboratory from chitin, a substance found in the shells of shrimp, crab, lobster, and other sea creatures. It is not obtainable from natural food sources. For osteoarthritis, the typical dose of glucosamine used in most studies was 500 milligrams of glucosamine sulfate taken three times a day.

Research indicates that glucosamine sulfate can be effective in the treatment of osteoarthritis, particularly of the knee. It is believed that the sulfate, at the molecular level, benefits the synovial fluid by strengthening cartilage and aiding glycosaminoglycan synthesis.

However, this research also shows that only glucosamine sulfate -- as opposed to the non-sulfated forms of glucosamine -- is effective as complementary or alternative treatment for osteoarthritis, especially that of the knee.

Other forms of glucosamine include glucosamine hydrochloride, and N-acetyl-glucosamine. These different chemicals have some similarities; however, they may not have the same effects when taken as a dietary supplement. Most of the scientific research done on glucosamine has been done on glucosamine sulfate. Glucosamine is commonly taken in combination with chondroitin, generally made from cow cartilage. The medical community is, nevertheless, cautious about the efficacy of glucosamine although it does record that some patients on glucosamine/chondroitin have reported reduced doses of non-steroidal anti-inflammatory medication.

Glucosamine has also been used to treat rheumatoid arthritis and other conditions, such as inflammatory bowel disease, asthma, allergies, chronic venous insufficiency, sports injuries, temporomandibular joint problems (TMJ), chronic low back pain, and many others. Up to this point, however, these uses of glucosamine are not well supported by evidence from research studies.

Although relatively safe in terms of side-effects, people with allergies to shellfish should be wary of using glucosamine, since it could cause an allergic reaction. Those who have diabetes, kidney disease, heart disease, bleeding disorders, or high blood pressure should check with a doctor before using glucosamine. It is not recommended for children or for women who are pregnant or breastfeeding.

The most common side effects are increased intestinal gas and softened stools. However, animal research has raised the possibility that glucosamine may worsen insulin resistance, a major cause of diabetes. So far, studies in humans have not substantiated that risk. Nevertheless, people with diabetes should monitor their blood-sugar level particularly carefully when using that supplement. As for chondroitin, it can cause bleeding in people who have a bleeding disorder or take a blood-thinning drug.

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APAKAH GLUCOSAMINE?

Pasti, " Glucosamine " adalah perkataan yang panjang . Ia juga kedengaran sedikit menakutkan dan mungkin terlalu " perubatan". Jadi ini akan menjadi tempat yang hebat untuk membantu demystify bahan ini , biasanya diiktiraf , hari ini, sebagai kapsul gel dalam botol disusun dalam baris kemas di rak farmasi kegemaran anda.

Tekaan berpendidikan akan anda tertanya-tanya jika Glucosamine mempunyai apa-apa kaitan dengan glukosa, dan anda akan melihat pada! Sebagai teknikal perkataan mungkin kelihatan telinga yang tidak terlatih dan minda, anda mungkin terkejut apabila menemui Glucosamine yang sebenarnya adalah sebatian semula jadi yang didapati dalam rawan sihat. Ia dibuat dari glukosa dan glutamin asid amino, dan diperlukan untuk menghasilkan cecair glycosaminoglycan dan sinovial (cecair yang mengelilingi sendi) , molekul yang digunakan dalam pembentukan dan pembaikan rawan dan tisu badan yang lain.

Berita buruk adalah bahawa pengeluaran Glucosamine melambatkan dengan usia.

Oleh itu, Glucosamine boleh didapati sebagai makanan tambahan di kedai-kedai makanan kesihatan dan farmasi, dan dibuat di dalam makmal dari chitin, bahan yang terdapat dalam kerang udang , ketam , udang karang, dan makhluk laut yang lain. Ia tidak boleh didapati daripada sumber makanan semula jadi. Untuk Osteoartritis , dos yang biasa Glucosamine digunakan dalam kebanyakan kajian adalah 500 miligram Glucosamine sulfat diambil tiga kali sehari.

Penyelidikan menunjukkan bahawa Glucosamine sulfat boleh berkesan dalam rawatan osteoarthritis , terutama lutut. Adalah dipercayai bahawa sulfat , pada peringkat molekul , faedah cecair sinovial dengan menguatkan tulang rawan dan membantu sintesis glikosaminoglikan .

Walau bagaimanapun , kajian ini juga menunjukkan bahawa hanya Glucosamine sulfat - bertentangan dengan bentuk bukan sulfated Glucosamine - adalah berkesan sebagai rawatan pelengkap atau alternatif untuk osteoartritis, terutama lutut.

Lain-lain bentuk Glucosamine termasuk hidroklorida Glucosamine, dan N- asetil- Glucosamine . Bahan kimia yang berbeza mempunyai beberapa persamaan , namun mereka mungkin tidak mempunyai kesan yang sama apabila diambil sebagai diet tambahan . Kebanyakan kajian saintifik yang dilakukan ke atas Glucosamine telah dilakukan ke atas glukosamina sulfat. Glucosamine biasanya diambil dalam kombinasi dengan kondroitin , biasanya diperbuat daripada rawan lembu. Masyarakat perubatan adalah , bagaimanapun, berhati-hati mengenai keberkesanan glukosamina walaupun ia rekod bahawa sesetengah pesakit Glucosamine / kondroitin telah melaporkan dos dikurangkan bukan steroid ubat anti -radang.

Glucosamine juga telah digunakan untuk merawat artritis reumatoid dan syarat-syarat lain , seperti penyakit keradangan usus , asma , alahan, kekurangan vena kronik , kecederaan sukan , masalah sendi temporomandibular (TMJ) , sakit belakang kronik rendah, dan lain-lain lagi . Sehingga ini , walau bagaimanapun, penggunaan Glucosamine tidak disokong oleh bukti dari kajian penyelidikan .

Walaupun agak selamat dari segi kesan sampingan, orang-orang dengan alahan kepada kerang perlu berhati-hati menggunakan Glucosamine, kerana ia boleh menyebabkan tindak balas alergi. Mereka yang mempunyai penyakit kencing manis , penyakit buah pinggang , penyakit jantung , gangguan pendarahan , atau tekanan darah tinggi perlu menyemak dengan doktor sebelum menggunakan Glucosamine . Ia tidak digalakkan untuk kanak-kanak atau bagi wanita yang mengandung atau menyusukan bayi .

Kesan-kesan sampingan yang paling biasa adalah meningkat gas usus dan lembut najis. Walau bagaimanapun, penyelidikan haiwan telah meningkatkan kemungkinan bahawa Glucosamine mungkin menjadi lebih teruk rintangan insulin, punca utama diabetes. Setakat ini , kajian pada manusia telah tidak berasas risiko itu. Walau bagaimanapun , pesakit diabetes perlu memantau tahap gula darah mereka terutamanya berhati-hati apabila menggunakan tambahan yang . Bagi kondroitin , ia boleh menyebabkan pendarahan dalam orang-orang yang mempunyai gangguan pendarahan atau mengambil ubat darah - penipisan.

葡萄糖胺”是什么?

“葡萄糖胺”让人感觉好像是一个很长的名词，听起来有少许恐怖，又或是太过“医学性”了。借此机会，我们便来揭开这种通常在您临近药房架子上，以罐装软胶囊出现的神秘面纱吧!

从字面上您也许会猜测它跟葡萄糖有些关系，不错，您猜对了!普罗大众对它的功用性能可能一知半解，如果我告诉您它其实是在健康的人体软骨组织内的一种自然化合物，可别太惊奇。它是葡萄糖与谷氨酰胺的合成物，可被用作生产糖胺聚糖和滑膜粘液（包围着关节的润滑液体），也是用作生产修复人体内软骨组织和其它一些组织的物质。

可是葡萄糖胺的生产将会被老化影响而随之衰退减缓。
所以，在许多的保健食品店或药房的货架上皆可找到这种营养补充品的踪影。它是由科学实验室内从虾、蟹龙虾或其它海鲜的甲壳中萃取得到的甲壳素而生产出来的制成品，而并非来自天然食品。以骨性关节炎来说，许多研究中所摄取的葡萄糖胺剂量为每日3次500毫克的硫酸葡萄糖胺。

研究结果显示葡萄糖胺乃是对骨性关节炎，尤其是膝盖部位的骨性关节炎较为有效。研究指出这类硫酸类的化合物，可以化成分子进入人体，协助滑膜粘液来强化软骨，并且诱发生产糖胺聚糖。

然而，这项研究也显示只有硫酸葡萄糖胺，而并非其它非硫酸葡萄糖胺，才是骨性关节炎，尤其是膝盖部位骨性关节炎的治疗良方，也可作为后备疗方。

至于其它种类的葡萄糖胺有硫酸葡萄糖胺和N–乙酰基葡萄糖胺。虽然它们在某些方面相同，可是用作营养补充品时就会有不一样的效果，再加上多数的科研皆使用硫酸葡萄糖胺来进行。我们通常会将这类补充剂与另一种从牛软骨萃取，名为硫酸软骨素的化合物一起服用。虽然葡萄糖胺+硫酸软骨素这项组合的确让许多病患减少了服食非类固醇抗炎药物的机率，可是医药界却还有一些人置疑葡萄糖胺的可靠性。

它的功能并不止如此简单，它也被用来治疗类风湿性关节炎和其它的征状如、哮喘、敏感、、运动损伤、、急性腰背疼痛等。它的明确功效至今还未受到科研成果的肯定。

对多数人而言，葡萄糖胺属较低副作用的成品，可是那些对甲壳类海鲜敏感的人，则极可能会诱发他们的敏感症。还有那些罹患糖尿病、肾藏疾病、心脏疾病、流血失调症或高血压的，病患则须在摄取葡萄糖胺前，咨询他们的医生。此外，它亦不适合让儿童、孕妇或正在哺乳的女士。

服食葡萄糖胺所引发的常见副作用是多屁与粪便软化，可是一些动物科研中则指出摄取这种化合物会提高胰岛素的抗性，从而引发糖尿病。至今还未有任何科研显示它对人体构成威胁，但糖尿病患在服食这种辅助品时的留意他们的血糖浓度。至于，它可导致罹患流血失调症或服食稀释血液药物的病患产生意想不到的流血状况。

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A FUN FAMILY DAY AT HARI KELUARGA JIA 2013

By: Dr Tang Swee Ping

The JIA Family Day, held for the fifth time since the inception of the AFM Junior Club in 2005, saw over 75 participants making their way to the Selayang Hospital at 8 am on th 16th of November 2013 for the Hari Keluarga 2013 at the Klana Resort Seremban.

Upon arrival at the state-owned resort located close to the town centre, the participants were joined by more families who had chosen to self-drive. After a short briefing by the organising committee, the parents escorted their children to another seminar room while they converged for a series of educational talks on Juvenile Idiopathic Arthritis by Paediatric Rheumatologists Dr Tang Swee Ping and Dr Cham Weng Tarng.

The children's eyes grew wide with wonder as two representatives from Abbvie brought out face masks and paints for them to work on. Seated comfortably on the sheet-covered floor, they began creating wonderful works of art that were a sight to behold. What's more, the Abbvie boys went around snapping Polaroid shots of each child in action, bringing lots of laughter, shy smiles and wide grins all round!

The mood in the other seminar room was a little more sombre, however, as parents listened intently, first to Dr Tang who gave them an overview of their children's disease, then to Dr Cham's presentation on how to manage the illness.

Tears flowed as some parents shared their emotional turmoil, fears and anxieties, particularly those whose children were recently diagnosed. The forum provided a valuable platform for parents to discuss JIA with the doctors, while benefitting from other parents' experiences.

The cathartic experience gave the parents of the JIA patients a very valuable chance to bond, and this was evident in the Family Telematches that followed. The games, which usually see many opting out, saw almost all families taking part, to the delight of the game organisers!

Hot, hungry and happy with the telematch and their prizes, the participants were then treated to a sumptuous lunch at the Xin Jiang Restaurant. Even with ample time for lunch and rest, many had already disappeared as soon as they had eaten, heading to the venue of the afternoon's activities -- Klana Resort's beautiful swimming pool!

Two sturdy bamboo rafts awaited, and the hotel's event managers efficiently assigned some strong men and boys as rowers, while the smaller children sat in between the poles to enjoy a leisurely ride through the entire length of the spacious pool. Splashing away at the azure blue water and enjoying the beach-like ambiance with palm trees and lush gardens, both parents and children had a blast, some taking the opportunity to enjoy quality family time together, while many others were seen chatting with each other, sharing stories and exchanging contact details.

As if it was written in the stars, raindrops started falling around 3.30 pm, initially in slow lazy drops, and picking up speed to a steady shower, which got the participants scuttling to pack up without the organisers' cajoling. After getting showered and changed, the group trooped upstairs to nice warm tea and snacks before heading back to the bus or their cars to return to Kuala Lumpur.

The 2013 JIA Family Day was another successful family event following earlier trips to Breadtown Shah Alam (2005), Colmar Tropicale/Bukit Tinggi (2006), Kuala Gandah Elephant Sanctuary (2009), Sungei Klah Hot Water Springs (2011) and a one-day seminar in Kuala Lumpur (2009). The family-oriented events, targeted at smaller children, complement the JIA Independence Camps held on a biennial basis for teenage JIA patients on the verge of adulthood.

Report and photos: Chan Li Jin, Co-organiser Hari Keluarga JIA 2013

HARI KELUARGA JIA 2013 HARI YANG MENYERONOKKAN

Oleh: Dr Tang Swee Ping

Hari Keluarga JIA telah diadakan buat kali kelima sejak penubuhan AFM Junior Club pada 2005. Lebih daripada 75 orang peserta telah berada di Hospital Selayang pada pukul 8 pagi pada 16 November 2013 untuk menyertai Hari Keluarga 2013 di Klana Resort Seremban.

Setibanya mereka ke tempat acara, iaitu resort yang terletak tidak jauh dari pusat bandar, para peserta disertai oleh lebih ramai lagi keluarga yang memilih untuk datang sendiri. Selepas taklimat ringkas oleh ahli jawatankuasa penganjur, ibu bapa menghantar anak-anak mereka ke bilik seminar yang lain, manakala mereka pula berkumpul untuk mendengar ceramah pendidikan tentang Juvenile Idiopathic Arthritis (JIA) oleh Pakar Reumatologi Kanak-kanak, Dr Tang Swee Ping dan Dr Cham Weng Tarng.

Perasaan riang jelas terpancar di wajah kanak-kanak apabila dua orang wakil dari Abbvie membawa bersama topeng muka dan warna untuk mereka mencuba. Setelah lantai dialas, kanak-kanak mula melakukan aktiviti seni yang menyeronokkan. Wakil Abbvie pula sibuk mengambil gambar menggunakan kamera Polaroid, gambar kanak-kanak yang sedang sibuk beraksi, yang menambah lagi keseronokan mereka!

Keadaan di bilik seminar yang lain pula lebih serius, di mana ibu bapa mendengar ceramah dengan khusyuk. Mula-mula, Dr Tang memberi gambaran keseluruhan tentang penyakit anak-anak mereka. Kemudian, Dr Cham pula membentangkan bagaimana menguruskan penyakit tersebut.

Terdapat beberapa orang yang mengalirkan air mata apabila berkongsi pengalaman mereka tentang emosi, perasaan takut dan gusar, terutamanya bagi mereka yang baharu sahaja didiagnosis. Forum ini menyediakan platform yang berharga untuk ibu bapa membincangkan tentang JIA dengan para doktor, di samping belajar daripada pengalaman ibu bapa yang lain.

Pengalaman ini memberi peluang berharga kepada ibu bapa pesakit JIA untuk mengenali antara satu sama lain dan ini terbukti dalam Pertandingan Sukaneka Keluarga yang berikutnya. Permainan, yang selalunya tidak ramai yang mahu menyertai, kali ini sungguh berbeza apabila hampir kesemua keluarga mengambil bahagian.

Pertandingan sukaneka berakhir dengan peserta yang kelaparan, namun gembira dengan pertandingan tersebut dan hadiah-hadiah yang diterima. Para peserta kemudiannya dijamu dengan hidangan makan tengah hari di Xin Jiang Restaurant. Walaupun masih banyak lagi masa untuk makan dan rehat, kebanyakan peserta berlalu selepas makan, menuju ke tempat untuk aktiviti tengah hari - di kolam renang Klana Resort yang cantik!

Dua buah rakit buluh telah menunggu dan pihak pengurusan acara hotel telah pun meletakkan anggota lelaki sebagai pengayuh, manakala kanak-kanak yang lebih kecil duduk di antara tiang untuk menaiki rakit, melalui di sepanjang kolam yang luas itu. Dengan alunan air biru, mereka menikmati suasana ala pantai dengan pokok palma dan taman menghijau, ibu bapa dan anak-anak mengambil peluang berseronok menikmati masa keluarga berkualiti bersama, manakala yang lain pula berbual-bual, berkongsi cerita dan bertukar-tukar nombor telefon.

Hujan mula turun anggaran pukul 3.30 petang, bermula dengan gerimis sebelum turun lebat. Para peserta pun berebut-rebut berkemas. Selepas mandi dan bertukar pakaian, kumpulan naik ke atas untuk minum petang... teh panas dan kuih muih sebelum berlepas pulang sama ada dengan bas atau kereta masing-masing ke Kuala Lumpur.

Hari Keluarga JIA 2013 merupakan satu lagi acara keluarga yang berjaya selain daripada rombongan ke Breadtown Shah Alam (2005), Colmar Tropicale/Bukit Tinggi (2006), Pusat Perlindungan Gajah Kuala Gandah (2009), Taman Rekreasi Air Panas Sungei Klah (2011) seminar sehari di Kuala Lumpur (2009). Acara berasaskan keluarga ini disasarkan kepada kanak-kanak yang lebih kecil, melengkapi JIA Independence Camps yang diadakan setiap dua tahun untuk pesakit JIA remaja yang menghampiri usia dewasa.

Laporan dan gambar: Chan Li Jin, Penganjur bersama Hari Keluarga JIA 2013

欢乐无限

著：唐瑞屏医生（译音）

2013年度JIA家庭日

自从马来西亚关节炎基金会（AFM）少年俱乐部于2005年成立以来，已是成功地举办了第5次的幼年特发性关节炎(JIA)家庭日。此次家庭日共迎来了逾75名兴致勃勃的公众于2013年11月16日早上8时先于士拉央中央医院集合，然后再浩浩荡荡地前往芙蓉的卡拉娜度假村。

一众人到达了这间位于闹市中翠绿如画的度假村后，便与一些自己驱车到场的参与者集合。聆听了主办委员们的精短讲解后，与会的双亲护送本身的孩童们到另一个会议厅后，便聆听了一连串由两位儿童科类风湿性关节炎专科医生——唐瑞屏医生和詹翁谭（译音）所主讲，关于幼年特发性关节炎的座谈会。

在严肃的座谈会的另一厢边，与会的孩子们被这两位来自艾伯维（Abbvie）的代表所带来的面罩与漆料吸引。孩子们舒适地坐在铺着毯子地上，然后便将本身才华横溢的一面通过艺术的形式展现出来。同时，两位代表则充当摄影师，将小朋友们最真实的一面用宝丽来照相机一一地摄下来，现场不时爆出欢愉的大笑、腼腆的欢喜、会心的一笑等最无伪装的欢乐声。

在欢乐园外的另一间会议室则相对地较为严肃。因为身为父母的聚精会神地倾听由唐医生所讲解关于他们子女病情的概况，然后再由詹医生担纲，引导指引父母得如何面对该疾病。

在众多与会者中，一些近期内被诊断其子女罹患幼年特发性关节炎的父母们则心境较为波动，尤其是在叙述被断诊后的情绪、恐惧与焦虑。这项座谈会不仅提供了与会的父母们在专科医生的陪同下，大家开城不恭地交流相关的心得，从中受惠。

这些催发情绪的心得分享让罹患幼年特发性关节炎的病患父母们更通力合作，对抗病魔。他们的互助精神更通过精心设计的家庭竞技活动中获得验证。在主办单位精心策划下，几乎所有的家庭皆踊跃参与，并无冷场！

在刺激紧张的竞技比赛后，参赛者们带着饥肠辘辘但欢愉的身心，还有在竞技场的斩获，一起到新江酒家享用丰盛的犒赏。许多精力旺盛的参赛者在用完餐点后，便趁着餐后小休的空档，迫不及待地往下一个节目——卡拉娜度假村内清爽冰凉的泳池出发了！

碧波轻荡的泳池内，度假村节目经理早就安排了两个竹筏和数位猛男当我们的船夫，为我们在宽阔的泳池享受泛舟之乐。碧绿的池水、婆娑的椰树、凉风习习的环境等等，都让所有人沉醉当中。在这么轻松的时刻，有些放开胸怀与家人享乐，与亲友天南地北一番，有些更交换联络资料呢！

可惜天不作美，下午3时半左右，老天召来了绵绵细雨，不一会功夫细雨转成了大雨，迫使大伙在无需主办当局诱骗之下，急急离开这美丽的池边。梳洗之后，大伙又再次聚集，享用一些温馨的下午茶后，才依依不舍地启程，乘坐巴士或自己的汽车，返回都门。

续2005年莎亚南的面包城之旅、2006年格玛特皮卡/武吉丁怡之旅、2009年瓜拉甘达大象保育区之旅、2011年双威格拉温泉之旅和2009年于吉隆坡所举办的一日座谈会之后，2013年的JIA家庭日又再缔造另一项辉煌的成就。这项由JIA独立生活营主催，目标为协助孩童稳健地步入青春期而主办的双年度家庭活动，圆满结束了。

报导与摄影：陈丽锦，2013年JIA家庭日协办单位

娇小精悍

若不特别着墨，艾丽亚　阿米拉其实很平凡。这位正在国际伊斯兰大学（IIU）求学的本科生有很高的新闻价值，她真诚、淡定、毫无隐瞒地娓娓而谈。可是这并非这位少女最引人注目之处，如果您知道她已经与幼年特发性关节炎一起生活了近10年的话，您也许还未看到这顽疾为这位娇滴滴的少女所带来的身心转变。请细读以下的问答：

您几时被确诊罹患幼年特发性关节炎呢？

就在2004年7月左右，当时才12岁。那是我在2个月内断断续续地发烧，每次我都会上诊所求医。只要我按时吃发烧药，我便没事。可是只要退烧药一吃完，可恶的发烧就会回来。这情况在1个月后就开始出现关节肿胀，我的膝盖处肿胀至影响我祈祷。然后便蔓延至我的手肘，那时梳头都很麻烦。

您有多少兄弟姐妹？只有罹患幼年特发性关节炎吗？

家里共有7个兄弟姐妹，我排行第2，上有1位哥哥，下有1位弟弟和4位妹妹。只有我患上幼年特发性关节炎。

您的家人支持您吗？

当然啦！被确诊后，我变得彷徨痛苦，还一度将自己反锁在房间里拒绝出来。妈妈用尽法宝才将我哄出来，她令我相信情况并非如此恶劣，只要遵循正确的方法，春天还是会回来的。爸爸妈妈便一直鼓励安慰我。

幼年特发性关节炎如何影响您的生理与心理/心灵呢？

一开始，我很困扰，又很沮丧，因为我在学校乃是运动健将。可是确诊之后，我得作出改变——改变运动方式，改变一些作息习惯。然而，在家人与有效的医药管理等等的支持管道协助之下，我还是自己人生的主宰。在历经了病痛的折磨后，我建立了本身的精神支柱与应对策略，让我成功地挨到现在。现在，我正在大学修读精神科系。我想这病反而让我成功地迈向这项学科。如今我立志要协助其他像我一样患上幼年特发性关节炎的病患面对挑战。以生理来说，幼年特发性关节炎的确深刻地影响了我。首先便是抵抗肿胀而得服食的类固醇，它激发了我的食欲，使我的身形明显地向横发展，尤其是在我的脸部。以青春期时的怀春少女来说，这种改变是特别令人难受的，亲友们的那句：“　比较有料（肥胖）哦”令我极为尴尬。

自13岁被确诊患病兼开始服药之后，我便不再长高了，现在的我1.54米高，是家里的小矮瓜。有时亲戚们半开玩笑地把我们兄弟姐妹拿来比较时说我应该是排行最小的，我就会回敬他们我是娇小，并非矮小。还有，我的膝盖部位有难看的肿胀遗痕，那是当病发时膝盖肿胀的好像中型椰子般大时所留下的难看印记。这些难看红棕色交错的线条，让我泄气心灰。有时我还会以为那是孕妇的膝盖。庆幸的是我及早发现兼即时就医，关节尚未变形或受损，不像其他病患一样关节已经毁坏变样了。

您对前途还抱任何希望吗？

当然，我很充满希望呢！我期盼2014年初毕业之后就马上能开始我的助人事业，我还想要环游世界，到处去帮助他人，还有和其他人分享我从中所领悟到的痛苦管理与情绪管理。以前，我都是通过由大马关节炎基金会所主办的幼年特发性关节炎营或旅行来分享我的经验。我通过它们来向那些年幼或尚在小学求学的病患献上我的鼓励，这些小小病患在面对这病症时比较会灰心绝望。我觉得我会更坚强，更好。这些年来，我病发的次数逐渐减少了，所以类固醇的分量亦相对的减低了。每当病发时，我变得越来越懂得以精神层面来适应疼痛，用念力战胜它。而且，我不再有肥胖的“泡泡脸”了，膝盖的明显遗痕也慢慢地退化为苍白的交错线了。

我是如此充满期望与希望，因为我知道其他幼年特发性关节炎的病患——现在已经是花样少年的同辈们都已经治愈，不再需要服药了。我的医生告诉我我有约百分之60的机会可以痊愈。这个三月，我参加了一项为期三天，从鹅麦至卡仑邦的越野慢走活动。我要借此挑战以证明我绝对不会让幼年特发性关节炎控制我或折磨我，我很清楚自己身体的意愿，也了解它的极限。

您还想给其他罹患幼年特发性关节炎的病患什么忠告吗？

心境开朗是最佳良药！

SMALL BUT STANDING TALL

Aliah Amirah is nothing if not articulate. The 21-year-old undergraduate of University Islam Antarabangsa (UIA or International Islamic University, IIU) is every interviewer's dream subject; she expresses herself clearly and has the confidence to state her views in no uncertain terms.

But that is not the most outstanding feature of this very driven young adult. Once you realise that she has been living with Juvenile Idiopathic Arthritis (JIA) for about a decade now, it dawns on you how much more of a challenge it has been for this fourth year psychology major to get to where she is now. Read all about it in the following Q&A:

When were you diagnosed with JIA?

In July 2004, when I was 12. I had an on-again / off-again fever for over two months. Of course, at that time I was taken to a medical clinic. As long as I was on fever medication I would seem to be okay, but once the fever medication prescribed ran out, the fever returned. After a month of this, I started to experience joint inflammation. The joints that were affected were my knees which made it very difficult for me to pray. After my knees, my elbow became inflamed to the point where I could not even comb my hair.

How many siblings do you have, and are you the only one with JIA?

I have 6 siblings; we are 7. I am #2, with one older brother and one younger brother, and four younger sisters. And yes, I am the only one of us with JIA.

Would you say that your family is supportive?

Yes, of course. After the first flare-up after my diagnosis, I was in such pain that I became very down and depressed. I locked myself in the room and refused to come out. My mum had to coax me out and then she convinced me that with the correct management, everything would be okay. My parents motivated me to keep up my spirits.

How has JIA affected you on the physical as well as emotional / mental levels?

Mentally, I was initially very disturbed and depressed mainly because I was very active in sport at school and after diagnosis, I had to change the way I played and did things. However, with a good support system that is my family and sound medical management, I feel that I can achieve everything I set out to achieve.

Experiencing the pain and then having to build the mental coping strategies have inspired me to do what I am doing today, that is, majoring in psychology at university. I guess you could say that JIA has helped me find my path in this field. I now want to make a career in helping others deal with their personal challenges the way I have had to deal with mine.

At a physical level, JIA has had a significant impact on me. First, it was the steroids that I had to take to fight the inflammation. They really stimulated my appetitie and caused pretty significant bloating, especially my face. This is tough when you are a teenager at possibly the most self-conscious stage of your life. Relatives commented that I was "lebih berisi" (more meaty).

Also, since 13, a year after diagnosis and being on medication, I have not grown any taller, remaining, until today, at 1.54 metres tall. I am the smallest of the family. Relatives do compare me to my siblings and joke that I should be the youngest. I say I am small, not short.

Then, of course, there were the stretch marks around my knees that would swell to the size of medium coconuts during flare-ups. I felt really disheartened, looking at my knees that had angry red jagged lines all around them. It was as tough I had pregnant knees. However, I am thankful that my joints are not disfigured or damaged because I started medication early; I know other JIA patients who have damaged joints.

Are you hopeful for the future?

Yes, very! I am looking forward to graduation in early 2014, and to beginning my career assisting others. I want to travel the world to help others; to share with them what I have learned about pain and emotional management. These days I do this especially during the JIA camps or trips organized by the AFM. I make it a point to motivate and speak with the younger, still primary school-going JIA patients who are visibly down and demotivated about themselves and their situations.

I also feel that I am getting better and stronger. Over the years, the frequency of my flare-ups have been going down, and so have the dosage of the steroids that I have been on. I still do have bad days, but I have become more adept at dealing with the pain on a mental level. I have learnt to use my mind to overcome it. What's more, my face is no longer bloated, and the stretch marks around my knees have faded from angry pink to feint white lines.

I am hopeful also because I know of other JIA patients, my peers, who are now young adults who seem to have been cured. They are no longer on medication and steroids. My doctor tells me that there is a 60 percent chance of being cured of JIA.

This March, I participated in a walking expedition from Gombak to Kalumpang that took three days. I make it a point to participate in such challenges as I determined not to allow JIA to get the better of me and my life. I have learned to listen to my body and know is limits.

What would you want to say to another, perhaps more despondent JIA patient?

Positivity is your best medicine!

KECIL TETAPI BERHATI BESAR

Aliah Amirah petah bercakap. Pelajar Universiti Islam Antarabangsa berusia 21 tahun ini mudah disukai oleh penemu duga kerana dia dapat memberi jawapannya dengan jelas serta mempunyai keyakinan untuk menyatakan pendapatnya. Tetapi kepetahan bukanlah cirinya yang paling hebat. Jika anda mengetahui yang dia menghidapi Juvenile Idiopathic Arthritis (JIA) selama hampir satu dekad, baru anda menyedari akan cabaran yang perlu diharunginya bagi pelajar tahun empat jurusan psikologi untuk berada di tahap sekarang ini. Sila baca soal jawab berikut:

Bilakah anda didiagnosis menghidapi JIA?

Pada Julai 2004, ketika saya berumur 12 tahun. Ketika itu saya selalu demam-demam dalam tempoh dua bulan. Masa itu saya hanya pergi ke klinik sahaja. Bila saya makan ubat demam, saya akan okay tetapi bila ubat demam habis, saya akan demam semula. Selepas sebulan, saya mula mengalami bengkak-bengkak sendi. Sendi yang terjejas adalah lutut saya yang membuatkan saya sukar sembahyang. Selepas lutut, siku saya pula membengkak sehingga sukar untuk saya menyikat rambut.

Berapa ramai adik beradik anda dan adakah anda seorang sahaja yang menghidapi JIA?

Saya ada 6 orang adik beradik; jadi 7 orang kesemuanya. Saya anak kedua dengan seorang abang, seorang anak lelaki dan empat orang adik perempuan. Ya, saya seorang sahaja yang menghidapi JIA.

Adakah keluarga anda memberi sokongan?

Ya, sudah tentu. Selepas keradangan pertama selepas didiagnosis, saya mengalami kesakitan yang membuatkan saya sedih dan murung. Saya berkurung dan tidak mahu keluar bilik. Ibu saya memujuk saya keluar dan meyakinkan saya bahawa dengan pengurusan yang betul, semuanya akan okay. Ibu bapa saya banyak memberi motivasi kepada saya supaya saya bersemangat.

Bagaimana JIA memberi kesan ke atas keadaan fizikal serta tahap emosi / mental anda?

Daripada segi mental, mulanya saya agak terganggu dan murung kerana saya sangat aktif dalam sukan di sekolah. Selepas diagnosis, saya terpaksa mengubah cara saya bermain dan melakukan sesuatu. Walau bagaimanapun, dengan sistem sokongan yang baik yang diberikan keluarga dan pengurusan perubatan yang mantap, saya rasa saya boleh mencapai semua yang saya inginkan.

Mengalami kesakitan dan kemudian membina strategi untuk menguatkan mental telah memberi inspirasi untuk apa yang saya lakukan kini, iaitu belajar psikologi di universiti. Saya rasa boleh dikatakan yang JIA membantu saya menjurus dalam bidang ini. Saya kini mahu mempunyai kerjaya membantu orang lain menangani cabaran peribadi mereka, seperti saya.

Daripada segi fizikal, JIA mempunyai kesan yang ketara. Pertama, steroid yang saya perlu ambil untuk keradangan benar-benar menaikkan selera dan membuat saya sembap, terutamanya di bahagian muka. Ini memang sukar kerana usia remaja ialah peringkat di mana anda mudah berasa malu. Saudara mara pun menegur yang saya nampak "lebih berisi".

Juga, sejak berumur 13 tahun, iaitu setahun selepas diagnosis dan makan ubat, saya tidak meninggi, sehinggalah sekarang, masih dengan ketinggian 1.54 meter. Sayalah yang paling kecil dalam keluarga. Saudara mara pun membandingkan saya dengan adik beradik yang lain dan berjenaka yang sepatutnya sayalah anak bongsu. Saya kata saya mungkin kecil, tetapi bukan pendek.

Terdapat juga tanda-tanda regangan, lutut saya yang akan bengkak hingga sebesar buah kelapa bersaiz sederhana bila keradangan. Saya rasa sedih melihat lutut saya yang kemerah-merahan. Memang sukar bila lutut saya bengkak. Walau bagaimanapun, saya bersyukur yang lutut saya tidak cacat atau rosak kerana saya sudah mula makan ubat pada peringkat awal; saya tahu pesakit JIA lain yang mempunyai sendi yang rosak.

Adakah anda bersemangat untuk masa akan datang?

Ya! Saya teruja untuk menamatkan pengajian pada awal 2014, dan untuk memulakan karier saya membantu orang lain. Saya mahu berjalan ke serata dunia membantu orang lain dan berkongsi dengan mereka apa yang saya belajar tentang kesakitan dan pengurusan emosi. Sekarang saya sering memberi ceramah semasa kem atau rombongan JIA yang dianjurkan oleh AFM. Saya pastikan saya bercakap kepada pesakit muda yang masih di sekolah rendah yang jelas bersedih dan hilang motivasi terhadap diri dan situasi mereka.

Saya juga rasa yang saya semakin baik dan tabah. Selepas beberapa tahun, saya kurang mengalami keradangan dan dos steroid pun semakin kurang. Saya masih mengalami hari-hari yang sukar tetapi saya mampu menangani kesakitan saya di tahap mental. Saya juga sudah belajar untuk menggunakan minda bagi mengawal kesakitan. Selain itu muka saya tidak sembap lagi dan tanda-tanda regangan di lutut pun semakin pudar, dari kemerah-merahan kini tinggal garisan-garisan putih sahaja.

Saya juga tidak putus harapan kerana saya tahu pesakit JIA lain, iaitu rakan-rakan saya, yang kini sudah dewasa juga nampak seperti telah sembuh. Mereka tidak lagi makan ubat dan steroid. Doktor saya juga memberitahu bahawa terdapat 60 peratus peluang untuk sembuh daripada JIA.

Bulan Mac lalu, saya menyertai ekspedisi berjalan dari Gombak ke Kalumpang, yang mengambil masa selama tiga hari. Saya memang menyertai cabaran seperti ini kerana saya tidak mahu JIA mengawal saya dan kehidupan saya. Saya telah belajar mengenali tubuh saya dan saya tahu had-hadnya.

Apakah yang ingin anda katakan kepada orang lain, terutamanya pesakit JIA yang kecewa?

Sikap positif adalah yang terbaik!

FIND A RHEUMATOLOGIST

The following is a list of hospitals which offer Rheumatology services:

Wilayah Persekutuan

- Ampang Putri Medical Centre, Kuala Lumpur
- Gleneagles Intan Medical Centre, Kuala Lumpur
- Hospital Kuala Lumpur, Kuala Lumpur*
- Hospital Pusrawi, Kuala Lumpur
- Hospital Putrajaya, Putrajaya*
- Hospital Universiti Kebangsaan Malaysia, Kuala Lumpur*
- Al-Islam Specialist Hospital, Kuala Lumpur
- Pantai Hospital, Kuala Lumpur
- Prince Court Medical Centre, Kuala Lumpur
- Pusat Pakar Tawakkal, Kuala Lumpur
- Pusat Perubatan Universiti Malaya, Kuala Lumpur**

Selangor

- Hospital Selayang, Batu Caves*
- Hospital Serdang, Serdang*
- Sime Darby Medical Centre, Subang Jaya, Petaling Jaya
- Damansara Specialist centre, Petaling Jaya
- Sunway Medical Centre, Petaling Jaya
- Hospital Tengku Ampuan Rahimah, Klang*

Pulau Pinang

- Hospital Pulau Pinang, Pulau Pinang*
- KPJ Penang Specialist Hospital, Bandar Perda, Seberang Prai

Melaka

- Hospital Melaka*

Johor

- Hospital Sultan Ismail, Pandan, Johor Bahru*
- Columbia Asia Hospital, Nusajaya, Johor.

Kedah

- Hospital Sultanah Bahiyah, Alor Setar*

Negeri Sembilan

- Hospital Tuanku Jaafar, Seremban*

Perak

- Hospital Raja Permaisuri Bainun, Ipoh*
- Hospital Pantai Putri, Ipoh

Kelantan

- Hospital Raja Perempuan ZainabII, Kota Bahru*

Terengganu

- Hospital Sultanah Nur Zahirah, Kuala Terengganu

Sabah

- Hospital Queen Elizabeth, Kota Kinabalu*

Sarawak

- Hospital Kuching, Kuching*

** Government or University Hospital - Patients wishing to see a rheumatologist at a government or university hospital require a referral letter from their general practitioner or another doctor.*

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