



August, 2010

## Editorial

Parenting is fraught with challenges, from start to finish, and it's even harder when your child has been diagnosed with a chronic and debilitating disease like Juvenile Idiopathic Arthritis. This issue, we meet and share the stories of three young arthritis patients, all of whom manage to live full lives despite their illness. This is of course due in no small part to parents who have remained committed and involved in dealing with their respective child's JIA, constantly facing down discouragement and setbacks.

Through weeks, months and even years of continuing ailments and with no diagnosis in sight, parents of these three young JIA patients searched for answers, and provided the care and comfort needed by these children, without neglecting the family's other needs.

And we soon learn that while remission is something all hope for in facing diseases such as arthritis, not all patients will be that lucky, and despite the fact that full recovery is not on the horizon, managing and dealing with the disease is the key to a successful and fruitful life.

In this issue too, we have coverage of the Kordel's – AFM Walkathon 2010, and take a closer look at the Arthritis Fund, and its recipients. Fund raising becomes all the more imperative when we meet the people who need help. Monies raised by the Walkathon will go to making the difference in lives of individuals like Shantabai, who is our Arthritis Fund patient focus this issue. Funding makes the difference between a pain-free and a pain-laden life, of walking instead of being wheelchair bound and of being independent instead of dependent on others for living day to day.

For this reason, AFM is casting its net wider in order to raise more for the Arthritis Fund, and in order to do so, it will also need members to support its fund raising efforts, not merely in monetary contributions, but in terms of time, and effort, in sharing with others the existence of the AFM and the work that it does through the Arthritis Fund.

As we move towards the year-end, members can also look forward to the World Arthritis Day celebrations in October, and the Junior Club's annual independence camp in November. Details will follow, keep your eyes and ears peeled, and don't forget to log on to AFM's website, [www.afm.org.my](http://www.afm.org.my) for details!

I wish you good health and continued wellbeing,

**Diana Oon Abdullah**  
Editor

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Send your ideas, articles, materials or medical questions to:

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# Word from the President



Is change good? Taking on something different that will change how things work, either at individual or organisational level, is often a daunting process.

The unfamiliar can be scary and often times change is resisted to maintain a comfort level, even though it is obvious that the change is necessary to move forward.

We change all the time at an individual level - we change jobs to have better financial security, we ask our children to change schools because of perceived differences in the quality of their education, we sometimes even ask them to leave home, leave the country, to pursue further education.

Change at an organisational level can be more difficult depending on the size of the organisation as well as individuals within the organisation too.

Of course, change for its own sake without good reason does not always lead to satisfactory results. There should be a clear goal. It will of course, not eliminate the fear of the unknown, but often the characteristic required to overcome this is not bravery but common sense.

The Arthritis Foundation has been privileged to have committed members and sponsors, without whom we would not have been able to perform our main objectives of increasing awareness of arthritic conditions and looking out for the welfare of people with arthritis. Looking at our achievements of the past, we can be proud of how things have turned to what it is today.

The AFM committee has been looking at ways of how we should build on this and perhaps take this further. We would like to look at different ways in which we can seek contributions from a diverse range of sponsors. The process of doing so will almost inevitably also lead to awareness of our activities to a larger section of society which, conveniently, fulfills our objectives in the first place. I am very keen to hear any suggestions you may have to help us in this process of change. You can write to me at the AFM's address or you could email me at president@afm.org.my.

As for our recent events, we had a great 2nd AFM-Kordel's walkathon at the Kelana Jaya park in June. If anything, it built upon last year's great success and was even better this year, so I would like to thank all those who participated, even though I suspect that there may have been some running involved! Once again we are indebted to Cambert for their fantastic efforts in not only organising the event but also for being the main sponsors. I would also like to thank Cambert (M) Sdn Bhd director Dr Daniel Zuellig, who, for the 2nd year running, has very generously offered to sponsor a joint replacement to a recipient selected by the AFM's Arthritis Fund. Our National RA Day this July was also well attended, and it provided an informative day for all concerned. I thank Abbott Diagnostics and MyORTHO Rehab Sdn Bhd, our sponsors for that event, for their help in making it a success.

With Warmest Regards,

**Dr Amir Azlan Zain**  
President  
AFM

# 主席的话

改变是不是一件好事？做些转变，并因为这转变而改变事情的运作模式，不论是在个人或组织的立场上，都不是一件容易的事。

即使明显的知道为了进步就必须做出改革，但是对事情的不熟悉会令人感到害怕，因此很多时候我们为了要维持安定的现状而拒绝改变。

作为一个个体，我们经常在转变-为了更好的经济保障我们转换工作，因为觉得教学水准有差异而要孩子转校，有时还要他们离乡背井到外地或外国去追求更高学问。

作为一个组织，若要改变就不那么容易，决定因素在于组织的大小还有组织内的每个人。

当然，如果欠缺一个好理由，而改变纯粹是为了要改变的话，经常就不会有什么好成果。改变应该要有明确目标。目标明确并不保证会消除对未知而生的害怕，但是许多时候克服这害怕的并不是勇气，而是常识。

会员和赞助商的致志效劳，令关节炎基金会深感荣幸。要不是因为他们的支持，我们就很难履行提高关节炎疾病醒觉并同时照顾关节炎患者福利的这两个首要目标。回顾过去所完成的种种，我们对今天所达到的成就感到骄傲。

马来西亚关节炎基金会的理事们不断想方设法，希望有更多新作为，期望令会务更上一层楼。我们也欲尝试通过不同途径征求来自广泛赞助商的捐输。在实现这个目标的过程中，我们所推行的一切，无可避免的就会更广为人知，很容易的就达成了当初成立基金会的宗旨。如果你有任何可以帮助我们完成这种改革的建议，请不妨告知。你可以把建议寄来关节炎基金会，或写电邮到 president@afm.org.my 给我。

近来在活动方面，我们于六月份假格拉娜再也市政公园举行了第二届的AFM-Kordel's义善行。去年的好成绩为今年的义善行打响了名堂，而今年的成绩更是比去年好。虽然我怀疑竞赛中可能有人偷偷跑步而不是全程徒步，我还是要在此向所有参与义善行的热心健儿们致谢，感谢大家的参与。义善行能够成功完成，负责筹备同时也是首要赞助商之一的Cambert (M) Sdn Bhd功不可抹，本基金会在致上衷心的感激。我也感谢其董事长Daniel Zuellig博士再次慷慨承诺协助一位由本基金的关节炎基金小组遴选出来的贫困关节炎患者做关节置换手术。我们今年七月办的全国类风湿性关节炎日也有很不俗的反应，为所有到场与会的人士提供了许多有益资讯。我谨在此由衷感谢热心赞助本次全国类风湿性关节炎日宣扬活动的赞助商Abbott Diagnostics 和 MyORTHO Rehab Sdn Bhd的支持，让此活动得以成功举行。

谨祝安康  
**Amir Azlan Zain 医生**  
大马关节炎基金会主席

# Sepatah kata daripada Presiden



Adakah perubahan sesuatu yang diingini? Mengubahkan cara sesuatu dilakukan, secara individu atau sebagai satu organisasi, biasanya sangat meggentarkan.

Sesuatu yang kurang dikenali mungkin menakutkan, dan biasanya, perubahan tidak disambut kerana kami ingin tetap saja dengan apa yang sudah difahami, walaupun jelas ternyata bahawa perubahan itu diperlukan untuk mencapai kemajuan.

Kami sentiasa mangalami perubahan sebagai individu – kami bertukar pekerjaan untuk meningkatkan daya mata pencarian, kami menukar sekolah anak jika mempercayai yang ia boleh membawa taraf pengajaran yang lebih tinggi, dan kadangkala, anak kami disuruh meninggalkan keluarga, demi mengejar pelajaran yang lebih tinggi.

Perubahan sesebuah organisasi mungkin lebih susah untuk dicapai. Ia bergantung kepada saiz organisasi tersebut, serta setiap individu yang terlibat dengan organisasi tersebut.

Ternyata bahawa perubahan yang tidak bersebab, tidak akan membawa faedah. Perubahan mesti diiringi dengan cita-cita, atau matlamat, yang ingin dicapai. Ini tidak akan mengurangkan rasa keimbangan ketika mengikuti perubahan tersebut, tetapi rasa keresahan itu biasanya diatasi dengan sifat keberanian, dan bukannya kerana penggunaan akal.

Arthritis Foundation Malaysia sungguh bertuah kerana ia mempunyai ahli dan penderma yang sangat mengutamakan keperluannya. Tanpa mereka, tidak mungkin AFM akan dapat melaksanakan funginya dan mencapai matlamatnya, iaitu untuk meningkatkan pengetahuan artritis di khalayak ramai serta menolong pesakit artritis. Kami bangga atas apa yang telah kami capai setakat ini.

Pihak jawatankuasa AFM telah lama mencari jalan untuk meningkatkan lagi tahap sumbangannya. Kami ingin mencari cara baru untuk menjana dana dari kumpulan penderma yang lebih luas. Dalam mengusahakan ini, kami harap yang ia juga akan meningkatkan pengetahuan masyarakat mengenai aktiviti kami, dan ini adalah matlamat yang paling kami inginkan.

Saya sangat berbesar hati jika ada di kalangan kamu, si pembaca, yang boleh menyumbang idea terhadap proses perubahan kami. Sila hubungi saya melalui alamat AFM, ataupun melalui e-mel, di [president@afm.org.my](mailto:president@afm.org.my).

Beralih pula ke aktiviti kami yang terkini, kami telah mengadakan Walkathon AFM-Kordel's yang kedua di Taman Perbandaran Kelana Jaya pada bulan Jun yang baru lepas. Acara ini lebih meriah lagi pada tahun ini, dan telah bertambah besar lagi dari acara julung kali yang diadakan tahun lalu. Saya menghargai penyertaan kesemua yang hadir. Pihak AFM juga menghargai sumbangan besar Cambert Malaysia, yang meluangkan masa dan tenaga untuk mengaturkan acara tersebut, selain daripada menjadi penaja utama acara tersebut.

Penghargaan yang besar juga harus diberi kepada Dr Daniel Zuellig, pengarah Cambert (M), kerana, untuk dua tahun berturut-turut, beliau telah bersetuju untuk menaja pertukaran sendi salah satu pesakit yang akan dipilih melalui program Tabung Amal Artritis (Arthritis Fund) kami.

Sambutan Hari Reumatoid Artritis yang diadakan pada bulan Julai baru-baru ini juga mendapat sambutan hebat, dan para hadirin memang dapat berbagai faedah dari penyampaian beberapa penghujah pada hari tersebut. Abbott Diagnostics dan MyORTHO Rehab Sdn Bhd harus dihargai kerana sumbangan mereka sebagai penaja acara tersebut telah lebih menjayakannya.

Salam Ikhlas,

**Dr Amir Azlan Zain**  
Presiden AFM

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# JUVENILE IDIOPATHIC ARTHRITIS

## What is it?

An physically active twelve-year old girl felled by almost continuous fever for a month; an 11-year old boy whose feet and heels began to hurt, then swell, along with his knees. A 2-year old toddler who was often ill with fever, and then, began limping even before she could really even toddle.

Disparate symptoms of a varied and multi-faceted disease, known as Juvenile Idiopathic Arthritis, or, JIA. As is often the case in medical practice, the label is nothing more than a description of symptoms of the illness.

This chronic disease is called "Arthritis" because it is characterised by persistent joint inflammation, where typical signs of joint inflammation are pain, swelling and limitation of movement. "Idiopathic" is used because it means that we don't know the cause of the disease and "Juvenile", because symptoms appear before 16 years of age. Within this broad category, there are sub-categories which differentiate the disease according to which part of the body is affected and for how long.

JIA can be divided into oligoarthritis, polyarthritis, systemic, juvenile psoriatic, enthesitis related arthritis and undifferentiated type.

JIA is now an umbrella term which also encompasses juvenile psoriatic arthritis and enthesitis related arthritis (which is the new name to what was previously referred to as juvenile



ankylosing spondylitis), and it is therefore very different from what the term that was previously used for childhood arthritis, Juvenile Rheumatiod Arthritis (JRA)

Like adult arthritis, JIA is believed to be a result of an abnormal response of our immune system, which, due to unknown causes, loses part of its capacity to distinguish between cells which are foreign to the body, and our own cells. This results in the body's immune system attacking its own joint components.

It is not a hereditary disease but it is contributed to by genetic factors, in combination with environmental factors, and it is rare for two children in one family to be affected by it.

Doctors diagnose someone as having JIA when the onset of the disease is before the age of 16 years, arthritis lasts for more than six weeks and the causes are unknown (which means that all other diseases responsible for arthritis have been ruled out).

The arthritis must be present for more than six weeks in order to exclude forms of temporary arthritis that have been known to follow viral infections.

The diagnosis of JIA is, therefore, based on the presence and persistence of arthritis and the careful exclusion of any other disease by medical history, physical examination and laboratory tests.

Resources for JIA: <http://www.printo.it/pediatric-rheumatology/information/UK/1.htm>

# JUVENILE IDIOPATHIC ARTHRITIS

## Radang Sendi Kanak-kanak

### APAKAH IA ?

Seorang kanak-kanak berusia 12 tahun yang tiba-tiba jatuh demam selama sebulan; seorang budak lelaki yang mengalami kesakitan dan kebengkakan di bahagian kaki dan tumit, dan juga lututnya. Seorang kanak-kanak yang berusia 2 tahun yang sering demam, dan kemudiannya mula tempang sebelum ia benar-benar boleh berjalan.

Simptom yang sungguh berbeza yang menjadi tanda sesuatu penyakit yang sememangnya berpelbagai, yang kini dikenali sebagai Juvenile Idiopathic Arthritis, ataupun JIA, iaitu, Radang Sendi Kanak-kanak.

Sememangnya, label ini tidak memberi maklumat yang selebihnya, ianya hanya sekadar memberi penggambaran simptom penyakit tersebut.

Penyakit yang kronik ini dikenali sebagai "Artritis" kerana ia disifatkan oleh keradangan otot yang berterusan, dan ia dinamakan "Idiopathic" kerana punca penyakit itu tidak diketahui. Ia pula diberi nama "Juvenil", kerana simptom tersebut muncul kepada kanak-kanak yang dibawah umur 16 tahun.

Kategori yang agak luas ini dipecah-belahkan lagi mengikut bahagian tubuh yang terlibat, dan untuk berapa lama. Walaupun JIA merupakan artritis yang paling kerap berlaku ke atas kanak-kanak, penyakit tersebut memanglah sangat jarang berlaku. Ia dianggar melibatkan antara 80 hingga 90 kanak-kanak dalam setiap 100,000 kanak-kanak.

Oleh kerana penyakit ini sangat jarang berlaku, maka ia selalu mengelirukan dan menyebabkan diagnosis lambat diberi. Penyakit yang pada masa ini dikenali sebagai JIA sebelumnya diberi nama Juvenile Chronic Arthritis (Arthritis Kronik Juvenil) ataupun Juvenile Rheumatoid Arthritis (Arthritis Reumatoide Juvenil). Simptom JIA berlainan dari simptom artritis yang dialami para dewasa.

JIA kini isitihal yang diberi untuk meliputi pelbagai artritis juvenile, iaitu, oligoarthritis (oligoarthritis), poluarthritis (polyarthritis), systemic (systemic), juvenile psoriatic (psoriatic juvenile), enthesitis related arthritis (arthritis yang berkaitan dengan entesitis) serta undifferentiated type (jenis yang tidak dibezakan).

Seseorang pesakit akan disahkan sebagai mengidap JIA jika pesakit itu adalah kanak-kanak atau remaja yang dibawah umur 16 tahun, yang mengalami radang yang melibatkan satu atau lebih sendi badan yang menyebabkan kesakitan, sendi merasa ketat dan bengkak selama sekurang-kurangnya 6 minggu; dan punca keradangan dan kesakitan tersebut tidak diketahui. (Ini bermakna bahawa penyakit-penyakit yang lain yang mungkin memberi simptom yang sama telah dikecualikan.)

Artritis tersebut perlu hadir selama 6 minggu untuk mengecualikan artritis yang berbentuk sementara yang kadang-kadang mengekori jangkitan virus.

Pendekata, JIA hanya akan didiagnosis jika adanya artritis yang berpanjangan, dan penyakit-penyakit yang lain telah dikecualikan, berdasarkan rekod perubatan, penelitian fizikal serta ujian makmal.

# 少年原发性关节炎

### 那是一种怎样的疾病？

一个时常蹦蹦跳跳的12岁女孩因为一个月里几乎每天都发烧而变得活跃不起来；一个11岁男孩的脚和脚跟先是会痛，然后竟和膝盖一起肿了起来；一个时常生病发烧的2岁小娃儿，还未真正学会走路就已经先跛脚了。

以上皆是少年原发性关节炎的各种不同症状，它是多种类、病况多面性的一种疾病。在医药实践里，疾病的名称通常只不过是对该疾病所出现的症状的描述而已。

这种慢性病被称为“关节炎”因为其特色是持续的关节发炎，说它“原发性”是因为我们都不知病因，“少年”是因为症状在16岁以前出现。在这个广泛的归类里，我们还可以按照身体受影响部位、受影响多久，来进行细分类。

尽管少年原发性关节炎是儿童之间最常见的关节炎，但它本身却是一种罕见疾病。每10万名儿童当中，只有80至90人得此病。也因为它罕见，出现症状时会造成混淆并拖

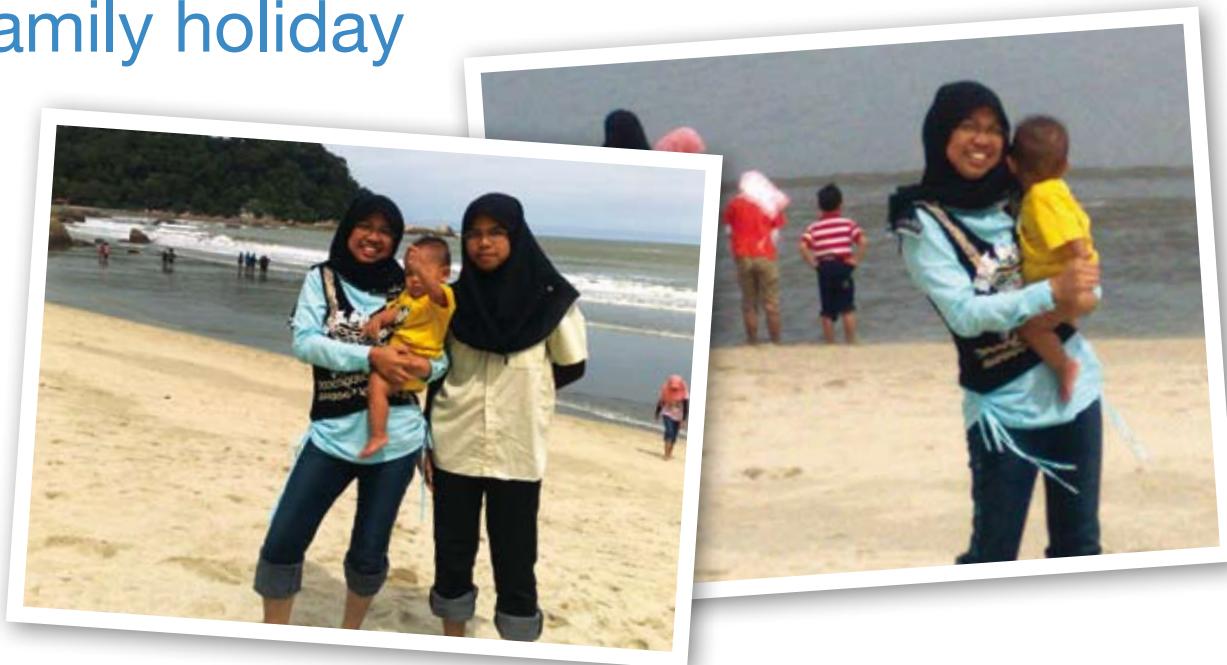
延诊断。过去，它曾被称为少年慢性关节炎或少年类风湿性关节炎，目前普遍被称为少年原发性关节炎，英文缩写JIA。少年原发性关节炎所呈现的症状，跟成人关节炎的症状并不相同。

今天，少年原发性关节炎是一个大总称，它包含了少关节型关节炎、多关节型关节炎、系统性关节炎、少年牛皮癣关节炎、与附着点炎症相关的关节炎，以及不属以上任何类型的关节炎。

医生诊断少年原发性关节炎是基于：疾病在16岁以前出现关节炎的问题存在了6周以上，而造成关节发炎的原因不详（即是说所有其他可能引起关节炎的原因都已经排除了）。

有关的关节发炎必须持续了6个星期以上，是因为要排除那不是病毒感染引起的短暂性关节炎。因此，医生诊断少年原发性关节炎是基于关节炎是否存在、持续多久，并按照病历、体检和化验结果来小心排除其他任何可能疾病。

# ALIAH in blue, with her siblings on a recent family holiday



Aliah Amirah's journey to the hospital which finally diagnosed her as having Systemic JIA at age 12 years began with a series of visits to general practitioners to treat almost continuous bouts of fever over the period of one month, before a visit to the hospital led to a two-week hospitalisation, where a battery of tests ruled out other possible illnesses, like leukaemia. Steroid treatment was started and there was steady improvement, but no miracle cure - she continued to feel unwell, only less so.

Now, more than six years after her initial diagnosis, Aliah has the upper hand on her illness. Consultant paediatric rheumatologist Dr Tang Swee Ping, who has been treating Aliah holds her out as a model patient, for the responsibility she holds over her own treatment regime. "The medicines have reduced over time. My daily dose of tablets has gone down from 10 to 4 now," she says with a degree of satisfaction.

Aliah's independence stems from the support and encouragement of her parents. She practices what her father taught her : "As far as possible, I do things for myself, and only when I find I am unable to, do I ask for help."

With this, Aliah managed to take over the responsibility of her own injections when she switched medications two years after

her diagnosis. Etanercept required twice weekly injections, and it was impossible to work hospital visits into her school schedule, so Aliah learnt to self-administer her injections when she was 14, and went on to boarding school at the age of 16.

She counts her parents as providing the greatest support at the most critical moments. Taking steroids, with the resulting weight gain and acne, added greater social pressure on what is normally a difficult period for any teenager. "I do remember once, feeling terribly depressed by the medication and seemingly endless problems of the disease. I locked myself in my room to cry, I felt like stopping all treatment. My mom found out and sat me down, and gave me a pep talk. She listed all the reasons why I should not give up, she encouraged me. Since then, I have tried never to have negative thoughts and just focused on trying to improve my situation," she says resolutely.

And by all accounts, she has. Currently registered in a matriculation programme for a degree in Psychology, Aliah still manages to see the positive side of having arthritis. "I feel I am stronger, and more able, and my friends, when I tell them about what I have faced and what I have to do for my JIA, think so too," she says.

## AFM Junior Club

AFM has a Junior Club which caters to the needs of its younger members, and their families. Junior Club activities focus on group-based activities for increased member interaction, and to build support group networks. The AFM Junior Club will be holding its annual independence camp in November or December this year.

For further information please contact:  
**AFM Junior Club, Arthritis Foundation Malaysia,**  
Tel 03-5621 6177 (Ms Shanta, Monday to Friday, 0900 to 1230)

# ALIAH berbaju biru, bersama adiknya ketika bercuti bersama keluarganya



Perjalanan Aliah Amirah ke hospital yang akhirnya mengesahkan bahawa ia mengidap penyakit JIA Sistemic pada masa usianya 12 tahun bermula dengan lawatan berturut-turut ke beberapa klinik untuk merawat demam yang berpanjangan selama sebulan.

Akhirnya Aliah dimasukkan ke hospital di mana ujian bertubi-tubi dijalankan selama dua minggu, mengecualikan penyakit lain seperti leukemia. Dengan itu, Aliah mula diberi ubat steroid dan keadaannya mula beransur pulih, sedikit demi sedikit.

Kini, lebih dari enam tahun selepas diagnosis itu diberi, Aliah sudah dapat menangani penyakit yang dihidapinya itu.

Pakar reumatologi pediatrik Dr Tang Swee Ping, yang menjadi doctor Aliah sejak enam tahun yang lalu mengalukan sikap dan perangai Aliah, yang katanya, harus dicontohi pesakit-pesakit JIA yang lain. Aliah, kata Dr Tang, adalah pesakit yang bertanggungjawab atas perkara-perkara pengubatannya sendiri.

"Ubat-ubat yang diambil kian berkurangan. Sekarang saya hanya mengambil empat biji pil sehari, berbanding dengan 10 biji pil beberapa tahun yang lalu," ujarnya dengan suara yang menggambarkan perasaan puas hatinya.

Sikap berdikari Aliah berpunca dari dorongan dan sokongan kedua ibubapanya. Dia sering mengingati pengajaran bapanya, yang selalu mengingatinya : "Selagi mampu, buatlah apa-apa sahaja untuk diri sendiri, kalau tidak mampu, barulah minta tolong."

Dengan itu, Aliah telah bertanggungjawab ke atas suntikan yang diperlukannya, apabila dia bertukar ubat dua tahun selepas dia mula-mula diberi diagnosis. Jadual persekolahannya tidak memberi peluang untuk dia ke hospital untuk mendapat suntikan Etarnacept dua kali seminggu. Oleh itu, Aliah mempelajari cara untuk memberi suntikan itu kepada dirinya sendiri pada masa usianya hanya 14 tahun, dan meneruskannya apabila dia menuntut di sekolah berasrama pada masa usianya 16 tahun.

Aliah cukup menghargai sokongan ibubapanya, yang memberi dorongan pada saat-saat yang genting. Pengambilan ubat steroid, yang membawa kesan sampingan kenaikan berat badan naik serta ketumbuhan jerawat, sangat merunsingkan, terutama sekali kerana ia berlaku pada masa keremajaan. "Saya ingat ada satu masa, saya berasa sangat sedih dan kecewa, saya rasa hendak berhenti makan ubat, jadi, saya menangis sendiri dalam bilik. Mak dapat tahu, dan dia terus memberi nasihat dan sebab-sebab mengapa ubat itu diperlukan. Dia menggalakkan saya. Sejak itu, saya tidak mahu memikirkan benda-benda yang negatif, dan terus berusaha untuk bertambah sihat," katanya dengan penuh semangat.

Jelas ternyata yang Aliah telah berjaya. Dia kini penuntut matrikulasi untuk ijazah Psikologi, dan dia juga dapat menhangai kesan-kesan positif mengidapi penyakit arthritis. "Saya rasa saya ini sangat kuat, dan boleh buat apa saja. Kawan-kawan saya juga rasa begitu, apabila mereka dapat tahu apa yang saya perlu buat untuk menjaga diri saya," katanya.

## 艾丽娅的故事 蓝色衣服，最近与她的家人在度假

艾丽娅(Aliah Amirah)12岁的那年，突然一连整个月都断断续续的发烧。她先是经常往普通科医生诊所跑，后来才到医院去检查，结果还住院留医了两个星期。留医期间，医院给她做一系列检查以排除其他可能疾病(例如白血病)之后，终于诊断她是患上系统性少年原发性关节炎。她的情况在医院采用类固醇为她治疗之后有了好转，但并非药到病除——她还是感觉不适，只是不那么难受而已。

艾丽娅被诊断患此病至今已6年多，她已经懂得如何驾驭自己的病。多年来为她治疗的小儿关节炎科顾问医师邓瑞萍医生，更当她是模范病人，因为她为自己的治疗方案履行责任。艾丽娅满意的说：“我吃的药越来越少，药丸的每日剂量从以前的10粒减到目前的4粒。”

父母亲给她的支持和鼓励，养成了艾丽娅的自立。生活中秉持父亲教诲的她说道：“我尽可能自己动手做事情，只有当我做不来的时候，才找人帮忙。”

本着这个概念，艾丽娅在得病两年后改换治疗药物时，才得以自己为自己打针做注射。由于Etanercept必须每周注射两次，而求学中的她又很难经常往医院跑，所以她14岁时就学会自行注射，16岁还转入住宿学校求学。

她认为双亲是在她病得最严重时给她最大扶持的人。因为服用类固醇，她不但变胖，脸上还长了许多暗疮，让她的青少年时代比一般青少年多了不少社会压力。她说：“还记得有一次我因为药物副作用，也因为疾病带来的麻烦老是没完没了而感到非常忧郁。我因此把自己锁在房间里哭，我当时很想停止所有治疗，但是妈妈要我坐下来好好听她开导。她列出许多我不该放弃的理由，她也鼓励我勇敢面对。那次以后，我就尝试不再钻牛角尖，而是专注于改善自己的病况。”说的时候，艾丽娅脸上流露出一副坚决的神态。

经过许多努力，她做到了。她现在已经报名修读心理学学士学位先修课程，对自己身患关节炎一点也不感到消极。她说：“我觉得自己比过去更坚强、更能干。当我向朋友谈及自己以前所面对的种种以及对未来的打算时，他们都认同我的看法。”

# SASI

## From bench warmer to Hockey Captain.....

**S**asidharan, or Sasi to those who know him, spent his early teens watching sports from the sidelines. "I would sit there, just hoping, one day, I could do the same," says this bubbly and cheerful 18-year old.

For years, Sasi suffered from swollen ankles and knees, unable to walk more than a hundred metres before having to sit down for a rest, because of the intense pain he experienced almost constantly.

"It began suddenly when I was 11, first my feet and heels began to hurt, and then my knees swelled really large and I could barely walk," he recalls. Extensive tests, including taking a sample of bone marrow, at the General Hospital in Seremban yielded no conclusions. Further consultations at the paediatric clinic were also futile.

For the next three years, Sasi endured the almost constant pain in his legs, and learnt to live with the limitations presented by his condition. "My parents spent a lot over that time, on traditional healers, and I did not get better," he says. Despite which, he tried to keep things as normal as possible, with the help of his parents, and younger siblings. "We still did normal things, like taking family holidays, I would just rest a lot in between walking."

Sasi and his parents never gave up, and they continued to seek medical advice, but it was not until three years after the onset of his symptoms that he finally was diagnosed with JIA. His responded positively to a regime of Methotrexate, although it was not easy taking the 6-tablet weekly dose, "I felt very nauseous," he says, "but my mom helped me."

A year of medication and treatment cleared up Sasi's illness and he was, as he'd hoped to be, normal. Indeed, he managed to be made captain his school's hockey team by the time he was 17. And today, other than a six-monthly blood test, he is like any other 18-year old, pursuing a diploma in medical lab technology, with hopes of taking a further degree overseas.

Not all cases of Polyarthritic JIA resolve so happily, Sasi is, "one of the lucky ones," says Dr Tang. All he has to remind him of the years of pain is the need for half-yearly blood tests.



# SASI

## Dari kaki bangku ke

**S**asidharan, yang lebih senang dengan panggilan pendek Sasi, mengingati saat awal keremajaannya, yang penuh detik pilu. "Saya sering duduk di tepi padang dan hanya mampu melihat kawan-kawan bersukan. Saya hanya boleh berharap yang saya juga boleh bersama mereka pada suatu hari nanti," kata pemuda yang kini berusia 18 tahun.

Sasi menderita menahan sakit dari buku lali dan lutut yang bengkak dan radang selama beberapa tahun. Ketika itu, dia hanya mampu bertapak kaki untuk jarak seratus meter sebelum dia perlu duduk untuk berhatah. Tambahan pula dia terpaksa menahan rasa sakit sepanjang masa.

"Ianya bermula dengan tiba-tiba pada masa saya berumur 11 tahun. Pada mulanya, bahagian kaki dan tumit saya terasa sakit, kemudian lutut saya pula bengkak, dan saya mengalami kesusahan ketika berjalan," kata Sasi. Pelbagai ujian dijalankan di Hospital Besar Seremban, termasuk pengambilan sampel sum-sum (untuk mengecualikan penyakit leukemia), tetapi tiada keputusan yang dapat diberi. Selanjutnya, beberapa lawatan ke klinik pediatrik juga tidak memberi apa-apa jawapan.

Selama tiga tahun yang berikutnya, Sasi menderita kerana terpaksa menahan sakit yang berpanjangan di bahagian kakinya. Dia terpaksa mengubahsuai kehidupannya kerana rasa sakitnya itu. "Ibubapa saya banyak berbelanja untuk perubatan tradisional, tetapi tidak sembuh," katanya.

Walaubagaimanapun, dia tidak mahu kehidupan keluarganya terjejas kerana penyakit yang dihidapinya. "Keluarga kami sama seperti keluarga yang lain. Kami juga melancung pada masa cuti, hanya saya perlu banyak berhatah ketika berjalan dan makan angin," kata Sasi.



## 萨西 从坐冷板凳到曲棍球 队长……

认识萨西达兰 (Sasidharan) 的朋友都叫他萨西。他十二、三岁的时候都是在球场边缘观赛。这位18岁的开朗年轻人说：“我就那么的坐在那边看，希望有一天我也可以上场比赛。”

萨西的脚踝和膝盖肿了很多年，几乎经常都很痛，以致他走不了一百米就因为疼痛难当而必须坐下来歇息。

“那是我11岁的时候突然开始的。起初是双脚和脚跟会痛，跟着我的膝盖也肿了起来，而且肿得很大，我那时走路也很困难，”他回忆着说。他在芙蓉医院做了很多检测，包括还抽了骨髓检查，但是都没有结果，找不出病因。后来到小儿科诊所求医也是得不到个所以然。

下来的三年，萨西忍受了脚部一直地疼痛，学会了在病情限制下过生活。“那个时期我的父母花了很多钱在传统疗法上，但是我却一点也没有好起来，”他说。虽然如此，他还是在父母以及弟妹们的帮忙下，尽量过正常生活。“我们日子还是照常过，比如一家人出门度假，只不过我得走走停停，歇息歇息。”

萨西和他的父母从来没有放弃过，他们不断地到处求医，但却直到发病三年后才得以诊断是少年原发性关节炎。虽然每星期一次、每次服下六粒Methotrexate药丸是一件很难受的事，但他对这种药物的治疗有很好的反应。“那些药丸令我觉得很恶心、想作呕，但是我妈妈帮忙我熬过去。”

经过一年的治疗，萨西的病也好了，他也如愿的恢复正常。17岁那年他还当上了学校曲棍球队长呢！今天，除了必须每6个月做一次血液检验之外，他其实跟别的18岁少年没两样。萨西现在选修医药化验技术文凭，希望日后可以到国外去修读学士课程。

并非所有多关节型少年原发性关节炎都会有这样的愉快结果，邓医生说萨西是“运气比较好的患者之一”。现在，唯一能够让他记起多年难熬之痛的就是那半年一次的验血而已。

### Kelab Junior AFM

AFM ada menganjur kelab khas untuk ahli-ahli muda dan remaja, serta anggota keluarga mereka, yang dikenali sebagai AFM Junior Club. Kelab Junior ini menjalankan aktiviti yang menekankan pesertaan sekumpulan untuk meningkatkan lagi interaksi di antara ahli-ahli kelab, demi menjalinkan hubungan yang lebih erat di antara para ahli. Kelab Junior AFM akan mengadakan kem berdikari di bulan November atau Disember tahun ini.

Untuk maklumat selanjutnya, sila AFM Junior Club: **AFM Junior Club, Arthritis Foundation Malaysia**, Tel 03-5621 6177 (Cik Shanta, Isnin hingga Jumaat, 0900 to 1230)

# LIBERTY

## sentiasa bergerak



## LIBERTY always on the go

**L**iberty's story of parental persistence mirrors that of Sasi's. Terence Beck, Liberty's father recalls five months of frustrating to-ing a fro-ing, where "We tried almost everything family and friends suggested: bone specialist, neurologist, Chinese doctors. Sometimes the opinions are so contradictory, it was very frustrating. We felt that we were no closer to getting to the bottom of our daughter's problem."

All they had to go on was Liberty's frequent fevers, and a limp caused by a stiff knee.

She was only 2 years old then, and would cry in the mornings when she woke with a stiff knee which would gradually loosen to allow her to walk later in the day. So it was with great relief that a full diagnostic test run in Pantai Hospital led them to Selayang Hospital, and Dr Tang, who began treating Liberty with steroid injections to the affected knee, and pain medication in the form of ibuprofen. Now, Liberty has moved on to Methotrexate and despite the concerns of toxic build-ups and resulting blood tests to monitor this, Terence says, "We feel it was a good move. Liberty is 4 and half years old now, it has been more than 2 years. Her legs are now straighter. She walks without a limp and doesn't tire easily as before. She looks like any other child in kindergarten, very active and playful. No one would have guess that she has this condition."

In the case of very young patients, parental involvement is at its highest, and it is often their keen observation which leads to an early diagnosis. They also have the painful responsibility of putting a child through treatment which is hard to explain to a young child.

Says dad Terence : "(Liberty's illness) put a lot of mental stress on us. The entire family was very worried that whatever she has might handicap her for life. My wife applied a lot of long leave from work just to care for her. She and my mother were emotionally affected the most during that difficult period. More so when we found out that not only was her left knee, but her right wrist, ankle and toes were also showing symptoms of JIA."

What has helped is the progress that Liberty has shown under treatment, and the hope that she will one day outgrow the disease. In Terence's words : "It was painful to put her through all those diagnosis, but I think our persistence in finding a solution paid off. All we wanted was for her to have a normal healthy childhood and we believe that we've somewhat achieved that for her."

Same seperti ibubapa Sasi, kedua ibubapa Liberty tidak pernah berputus asa ketika mencari penyelesaian untuk simptom yang dialami anak kecil mereka. Terence Beck, bapa kepada Liberty, masih ingat lagi perasaannya ketika Liberty belum diberi diagnosis. "Selama lima bulan, kami ke hulu dan ke hilir, demi mencari jawapan. Kami mencuba apa saja yang dicadangkan kawan-kawan dan keluarga kami – pakar tulang, pakar neurologi, tabib Cina. Ada kalanya apa yang diberitahu kami bertentangan antara satu sama lain, ia sungguh mengecewakan. Kami berasa seolah-olah tiada jawapan untuk masalah yang dihadapi anak kami."

Hanya demam yang berpanjangan, serta perjalanan Liberty yang agak tempang kerana lutut yang ketat dan sakit yang menjadi petunjuk arah.

Pada ketika itu, Liberty hanya berusia 2 tahun, dan akan menangis setiap pagi apabila dia bangun tidur dan rasa yang lututnya ketat dan sakit. Keadaan itu akan beransur pulih sepanjang hari dan lamakelamaan Liberty dapat juga berjalan bila keketatan itu reda.

Perassan lega tidak terkata apabila mereka akhirnya ditujukan ke Dr Tang di Hospital Selayang setelah penelitian medikal dijalankan di Hospital Pantai. Liberty terus diberi suntikan steroid ke atas lutut yang terlibat dan ubat tahan sakit, iaitu, Ibuprofen.

Liberty kini mengambil ubat Methotrexate, dan walaupun ada kekhawatiran mengenai kesan toksik ubat tersebut, Terence berkata, "Kami berasa bahawa ia adalah keputusan yang betul. Liberty kini berusia 4 tahun, lebih dari 2 tahun sudah berlalu. Kedua belah kakinya kini semakin lurus, dia tidak tempang ketika berjalan, dan dapat

bertahan lebih lama sebelum mula berasa penat. Dia sama seperti kanak-kanak yang lain di tadikanya, sangat aktif dan suka bermain. Tiada yang akan menjangka yang dia mengidapi penyakit ini."

Apabila penyakit ini melibatkan kanak-kanak yang masih berusia muda, ibubapalah yang terpaksa mengambil tahu. Seringkali, hanyalah dorongan ibubapa tersebut akan membawa diagnosis awal kepada anak mereka. Ibubapa juga terpaksa membuat keputusan perubatan untuk anak mereka, dan kadangkala ini adalah tanggungjawab yang berat.

"(Penyakit Liberty) sungguh menekankan pemikiran kami. Seluruh keluarga risau yang kehidupannya akan terjejas. Isteri saya mengambil cuti panjang untuk menjaganya. Dia, serta ibu saya, sangat tertekan pada masa itu. Lebih-lebih lagi apabila kami mendapat tahu yang penyakit itu bukan sahaja melibatkan lutu kirinya, tetapi pergelangan tangan, buku lali dan anak-jari kaki kanannya juga ada menunjukkan simptom JIA" kata Terence.

Pemulihan Liberty berikutan pengubatan yang diberi membawa sedikit keseronokan. Termasuk juga harapan yang mungkin suatu hari nanti, Liberty akan pulih dengan tersendirinya.

"Kami berasa amat susah apabila kami terpaksa membawanya ke merata tempat untuk mendapat diagnosis untuknya, tetapi saya berasa bahawa usaha berterusan kami sangat berbaloi. Kami hanya inginkan zaman kanak-kanak yang biasa dan sihat, dan kami berasa bahawa setakat ini, kami ada mencapai kejayaan.

## 活泼好动的丽柏蒂

丽柏蒂（Liberty）的双亲不放弃为孩子寻医的精神，跟萨西的父母亲很相像。她的父亲德伦斯贝克说：“在那5个月时间里，我们试尽了亲戚朋友所建议的各种方法，甚至去找骨科专家和脑神经专家等等，还有中医。有时候不同医生之间所说的完全相对，让人甚感沮丧，感到自己对女儿的病因完全就没有一点头绪。”

于是，丽柏蒂依然是经常发烧，走路时会因为膝盖僵硬而一拐一拐。

她当年才只有2岁，每天早上起来都会因为膝盖僵硬而哭。膝盖的僵硬要在一阵子之后才会松动，那时丽柏蒂才能舒服行走。后来，在班底医院进行全面辩证化验诊出了真相，接下来士拉央医院的邓瑞萍医生为她做膝盖类固醇注射，并且给她服用ibuprofen止痛药。那时丽柏蒂的父母才松了一口气。丽柏蒂现在使用Methotrexate治疗，因为担心药物毒性在体内堆积，她须定时验血监控情况。虽然如此，德伦斯说：“我们觉得这是正面进展。丽柏蒂现在4岁半，离开刚生病之初已经两年多了。她的脚比较直了，走路不再一拐一拐，也不会像以前那样

的容易疲累。她就跟其他幼儿园的小孩子一样，很活泼、很好玩。假如不说，没人会想到她有病。”

在年纪幼小患者的病例中，最需要父母亲的参与，而且通常都是因为他们的观察入微才会及早发现。要孩子接受治疗但是不容易向他们解释原因，是父母必须承受的另一个痛苦责任。

德伦斯说：“她的病给了我们很大的精神压力，我们一家人都担心她可能会因而终生残障。为了照顾丽柏蒂，我太太经常都得请长假。在那段艰难的岁月里，我太太和我妈妈的心情都非常差。当我们发现她不单单左边膝盖有问题，就连右手腕、脚踝以及大脚趾都有少年原发性关节炎症状的时候，那种心情简直是糟透了。”

丽柏蒂接受治疗并且进展良好，终于使他们的心情好了起来。他们同时也希望有一天丽柏蒂长大后，这个病不再来缠她。正如德伦斯所说的：“带她去做那各种各样的辩证检验确实令我们感到心疼，但是我们的坚持终于有了好结果。我们只希望她的童年健康正常，在这一点上，我们总算是做到了。”

## 马来西亚关节炎基金会儿童俱乐部

马来西亚关节炎基金会特为年幼的关节炎患者及家人设立了一个儿童俱乐部，并为他们安排群体活动来增进会员之间的互动，同时成立互助小组。今年的自立生活营将在今年11或12月间进行，确实日期尚有待敲定。

请拨电 03-5621 6177联系马来西亚关节炎基金会儿童俱乐部（Ms Shanta，周一至周五，上午9时至下午12时30分），查询进一步详情。

## **AFM ANNUAL GENERAL MEETING & PUBLIC FORUM MAY 2010**

AFM members and friends gathered at the Swan Convention Centre on the afternoon of May 15th, for the association's 17th Annual General Meeting, which was expected to be a low key affair given that it was not an election year.

Nevertheless, there was an eager audience for the talks which ran from 2.00 to 3.15 pm, by consultant rheumatologists Dr Amir Azlan Zain, who spoke on "What your doctor thinks about when you come with joint pain," and Dr S Sargunan.

Below is a synopsis of Dr Sargunan's talk on New Treatments in Rheumatoid Arthritis.

## **MESYUARAT AGUNG AFM DAN FORUM AWAM MEI 2010**

Ahli AFM berkumpul di Pusat Konvensyen Swan pada 15hb Mei, pada waktu tengahari, untuk mengadakan Mesyuarat Agung yang ke-17. Mesyuarat tersebut dijangka akan berlangsung dengan mudah, kerana ini adalah tahun kedua bagi pihak jawatankuasa terus berkhidmat sehingga 2011, dan tiada pilihanraya diadakan.

Namun ramai yang hadir untuk mendengar ceramah yang diadakan dari pukul 2.00 hingga 3.15 petang, yang disampaikan oleh pakar reumatologi Dr Amir Azlan Zain, yang memberi persembahan bertajuk "Perkara yang difikirkan doctor kamu apabila kamu berjumpanya kerana sakit-sakit sendi," dan Dr S Sargunan.

Ringkasan persembahan Dr Sargunan yang bertajuk "Pengubatan Baru untuk Reumatoid Arthritis," diberi di bawah.

## **2010年马来西亚关节炎基金会常年会员大会暨公众讲座**

马来西亚关节炎基金会于5月15日下午，假双威医院的天鹅会议中心召开第十七届常年会员大会。由于今年并非改选年，所以大会只以低调形式进行。

虽然如此，到场开会的会员以及朋友们却热切期待聆听大会过后的讲座。当天的讲座由下午2时开始，进行至3时15分结束；讲座会主讲人是风湿科顾问医师阿米尔医生（讲题为“你因关节痛就医时，医生会考虑到的事情”）以及沙谷楠医生（讲题为“治疗类风湿性关节炎的新方法”）。

以下是沙谷楠医生的讲题内容大意。

# **Treatment updates in Rheumatoid Arthritis** *by Dr S Sargunan*



*Painful and swollen joints should be seen by a specialist – faster diagnosis means better prospects for recovery.*

Covering developments in diagnosis, treatment and medication for RA in the last decade, Dr Sargunan's truly enlightening talk emphasised the need to see a rheumatologist as soon as possible after symptoms such

as stiff and swollen joints are noticed. New diagnostic tools in the form of anti-CCP tests allow for quicker and more definitive diagnosis of RA, resulting in intervention and treatment at an early stage, which increases the possibility of bringing the disease under control, or even into remission.

This is made possible due to a better understanding of Disease Modifying Anti-Rheumatic Drugs (DMARDs) which are now used in various combinations for greater efficacy. In this

light, the new designer treatments, or biologics, the most common of which is the anti-TNF's, have shown greater efficacy when used in combination with DMARDs, but the high cost of biologics still makes it the last resort for patient who do not respond to DMARDs.

Whatever the solution, rheumatologists now are treating patients with various combinations of medication, but such variations in therapy are only possible in close and regular consultation with a rheumatologist.

Dr Sargunan neatly summarised his informative and concise talk into three main points:

- If you suspect you have arthritis, arrange to see a rheumatologist without delay.
- For both new and established patients of RA, your rheumatologists have new strategies to manage your RA.
- In light of the new drugs that are available, each patient is different, and every patients' therapy needs to be tailored specifically.



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# Pengubatan baru Reumatoid Arthritis

oleh Dr S Sargunan

*Sendi yang sakit dan bengkak harus diteliti doctor pakar – diagnosis yang awal membawa harapan pemulihan yang lebih baik.*

Persembahan Dr Sargunan merangkumi perkembangan terkini dari segi diagnosis, rawatan dan pengubatan untuk RA dalam 10 tahun yang silam. Dia menekankan betapa mustahaknya untuk seseorang pesakit berjuma dengan pakar reumatologi sebaik sahaja simptom seperti sendi yang kaku dan bengkak mula-mula dirasai.

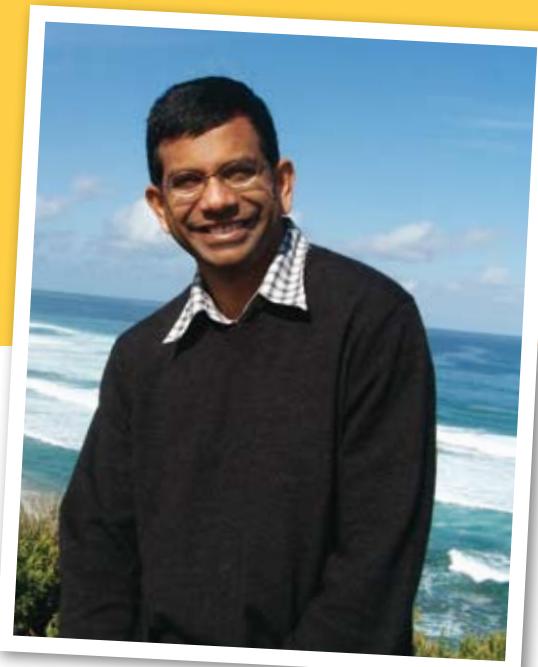
Alat pengesan penyakit yang baru, terutamanya ujian anti-CCP, boleh memberi memberi keputusan yang lebih cepat dan muktamad mengenai RA, dan ia akan membolehkan pengubatan yang lebih awal, yang selanjutnya membawa kemungkinan besar penyakit itu boleh dikawal dengan baik, malah, pesakit mungkin sembah.

Ini menjadi kenyataan kerana para doctor kini lebih faham akan ubat Disease Modifying Anti-Rheumatic Drugs (DMARDs) yang kini digunakan dalam pelbagai kombinasi untuk keberkesanan yang lebih tinggi. Dalam pada itu, rawatan baru, atau lebih dikenali sebagai biologic, dan antaranya, salah satu yang lebih terkenal, iaitu, ubat anti-TNF, kesemuanya telah menunjuk keberkesanan yang tinggi bila digunakan bersampingan dengan ubat DMARD. Walaubagaimanapun, oleh kerana harga biologic yang teramat tinggi, ianya hanya digunakan sekiranya seseorang pesakit itu tidak mendapat kesan langsung dari penggunaan ubat DMARD.

Walau apapun penyelesaiannya, pakar reumatologi kini menggunakan pelbagai kombinasi ubat untuk mengubati pesakit-pesakit RA, tetapi terapi kombinasi yang sering bertukar ini hanya boleh diusahakan sekiranya seseorang pesakit itu tetap mengunjung seseorang pakar reumatologi.

Dr Sargunan meringkaskan persembahannya seperti berikut :

- Jika kamu syak yang kamu mengidap arthritis, berjumpalah dengan pakar reumatologi secepat mungkin.
- Pesakit RA yang baru dan lama, kedua-duanya boleh menjana faedah cara pengubatan baru dari pakar reumatologi.
- Dari segi ubat baru yang kini ada di pasaran, setiap pesakit adalah unik, dan pengubatan setiap pesakit harus diubahsuai mengikut keperluannya yang tersendiri.



## 治疗类风湿性关节炎的新方法 (沙谷楠医生主讲)

若有关节疼痛或关节肿胀，应该找专科医师检查 – 越早确诊，康复机会越高。

沙谷楠医生在他的讲话中谈到过去十年来，医疗界在类风湿性关节炎的辩证、治疗和医药方面的进展，给听众带来很好的资讯。他在谈话中强调，一旦出现关节僵硬和肿胀的症状，就应该尽快向风湿病专科医师求诊。新式辩证方法如抗CCP检验，可以更快速及精准的辩证类风湿性关节炎，让医生可以尽早在病发之初即开始治疗，大大增加成功控制疾病或使疾病进入休眠期的机会。

如今可以做到这点，是因为医疗界已经更了解缓解病程抗风湿药物的用途。医生用它们来进行各形式的综合治疗，以达到更好的医疗效果。所以，当医生把一种称为生物制剂的新式治疗药物（当中最常用者为抗肿瘤坏死因子），合并着缓解病程抗风湿药物进行综合治疗时，它会有较好的治疗效果。然而，生物制剂价格昂贵，凡缓解病程抗风湿药物起不了治疗作用的患者，都会在没有办法之下才使用它。

不论用的是哪一种方法，当今的风湿专科医师们都以各不同形式的综合疗法来进行治疗；然而，这类的疗法需要由风湿专科医师紧密监控方可。

沙谷楠医生把他资讯丰富的讲话内容有条理的浓缩成以下三大重点：

- 一旦怀疑自己有关节炎，就应尽快安排让风湿专科医师检查。
- 不管你是新患或者是已经确诊的类风湿性关节炎患者，风湿专科医师都会有管理你的病情的方法。
- 在新药品的使用上，由于每个患者的情况都不尽相同，所以每个患者的治疗方案都必须按照个人所需来处方。

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1. Louis Draganich, Bruce Reider, Todd Rimington, Gary Piotrowski, Krishna Mallik and Scott Nasson. "The Effectiveness of Self-Adjustable Custom and Off-the-Shelf Bracing in the Treatment of Varus Gonarthrosis." *JBJS. J. Bone Joint Surg. Am.* 88:2645-2652, 2006. doi:10.2106/JBJS.D.02787.

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3. Kelly Krohn, MD and G. Kelley Fitzgerald, PT, PhD. "Nonpharmacologic, nonsurgical management of knee osteoarthritis." *The Journal of Musculoskeletal Medicine*; Vol. 23, Issue 6; June 2006.

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# Kordel's Charity Walk for Arthritis 2010

JOINT COLLABORATION FOR THE BENEFIT OF THE ARTHRITIS FUND



An overcast sky and the threat of rain did not keep away enthusiastic walkers from this year's Kordel's – AFM Charity Walk, which was held on Sunday, May 30 at Taman Bandaran in Kelana Jaya, Selangor.

Participants' determination were rewarded, as the cool morning afforded optimal walking conditions for the record number of 480 walkers, who were divided into 120 teams of 4 for the event.

Distribution of goodie bags, number tags and other items began as early as 6.30 am, and fifteen minutes before flag off, walkers were drawn by the cheerful exhortations of fitness trainer, Julian, who paced participants through a set of warm ups to ensure a safe race for everyone.

AFM President Dr Amir Azlan Zain's short speech suited the informal setting. He took the chance to thank all sponsors and also reminded all those present that arthritis patients needed help, because, although it was not a fatal disease, "it can cause a great deal of misery," adding that the funds from the walkathon would go long way in funding the work of Arthritis Foundation Malaysia, as well as pay for joint replacements for needy arthritis patients, through the Arthritis Fund. This year's joint collaboration raised a total of RM19,000 for the AFM.

Mr SL Ho, General Manager of Cambert (M) Sdn Bhd took the stage for Kordel's. He took only a few moments to underline the importance of the event to Kordel's, and to thank participants for their generosity of spirit, before getting the walkathon underway.

Walkers were flagged off at 7.30, and it took the winning group, "Yemmz!" an average of 23 minutes and 24 seconds to finish the 5 kilometre route, much to the surprise of the crowd at the finish line. There were also several teams vying for the "best dressed" special prize but it was "Ayam Toad Kordel's" who walked away with the day's honours. The team comprising three ladies and a gentleman were hard to miss, as they were tethered together, in keeping with their theme of being "towed".

Sponsors for the day outdid themselves with giveaways in the goodie bags, in addition to the free flow of Revive isotonic drinks, as well as food and other drinks, courtesy of Sunway Healthy Lifestyle. There were also soft rolls to be had from the Gardenia wagon. This year's sponsor list also included Nature's Valley, Health & Beauty Magazine, Kosmo, Fantastic, BIC, Antabax, Holiday Inn Glenmarie, Bleu, BROS, Nuvatea, Green Magma, BRUT, Denim, Juvanex, and Futura, which meant participants were able to win goodies to the value of RM 15,000 in the lucky draw, and from ensuing fun and games coordinated by the Red Ryders from RED FM. And to top it all this year's walkathon was featured on the NTV 7 Breakfast show.

Without doubt, the walkathon will prove to be a morning to remember, and here's to wishing for many more!

# Kordel's Charity Walk for Arthritis 2010

## KEMPEN BERSAMA UNTUK TABUNG AMAL ARTRITIS

Dengan tidak menghiraukan langit yang mendung, para pejalan kaki untuk acara Kordel's - AFM Charity Walk tahun ini, keluar beramai-ramai menuju ke Taman Bandaran Kelana Jaya, Selangor, pada hari Ahad, 30 Mei.

Keazaman para peserta untuk mengambil bahagian turut dibalas, dan suasana sejuk hening pada pagi itu menambahkan lagi suasana yang cukup sempurna untuk acara pagi tersebut. Seramai 480 peserta, yang dijadikan 120 pasukan beranggota 4 orang setiap satu, mengambil bahagian tahun ini.

Pemberian goodie-bag, tag nombor serta benda-benda yang lain bermula dari pukul 6.30 pagi, dan 15 minit sebelum bendera permulaan dijatuhkan, pelatih kesihatan Julian memberi petunjuk untuk senaman memanaskan tubuh untuk para peserta.

Presiden AFM Dr Amir Azlan Zain memberi ucapan yang pendek. Dr Amir mengambil kesempatan itu untuk berterima kasih kepada para pengajur dan peserta hari itu. Beliau juga mengingatkan para hadirin bahawa pesakit artritis memang memerlukan bantuan yang dihulurkan, kerana, walaupun penyakit artritis tidak membawa maut, pesakit akan menderita.

Wang sumbangan dari acara itu akan menyokong aktiviti AFM dan juga digunakan untuk membayai kos penggantian sendi untuk pesakit artritis yang kurang berada, melalui Tabung Amal Artritis. Tahun in, kempen bekerjasama ini mengaut sebanyak RM19,000 untuk pihak AFM.

Encik SL Ho, Pengurus Besar Cambert (M) Sdn Bhd pula ke pentas untuk Kordel's. Dia hanya mengambil masa yang singkat untuk memberitahu orangramai betapa mustahak acara itu kepada Kordel's, dan untuk berterima kasih kepada para peserta.

Para pejalan mula berlumba pada jam 7.40 dan ahli-ahli pasukan pemenang "Yemmz!" hanya mengambil purata masa 23 minit 24 saat untuk menhabiskan jarak 5 kilometer tersebut. Ada juga peserta yang memakai pakaian beraneka corak untuk mengaut hadiah "Pakaian terbaik". Hadiah kategori tersebut dimenangi pasukan yang menamakan diri "Ayam Toad Kordel's" di mana ketiga-kita ahli perempuan pasukan tersebut diikat dengan tali kepada peserta lelaki yang berjalan dihadapan, memberi gambaran yang pihak perempuan sedang ditarik.

Para pengajur sangat murah hati, dan para hadirin diberi peluang meminum minuman isotonic Revive tanpa had, dan juga menjamah makanan dan minuman yang dianjur Sunway Healthy Lifestyle. Van Gardenia pula sibuk memberi roti gulung lembut, dan lain-lain pemberian terdapat dari pihak pengajur, yang termasuk Nature's Valley, Health & Beauty Magazine, Kosmo, Fantastic, BIC, Antabax, Holiday Inn Glenmarie, Bleu, BROS, Nuvatea, Green Magma, BRUT, Denim, Juvanex, dan Futura. Kesemua pemberian ini member para peserta peluang untuk memenangi hadiah yang berharga RM 15,000. Pihak Red Ryders dari RED FM memeriahkan lagi acara tersebut dengan permainan yang dilaksanakan, di samping penayangan acara walkathon tersebut di Persembahan pagi NTV's Breakfast Show.

Pendekata, acara tersebut sukar dilupakan dan kami benar-benar berharap yang banyak lagi acara seperti ini akan diadakan!



## Kordel's义善行 为2010年关节炎义行 携手合作为关节炎基金募经费

本年度的Kordel's-AFM义善行已于5月30日，假雪兰莪州格拉娜再也的市政公园举行。当天早上即使天上乌云满布，看似随时会下雨，但是参加竞走的健儿们依然踊跃出席参加，完全不受影响。

结果，雨没下成，清凉天气正好是徒步竞走的好天气。今年的义善行有120支四人小组参赛，竞走人数达到480人，打突破了去年的纪录。

主办单位从早上6点30分开始就在现场向参赛健儿分发礼品包、参赛号码以及其他物项。开走前十五分钟，健儿们在健身教练Julian的带领下，先来一轮的事前暖身，操出最佳状态。

AFM（大马关节炎基金会）主席阿米尔医生于赛前做了一则精简说话，除了向各赞助商致谢意之外，他还在致辞中告诉各在场人士关节炎患者需要帮助。他指出，关节炎虽不至于致命，但是却会“陷入于极大的痛苦中”。他说，今次义善行所募得的义款不但可资助AFM进行为患者谋福利的工作，而且还能透过关节炎基金帮助贫困患者进行关节置换手术。今年AFM与Kordel's的联合募捐共筹得1万5千令吉。

代表Kordel's致词的是Cambert (M) Sdn Bhd总经理SL Ho先生。他在开赛前的简短说话中指出这活动对Kordel's是如何重要，也感谢各参与者的慷慨捐输和为善精神。

义善行在早上7点30分开走，“Yemmz!”组合平均只用了23分24秒就走完了全程5公里的路程勇敢夺冠，速度之快让观赛者甚感惊讶！特设的最佳服装奖由队形抢眼、互相牵绑在一起以表达“被拖曳”主题的“Ayam Toad Kordel's”夺得，让其他几支有意争夺此名衔的组合大叹不如。

当天的赞助商们都很落力且大方的派送礼品包，现场也有供应不断的Revive体育饮料。另外，Sunway Healthy Lifestyle亦在现场供应食物和其他饮料，而Gardenia面包车则到场供应松软可口的面包。参与赞助的热心商家还包括Nature's Valley、Health & Beauty Magazine、Kosmo、Fantastic、BIC、Antabax、Holiday Inn Glenmarie、Bleu、BROS、Nuvatea、Green Magma、BRUT、Denim、Juvanex及Futura。参加义善行的健儿们因此有机会从幸运抽奖以及从RED FM电台广播员主持的有趣游戏中，赢取了总值1万5千令吉的奖品。除此之外，这次的义善行也是NTV7当天早餐节目中谈及的内容之一。

毫无疑问的，这次的义善行肯定是各参与者的一个难忘早晨，希望将来还有更多类似的美好时光！



## National Rheumatoid Arthritis Day Life as usual

Continuing with one's life despite experiencing the debilitating symptoms of Rheumatoid Arthritis was what this year's AFM's 4th RA Day celebrations were about, and there was a strong turnout of well over 100 members and friends to this half-day event at the Swan Convention Centre on Sunday, 4th of July.

The day's programme began with a well-received talk by AFM president Dr Amir Azlan Zain, on "Ways to Detect RA Earlier and the Benefits of Earlier Detection." This tied in with the launch of a three-month Anti-CCP Testing campaign by Abbot Laboratories.

Dr Amir pointed out the increasing body of evidence which illustrates that early treatment of RA brought better results, in addition to speaking on and fielding more queries on the Anti-CCP testing now available in Malaysia, a test far more accurate than previous ones for identifying the existence of RA in a patient.

Next, was a talk on "Healthy Feet for an Active Life" by Edmund Lee, Managing Director of MyORTHO Rehab Sdn Bhd, and principal consultant at the Foot and Spine Healthcare Orthotic Centre in KL. Listeners were keen to learn to use orthotics to improve foot and spinal stability, alleviate pain and improve walking comfort. Many availed themselves to the free foot scan facilities provided by MyORTHO at the event.

In the afternoon, Master Yong Yew Tuck demonstrated his Cane Rejuvenation Exercises routine, a favourite with AFM's members. Using a simple 3 foot long rattan rod, Master Yong showed how simple movements repeated daily could improve overall circulation, flexibility and well-being.

Those interested in learning more of Master Yong's cane exercise technique, can join the practice sessions listed below, or contact the relevant persons.

WHO	WHEN AND WHERE	CONTACT
Master Yong	Wednesday mornings, 7.30 am SS3/14, Petaling Jaya	012-2142299
Master Yong	Every 1st and 3rd Monday of the month 7.30 am. Medan Damansara, Kuala Lumpur	012-2142299
Patrick	Bangsar	019 - 3339306
Dato Yee	Damansara Jaya	019-6686313
Mrs. Leong	OUG, Meru Road	03-79804798



# Tabung Amal Artritis

Tabung Amal Artritis adalah tabung kebajikan yang dikelolakan oleh Yayasan Artritis Malaysia (AFM) untuk membantu pesakit yang kurang berada untuk meneruskan program pengubatan mereka. Tabung ini, yang ditubuhkan pada tahun 2003, telah menolong membiayi pembedahan penggantian sendi untuk lebih daripada 50 orang pesakit dalam beberapa tahun yang lepas. Dengan adanya pembedahan tersebut, pesakit yang telah mengalami kerosakan sendi yang ketara dapat menghayati semula kehidupan tanpa sakit kerana kerosakan sendi, serta daya penggerakkan yang telah lama hilang. Pihak Yayasan sentiasa menerima dermaan terhadap tabung amal ini, dan orangramai diingati bahawa setiap pendermaan kepada Tabung tersebut dikecualikan cukai.

## SIAPA LAYAK ?

- Hanya penerima (pesakit) yang berkerakyatan Malaysia, atau penduduk tetap.
- Pendapatan bulanan penerima tidak melebihi RM 2,000.
- Subsidi akan membayar kos implant dan sampingan. Pembedahan harus dijalankan di hospital kerajaan dan dilakukan oleh Doktor Bedah Orthopedik yang berpengalaman. Wang tidak dibayar kepada pesakit. Pembayaran dibuat terus kepada pembekal implan.
- Setiap permohonan akan diteliti dan diluluskan oleh "Jawatankuasa Tabung Amal Artritis" yang terdiri daripada tujuh ahli. Kelulusan berdasarkan kelayakan dan adanya wang tabung amal.

## CARA MEMOHON:

- Dapatkan Borang Permohonan dari Sekretariat AFM (alamat di kulit) ataupun panggil 603-5621 6177 untuk borang dihantar melalui pos. Borang juga boleh dimuat-turun dari laman web AFM [www.afm.org.my](http://www.afm.org.my). Borang juga boleh didapati dari Unit Kebajikan Perubatan di Hospital Kerajaan.
- Isi Borang Permohonan dan serahkan kepada doktor yang menjaga kamu. Doktor akan mengisi butir-butir medikal serta keperluan kamu. Setiap permohonan mesti bersama rujukan daripada 2 orang doctor.
- Pegawai kebajikan akan menilai kelayakan kamu untuk mendapat sumbangan.
- Borang Permohonan yang lengkap dihantar kepada AFM, di mana ia akan diteliti oleh Jawatankuasa Tabung Amal Artritis.
- Jawatankuasa akan menjawab dalam masa 2 bulan samada permohonan kamu diluluskan atau tidak.

# 关节炎基金

关节炎基金是一个由马来西亚关节炎基金会管理的慈善基金，帮助关节炎患者治疗的需要。该基金成立于2003年，多年来已帮助了50个病人的关节置换手术费用支出，让关节损伤的关节炎病人恢复行动能力及减轻痛苦，重获新生。马来西亚关节炎基金会持续的请求对关节炎基金的捐款，所有的捐款是免税的。

## 谁符合申请条件？

- 受益人（患者）必须是大马公民或永久居民。
- 受益人的每月收入不可超过2000令吉。
- 财政包括支付人造关节费用以及一些相关的杂费。手术将由经验丰富的资深骨外科医生在政府医院里进行。
- 现金不会直接付予患者。款项将直接交付给人造关节供应商。
- 所有申请将由一个七人“关节炎基金委员会”进行审查和批准，批准与否得视申请者资格是否符合、基金经费是否足够。

## 如何申请？

- 亲临AFM秘书处（地址在封面）索取申请表格，或致电03-5621 6177要求将表格邮寄到府上，或者浏览[www.afm.org.my](http://www.afm.org.my)网站下载。政府医院的医药福利单位也备有申请表格供索取。
- 先把表格填写好，然后交给负责诊治的医疗团队，由他们提供病情资料以及你的治疗需要。每一份申请表格必须由两位医生加以证明。
- 社会福利部职员将鉴定你是否符合资格接受援助
- 填妥的申请表格将送往AFM，并由关节炎基金委员会进行审查
- 委员会将在两个月内作出答复，通知你申请获得批准与否。

# Shantabai's story



AF recipient Shantabai is unequivocal, "Knee surgery changed my life, and I have AFM to thank for that. I was walking with the aid of a walking stick, I could not climb stairs, could not squat, and could not use the toilet. Painkillers did not help with the pain, I was a total wreck."

Today, almost 3 years after her bilateral knee operation, Shantabai says, "My life is pain free. I am amazed at how fast I can walk, each day, I can do more."

Shantabai's knees were replaced in 2007 on the advice of a consultant orthopaedic surgeon in University Hospital. She was told she was 10 years too late in seeking medical help, her osteoarthritis had developed to the stage where bones in her knees were virtually fused together. Her condition was complicated by the fact that she was a polio victim.

Her neglect of her deteriorating physical condition was a result of financial pressures. As a single mother of three school-going children after the sudden demise of her husband, putting food on the table and providing for her family took priority over her own aches and pains. Nor could she believe that she could suffer from osteoarthritis, she was only in her early forties when the symptoms began. They coincided with the heavy workload as the family breadwinner, and she put the exhaustion, aches, and pains, down to overexertion.

But as pain reduced her mobility, Shantabai knew something was wrong, she just did not have the money to seek help for it. "As a food seller, I had customers who were drug company reps and they gave me supplements. I tried Viartril, there was no change," she recalls.

Shantabai credits her surgeon, Dr CC Tai, for smoothing the path to surgery. "He got me to the Welfare Department at UH, and they paid for the surgery fees of RM 4,500, and to the AFM, which, through the AF, gave me RM 9,300 for the knee replacements." With some effort, Shantabai's children raised RM 4,000 for her hospitalisation and medical charges.

AF made it possible for Shantabai to have her life-changing surgery sooner rather than later, giving her a chance to regain her life.

She is mindful of her new knees. "I understand that they have a lifespan of 15 years, that will give me till age 70, and that is more than enough, I am grateful," she laughs. As such, she is careful – "I make sure I sit on high chairs, with my knees no lower than 90 degrees, I drive with a cushion under me to raise the height of the car seat, I don't kneel, nor do I ever carry heavy things."

These minor restrictions are minor in comparison to the freedom the knee replacements have given her, and in conclusion, Shantabai says: "I only want to say, from the bottom of my heart, Thank you, AFM."

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