



**W**elcome to our first issue of Joint Efforts for the year 2016. A new year is always a harbinger of hope, optimism and positivity. It's a time of new resolutions, new approaches and new patterns of living and being. As life is always evolving; it is an on-going process for us to keep ourselves open to the latest research and information on diet, medication and exercise so that we are able to incorporate it in our lives, to make wiser choices, lead healthier lives.

This issue we have brought the spotlight on Juvenile Idiopathic Arthritis (JIA) as generally arthritis is seen as an old people's disease. So as you read the profile sections you will be very surprised to know that children even as young as 3 can be diagnosed with arthritis and that teenagers and young adults face very different challenges as they look into the future.

Whatever the state of our health and our lives at this point, it always gets better as long as we stay active, informed and connected. So stay involved with the various vibrant RASG activities that are conducted from time to time, do attend the fun-filled weekly PACE exercise sessions organised by AFM. Take one step today towards a healthier lifestyle. Do the things that bring you joy; have coffee with a friend, indulge in a massage, cultivate relationships, smell the flowers, admire the sunset, practice gratitude.

*"If more of us valued food and cheer and song above hoarded gold, it would be a merrier world." ~ J.R.R. Tolkien*

**Shailaja Menon**  
EDITOR

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### ANNOUNCEMENT

AFM Annual General Meeting / public forum will be held on 23 April 2016 at Crystal Hall Level 4, Crystal Crown Hotel, Jalan Utara, Petaling Jaya. Please visit our website for update and registration.

# <sup>1</sup> Improvement in symptoms:

**Reduction of WOMAC pain score in (88% of patients)  
CTX-II lowering (62% of patients)  
(biomarker of cartilage degradation)**

**Double-blind  
cross-over  
clinical study.<sup>1</sup>**

**No significant  
change in  
blood glucose.<sup>1</sup>**



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**References:**

<sup>1</sup> Kitidumrongsook P et al. *Efficacy and safety of Prosulf-Forte in the treatment of osteoarthritis of the knee at King Chulalongkorn Memorial Hospital.* Chula Med J 2012 May - Jun; 56(3): 289 - 95.

<sup>1</sup> Prosulf-Forte is the brand name of Artril Forte in Thailand.



I am pleased to introduce you to this year's first issue of Joint Efforts.

It was a joy to participate in what must be the most vibrant celebrations of the Lunar New Year I have ever seen. Social media sites were filled with photos of families celebrating the arrival of the year of the Fire Monkey. There were many photos of families wishing everyone a happy and prosperous New Year. This is in stark contrast to the doom and gloom described in both mainstream and online media. Well, mostly the online media. The mainstream media would probably say all is well, so that we can all prepare for the income tax season! Let's face it folks, it is your tax contributions, and only your tax contributions that will hopefully save the nation.

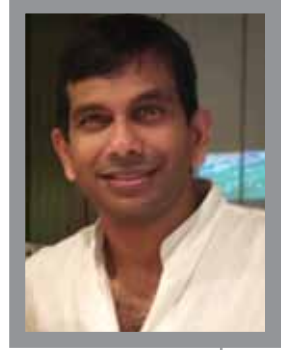
It is my hope that all who suffer from autoimmune disease will get the reprieve and deductions from their income tax

contributions. As I have mentioned in previous issues, it is time for the contributions of people who suffer from Rheumatoid Arthritis, Ankylosing Spondylitis and Psoriatic Arthritis be recognized and Arthritis Foundation Malaysia is committed towards achieving this goal.

The tremendous contribution of our lively Rheumatoid Arthritis Support Group (RASG) is testament to this effect. It is important for any sufferer of disease, to keep herself active, mindful and alert. The importance of group therapy must be emphasized and I encourage all, care-givers included, to take part in these events.

Let us hope for a great year ahead for everyone, as we take on all challenges with zest and enthusiasm.

*Dr. Sargunan Sockalingam*  
President, AFM



Saya dengan sukacitanya memperkenalkan terbitan sulung Joint Efforts bagi tahun ini.

Saya gembira melihat sambutan Tahun Baru Cina yang begitu meriah yang disambut baru-baru ini. Ruang media sosial telah dipenuhi dengan gambar-gambar keluarga meraikan kedatangan tahun Monyet Api. Masing-masing mengucapkan selamat tahun baru kepada kaum keluarga dan kenalan yang jauh dan dekat. Ini berbeza daripada suasana suram yang digambarkan oleh media arus perdana dan terutama media dalam talian. Media arus perdana mungkin menggambarkan semuanya dalam keadaan baik supaya kita boleh bersedia menghadapi musim cukai pendapatan! Sebenarnya sumbangan cukai kita yang diharapkan dapat menyelamatkan negara kita yang tercinta.

Sempena tahun baru ini, saya amat berharap agar mereka yang menghadapi penyakit auto imun mendapat pelepasan dan potongan daripada sumbangan cukai pendapatan mereka. Seperti yang sering saya nyatakan dalam terbitan yang lepas, sudah tiba masanya sumbangan warganegara yang menghidap penyakit Rheumatoid Arthritis, Ankylosing Spondylitis dan Psoriatic Arthritis diberi pengiktirafan dan Yayasan komited ke arah mencapai matlamat ini.

Sumbangan besar yang diberikan oleh Kumpulan Sokongan Rheumatoid Arthritis (RASG) kami yang aktif menjadi bukti kepada komitmen yang diberikan. Adalah penting untuk mereka yang menghidap penyakit ini untuk kekal aktif dan cergas. Manfaat terapi secara berkumpulan perlu ditekankan dan saya menggalakkan semua yang terlibat termasuk para penjaga untuk mengambil bahagian dalam acara-acara yang dianjurkan.

Marilah kita sama-sama berdoa untuk tahun yang lebih baik untuk semua dalam kita menghadapi cabaran dengan penuh semangat dan keyakinan.

*Dr. Sargunan Sockalingam*  
Presiden, AFM

新年伊始，我很高兴的在此为大家介绍本年度的第一期会讯，希望大家会喜欢。

农历新年在一片喜洋洋的欢腾气氛中到来，到处可见缤纷夺目的迎春装饰和庆祝活动，是我见过的最多姿多彩的一年。社交网站上不缺各家各户忙着迎接火猴年，以及互相祝贺新春吉祥的欢愉相片。这个欢腾现象，与主流媒体以及网上媒体报道（尤其是网上媒体）所反映的市道颓靡及民间生活艰苦，根本就是一个很大的反差！主流媒体尚且会说一切还不至于太差，生活依然好过，好让大家保持好心情来面对年度的纳税季节！唯有人人尽责缴税，国家的建设才会更好。

我希望所有身患自身免疫疾病的人士，都会享有减税的优惠。我在上一期会讯中已经指出，是当局应该承认身患类风湿性关节炎、僵直性关节炎以及硬皮症关节炎人士们，对国家所作贡献的时候了。大马关节炎基金会至志落力争取，坚决为达成此税务优惠的目标而努力。

类风湿性关节炎互助小组在过去的日子里，不遗余力为病友谋福利，正是对社会作贡献的好例子。不管患的是哪一种关节炎，患者有必要保持活跃、处事小心谨慎，也有所警惕。我在此一再强调群体治疗的重要，并鼓励所有患者，连同他们的照护人，都踊跃参与互助支援小组的活动。

且让我们一起放眼未来，愿大家以宽待及热忱来面对挑战，共度美好的一年！

大马关节炎基金会主席  
沙谷南医生

## “Triumph over Infirmity” Michelangelo created masterpieces despite degenerative arthritis

**3rd Feb 2016** In a news release published in the Journal of the Royal Society of Medicine, a study by Dr. Davide Lazzeri, of the Villa Salaria Clinic in Rome and his colleagues reveals that the hands of Michelangelo, one of the greatest painters and sculptors in history were working through the pain of degenerative arthritis to create masterpieces until the artist was nearly 89 years old. Michelangelo Buonarroti, who lived from 1475-1564, was the first artist to be recognized as a genius in his own lifetime. The crowds still flock to see the ceiling of the Sistine Chapel and the Pietà in St. Peter's, in Rome, Italy, among many other works of sublime beauty.

Dr. Davide Lazzeri and his colleagues analyzed three paintings of Michelangelo to find out more about his

health. The paintings depict the artist aged 60-65 years and reflect his progressive aging. The first, dated 1535, is by Jacopino del Conte. It was painted when Michelangelo was over 60. His left hand is shown hanging with apparent signs of a non-inflammatory articular disease, which could be osteoarthritis. Earlier portraits show him with no apparent signs of deformity in his hands. The researchers conclude that the artist's condition was probably made worse by prolonged hammering and chiseling.

They add that continuing to

work intensely may have enabled him to keep the use of his hands until his death.

Lead author, Dr. Lazzeri, who is a specialist in plastic reconstructive and esthetic surgery, says “It is clear from the literature that Michelangelo was afflicted by an illness involving his joints. In the past this has been attributed to gout but our analysis shows this can be dismissed.” The exclusion of gout was based on the fact that the hands show no signs of inflammation, nor was there any evidence of tophi. Tophi are small lumps of uric acid crystals that form under the skin of an individual with gout.

In spite of these setbacks, Michelangelo continued to produce masterpieces, and he was seen hammering up to 6 days before he died, 3 weeks before his 89th birthday. The findings, says Dr. Lazzeri, highlight Michelangelo's “triumph over infirmity.” Perhaps it was his very perseverance which enabled him to use his hands until the end.



## Abdominal obesity can increase fracture risk in women

**15th Feb 2016** A new study conducted by Harvard University in the US and the University of Oslo in Norway has offered evidence that, carrying excess weight around the abdominal area can make women more susceptible to bone breakages if their physical activity levels are low.

For this research, indicators of abdominal obesity and hip fracture were assessed among 61,677 postmenopausal women and 35,488 men above the age of 50, with data going back to 1986 and follow-up assessments occurring at two-year intervals.

During the assessed period, a total of 1,168 women and 483 men sustained a hip fracture, with increasing waist circumferences and waist-to-hip ratios both linked with a greater risk of breaking a hip bone.

### The role of gender and exercise levels

One of the key findings of the study was that this risk association was highly dependent on both gender and exercise habits, with no strong link seen between obesity and fracture rates in the male patients involved in the study.

Moreover, those in the highest waist-to-hip ratio category only had an increased risk of hip fracture if their physical activity levels were lower than the average amount, but not if it was higher. A similar pattern was found for waist circumference, suggesting getting more exercise can make a significant difference.

The researchers concluded that “Indicators of abdominal obesity were associated with increased hip fracture risk after controlling for BMI in women. The increased risk was restricted to women with low physical activity. In men, no significant associations were found.”

### Arthritis Research UK's view

Dr Katherine Free, research liaison and communication manager for Arthritis Research UK, said: “Regular physical activity is important for your general health and will also help to strengthen bones and muscles, reducing the risk of falling and fractures. Exercise also helps to maintain a healthy weight, which is important as we know that carrying excess weight can increase the risk of developing arthritic conditions such as osteoarthritis.

This study suggests that carrying increased weight may also increase fracture risk in women, highlighting the importance of exercise in this group particularly in later life, as women are more susceptible to fractures after the menopause. Researchers at our centre for musculoskeletal ageing are investigating interventions that could help maintain healthy bones and joints as we get older and promote healthy ageing.”

# PROTEIN THAT TRIGGERS JUVENILE ARTHRITIS IDENTIFIED



**25th Feb 2016** In a news release published online in the journal *JCI Insight*, a new study led by researchers at Albert Einstein College of Medicine and the Children’s Hospital at Montefiore (CHAM), offers evidence that a human protein called transthyretin (TTR) causes an autoimmune reaction in the joints of JIA patients.

Juvenile idiopathic arthritis, or JIA, is the most common form of childhood arthritis. It appears to be an autoimmune disease, caused by antibodies attacking certain proteins in a person’s own tissue. But no “autoantigens” – the proteins triggering an immune attack – have been linked to JIA.

“Our findings regarding TTR’s involvement in JIA point to a potential treatment – encouraging news for children with this debilitating disease,” said study leader Laura Santambrogio, M.D., Ph.D., professor of pathology, of microbiology & immunology, and of orthopaedic surgery at Einstein. JIA patients, she says, might benefit from a drug called tafamidis, which targets TTR. Tafamidis was approved in Europe and Japan for treating familial amyloidosis, which is also linked to TTR. The drug is now undergoing phase III trials in the U.S.

In the current study, Dr. Santambrogio and her colleagues looked for abnormal accumulations of proteins in the synovial

fluid (which bathes the joints) and blood of patients with JIA. They found a significant increase in TTR in 50 patients at the Children’s Hospital at Montefiore, but not in any of the 26 control children who did not have JIA. Further analysis revealed that some JIA patients had unusually high levels of antibodies to the TTR protein. To validate this finding, the researcher analyzed 43 other JIA patients and found a significant increase in TTR autoantibodies in all of them.

TTR is a molecular “chaperone” that transports various molecules, including thyroxine and retinol (vitamin A), in the blood and cerebral spinal fluid. The researchers suspect that JIA begins when TTR collects in the joints.

“The TTR protein has a tendency to misfold and then aggregate, which for some reason seems to occur in children with JIA,” said Dr. Santambrogio. “And when proteins aggregate, they tend to become more immunogenic.” Using mass spectrometry and other biophysical techniques, the researchers observed misfolded and aggregated TTR in the synovial fluid of JIA patients. The patients’ TTR protein was also heavily oxidized, which may further increase its immunogenicity. When abnormal TTR was administered to mice, it elicited a higher immunogenic response (i.e., caused more antibodies to be produced) compared to normal TTR.

---

**JIA affects about  
300,000  
children in the  
U.S. Symptoms  
include chronic  
joint pain, swelling  
and stiffness, which  
may persist for a  
few months or a  
lifetime. There is no  
cure. Treatments  
such as nonsteroidal  
anti-inflammatory  
drugs (NSAIDs) and  
biologic response  
modifiers are used  
to control symptoms  
and prevent  
complications.**

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# Juvenile Idiopathic Arthritis

## How Can You Support Your Child?



When informed that their child suffers from arthritis is devastating to parents, is ensuring that the child takes the prescribed medication and does regular follow-up checkups with the doctor enough? What else can be done to provide holistic care to the child?

### WHAT IS JUVENILE IDIOPATHIC ARTHRITIS (JIA)?

Juvenile means that the arthritis began before the child was 16 years old.

Idiopathic means that the cause is unknown. Arthritis, as one or more of the joints are inflamed for a period of at least 6 weeks.

### WHAT CAUSES JIA?

Your body has an immune system which fights germs from outside the body to keep you healthy. Sometimes the body's immune system mistakes a normal part of the body for something foreign (like a germ), and starts attacking the body itself. In JIA the immune system attacks the joints. This is called an auto-immune process. We still don't understand exactly why this happens.

### WHAT SHOULD PARENTS KNOW?

Dr. Tang Swee Ping, Consultant Pediatric Rheumatologist, Hospital Selayang emphasizes, "While monitoring medication and taking the child for regular check-ups is extremely important, it is also vital to pay attention to other aspects of managing the condition".

### SCREEN FOR UVEITIS

Uveitis is inflammation of parts of the eye, including the iris (the coloured bit of the eye) and the muscles and tissues that focus the eye. The inflammation is caused by an auto-immune process, just like in the joints. If uveitis is not treated it can make the vision blurry. **It is vital for parents to note that some children may not be able to appreciate the progressive blurring of their vision. This can eventually lead to blindness. So it is very important to schedule regular check-ups with an ophthalmologist (specialist eye doctor) to check for inflammation in the eyes.**

### PHYSIOTHERAPY

Physiotherapists are experts on how joints and muscles work. They will give your child exercises to keep their joints moving well, especially the affected joints, and to strengthen their muscles. A physiotherapist can also educate you on other methods of pain relief that work alongside the prescribed medications.

- Ice packs can be used to soothe hot, swollen joints.
- Heat packs help to relax tense, tired muscles.
- Splinting of swollen or painful joints may be helpful during a flare-up of JIA.
- Regular exercise will also stimulate production of the body's own natural pain-relieving hormones (endorphins).
- They can help you plan a graded exercise program, one that starts slowly and improves in small steps. Besides, they can also advise you on any special equipment or training that you'll need to get started.
- Physiotherapists may have access to a hydrotherapy pool where your child can exercise in warm water. Children naturally love to move in water; the warmth is soothing and the water supports their weight so they can move their joints and muscles without straining them.

### OCCUPATIONAL THERAPY

Occupational therapists can offer custom-made splints or supports that can ease stress on painful joints

and help prevent deformity. They can teach your child how to protect their joints by performing tasks in different ways than they're used to, such as using both hands or using an assistive device.

They also offer other aids for everyday activities that could prove to be challenging like getting dressed, writing or even eating. They also give suggestions on home or school modifications to allow children to be as normal as possible. Aids in school may include using a computer if they are unable to write. Aids help to maximize the child's ability to participate in activities safely and thus enhance their quality of life.



## DENTAL CARE

The temporomandibular joint (TMJ) is the joint in front of the ears where the lower jaw connects to the base of the skull. JIA may affect this joint in the same way it affects other joints and cause pain and stiffness in the child's jaw. It can also alter growth so that one side of the jaw grows faster than the other. This can make brushing and flossing teeth difficult.

To help prevent this, the child may need to do some jaw exercises. The dentist may suggest different types of toothbrush handles, electric toothbrushes, or floss holders to help maintain healthy teeth and gums.

Your child's dentist should know about the status of her JIA and medications she is taking, since they can also affect the state of her oral health. For example, the dentist needs to know if she has had a joint replacement, as she might need an antibiotic before any dental work.

- She may find it difficult to keep her mouth open for her routine dental check-ups. Then more frequent, shorter visits may be helpful.

## NUTRITION

### Low Appetite

- Serve small meals throughout the day at regularly scheduled times as they are easier than three large meals (breakfast, morning snack, lunch, afternoon snack, dinner and a healthful dessert).
- Encourage your child to take a few bites at least. Try combining multiple foods so he has a variety of taste sensations. Offer a few slices of apple and grapes with some yogurt or peanut butter.
- Ensure the foods you serve are nutrient-rich. If your child struggles to maintain or gain weight add healthy fats, such as olive oil and avocado to boost calorie content.
- Pay attention to calcium intake.
- Consult your physician or a registered dietitian to determine whether your child could benefit from a nutritional supplement.

### High Appetite

- Encourage your child to load at least half of the plate with fruits and vegetables at meals. Fruits and vegetables are low in calories and high in fiber, which helps children feel satisfied on fewer calories.
- Hunger can be confused with thirst. Making sure your child is well hydrated may help to normalize his appetite as well.
- Encourage your child to drink water and limit sugary beverages like juice and aerated drinks like coke, pepsi, sprite etc.
- Include protein and a fruit or vegetable in every snack (soya chunks with baby carrots, apple with low-fat cheese, low-fat yogurt and fruit, tofu with sliced capsicum, eggs with cucumber, lettuce and tomato salad) to help your child feel satiated without excess calories.
- Discourage grazing (letting kids eat whatever and whenever they want throughout the day). This can lead to an unbalanced and/or high-calorie diet.



## PSYCHOLOGICAL SUPPORT

Some children diagnosed with JIA may have adjustment disorders and subsequently low self-esteem. Psychologists and psychiatrists help kids and their families manage their feelings about JIA, and cope with the pain.

## SUPPORT GROUPS

It can be great for children to meet and bond with other kids with JIA. Arthritis Foundation Malaysia supports these little patients by holding regular fun activity days and camps for kids with JIA so they learn from a young age about their disease and be empowered to manage it themselves as they grow up.

Meeting other families who have a child with JIA can be a valuable experience for the whole family. It can help to share ideas and experiences with other families in the same situation.

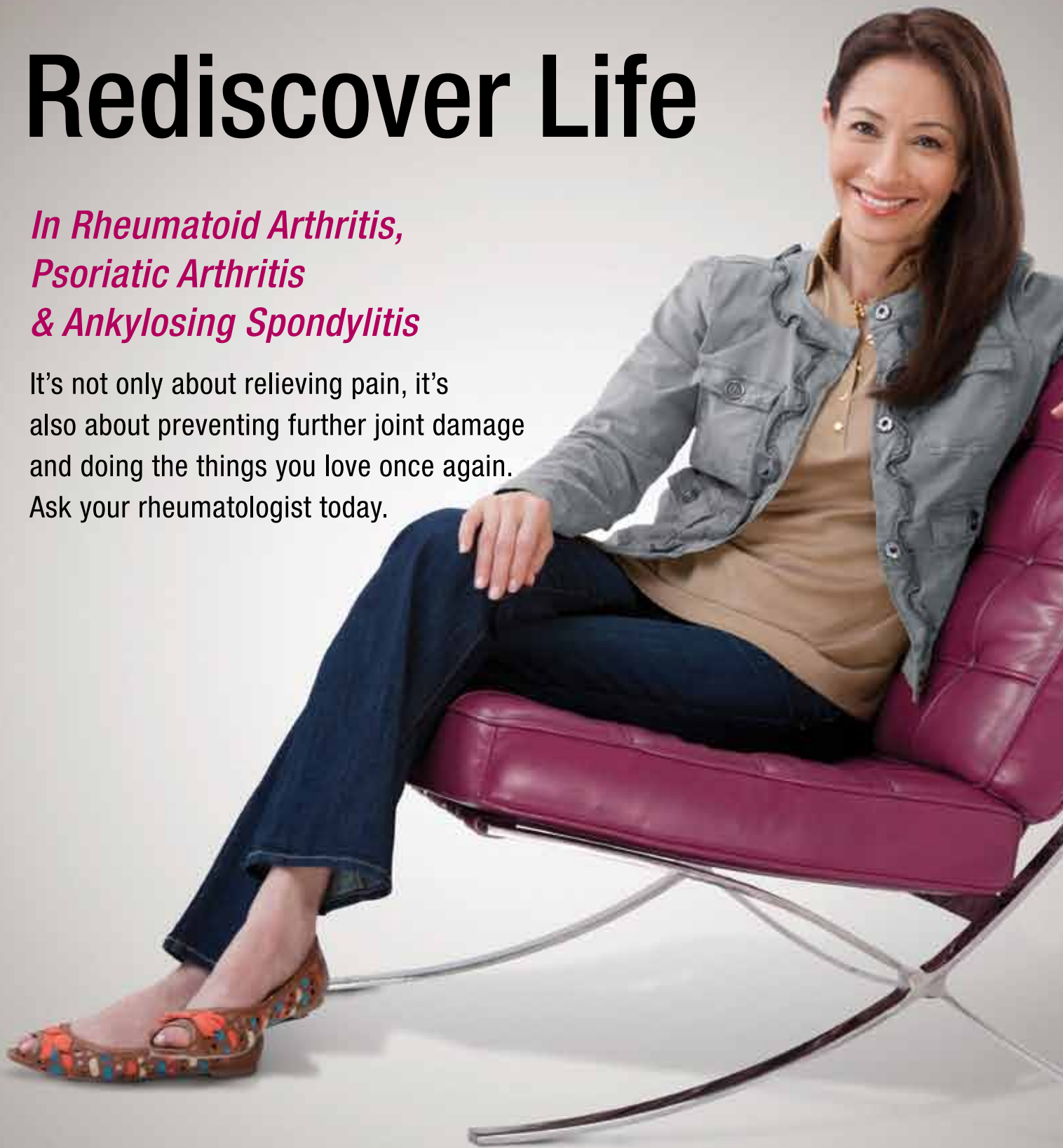
So stay connected with your doctors, stay involved with AFM and their various activities and empower yourself and your child with information to best cope with the varied aspects of their condition. Most importantly, involve the whole family to stay active and positive.



# Rediscover Life

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Psoriatic Arthritis  
& Ankylosing Spondylitis*

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# Juvenile Idiopathic Arthritis Bagaimanakah Cara Untuk Membantu Anak Anda?

Apabila dimaklumkan bahawa anak anda mengalami arthritis memberi kesan yang besar kepada ibu bapa. Adakah memastikan bahawa anak anda yang mengambil ubat-ubatan yang ditetapkan dan melakukan pemeriksaan susulan secara kerap dengan doktor sudah mencukupi? Apakah lagi yang boleh dilakukan untuk menyediakan penjagaan holistik untuk anak anda?

## APAKAH JUVENILE IDIOPATHIC ARTHRITIS (JIA)?

Juvenil bermaksud artritis bermula sebelum kanak-kanak mencapai usia 16 tahun. Idiopathic bermaksud bahawa puncanya tidak diketahui. Artritis, apabila berlaku radang pada satu atau lebih sendi untuk tempoh sekurang-kurangnya 6 minggu.

## APAKAH YANG MENYEBABKAN JIA?

Badan anda mempunyai sistem imun yang melawan kuman dari luar tubuh untuk mengekalkan kesihatan anda. Kadang-kadang sistem imun badan melakukan kesilapan dengan menganggap bahagian tubuh yang biasa sebagai sesuatu yang asing (seperti kuman), dan mula menyerang badan itu sendiri. Dalam JIA, sistem imun menyerang sendi. Ini dipanggil proses auto-imun. Kita masih tidak memahami dengan tepat mengapa ini berlaku.

## APAKAH YANG PERLU DIKETAHUI OLEH IBU BAPA?

Dr. Tang Swee Ping, Pakar Perunding Pediatrik Reumatologi, Hospital Selayang menekankan, "Walaupun memantau ubat-ubatan dan membawa anak itu untuk pemeriksaan secara berkala adalah sangat penting, anda juga perlu memberi perhatian kepada aspek-aspek lain dalam menguruskan keadaan."

## TAPISAN UNTUK UVEITIS

Uveitis adalah keradangan pada bahagian mata, termasuk iris (bahagian mata yang berwarna) dan otot-otot dan tisu-tisu yang memberi tumpuan untuk mata. Keradangan disebabkan oleh proses auto-imun, sama seperti pada sendi. Jika uveitis tidak dirawat ia boleh membuat penglihatan menjadi kabur. Ibu bapa perlu sedar bahawa sesetengah kanak-kanak mungkin tidak dapat membezakan penglihatan mereka yang semakin kabur. Ini akhirnya boleh membawa kepada buta. Jadi adalah amat penting untuk menjadualkan pemeriksaan secara berkala dengan pakar oftalmologi (dokter pakar mata) untuk memeriksa keradangan pada mata.

## FISIOTERAPI

Ahli fisioterapi memiliki kepakaran dan mengetahui bagaimana sendi dan otot bekerja. Mereka akan memberikan anak anda latihan untuk menjaga pergerakan sendi mereka, terutama sendi yang terjejas, selain menguatkan otot mereka. Ahli fisioterapi juga boleh memberitahu anda tentang kaedah lain untuk melegakan kesakitan yang bekerja bersama-sama dengan ubat-ubatan yang diberikan.

- Pek air batu boleh melegakan sendi yang panas dan bengkak.
- Pek haba membantu melegakan otot yang letih dan kejang.
- Splin pada sendi yang bengkak atau sakit boleh membantu ketika serangan JIA meningkat.
- Senaman yang kerap juga menggalakkan penghasilan hormon yang melegakan kesakitan secara semula jadi (endorphins).
- Ahli fisioterapi boleh membantu anda merancang program latihan berjadual, yang bermula secara perlahan-lahan dan bertambah langkah demi langkah. Mereka juga boleh menasihati anda tentang peralatan atau latihan khas yang anda perlukan untuk bermula.
- Ahli fisioterapi mungkin mempunyai akses kepada kolam hidroterapi di mana anak anda boleh bersenam dalam air panas. Kanak-kanak suka bergerak di dalam air; kehangatan air sangat melegakan selain menyokong berat badan mereka dan kanak-kanak boleh menggerakkan sendi dan otot mereka dengan mudah.

## TERAPI PEKERJAAN

Ahli terapi pekerjaan boleh menawarkan splin atau sokongan yang ditempah khas yang boleh mengurangkan tekanan pada sendi yang sakit dan membantu mencegah kecacatan. Mereka boleh mengajar anak anda bagaimana untuk melindungi sendi mereka dengan melakukan tugas dengan cara yang berbeza daripada kebiasaan, seperti menggunakan kedua-dua tangan atau menggunakan alat bantuan.

Mereka juga menawarkan bantuan lain untuk aktiviti harian yang mungkin mencabar seperti memakai pakaian, menulis atau makan. Mereka juga memberikan cadangan pengubahsuaian di rumah atau sekolah untuk membolehkan kanak-kanak untuk menjalani kehidupan yang normal. Bantuan di sekolah mungkin termasuk menggunakan komputer jika mereka tidak dapat menulis. Alat bantuan membantu memaksimumkan keupayaan kanak-kanak untuk mengambil bahagian dalam aktiviti dengan selamat dan meningkatkan kualiti hidup mereka.



## PENJAGAAN GIGI

Sendi temporomandibular (TMJ) adalah sendi di hadapan telinga di mana rahang bawah dihubungkan ke pangkal tengkorak. JIA boleh menjejaskan sendi ini dengan cara yang sama seperti kesan kepada sendi lain dan menyebabkan kesakitan dan kekakuan pada rahang kanak-kanak. Ia juga boleh mengubah pertumbuhan di mana sebelah rahang tumbuh lebih cepat berbanding sebelah yang lagi satu. Ini boleh menyebabkan aktiviti memberus atau menggunakan flos gigi menjadi sukar.

Untuk mengelakkan ini, kanak-kanak mungkin perlu melakukan senaman rahang. Doktor gigi boleh mencadangkan jenis pemegang berus gigi, berus gigi elektrik, dan pemegang flos yang berbeza untuk membantu mengekalkan gigi dan gusi yang sihat.

Doktor gigi anak anda perlu tahu:

- Mengenai status JIA dan ubat-ubatan yang diambil oleh kanak-kanak, kerana ini juga boleh memberi kesan kepada keadaan kesihatan mulut mereka. Sebagai contoh, doktor gigi perlu tahu jika kanak-kanak telah menjalani penggantian sendi, kerana mereka mungkin memerlukan antibiotik sebelum membuat apa-apa rawatan pergigian.
- Kanak-kanak mungkin sukar untuk membuka mulut untuk rawatan gigi. Rawatan yang lebih kerap dan lebih pendek masanya mungkin boleh membantu.

## PEMAKANAN

### TIDAK BERSELERA MAKAN

- Sediakan hidangan kecil sepanjang hari pada masa-masa yang dijadualkan secara tetap kerana cara ini adalah lebih mudah daripada makan hidangan yang besar sebanyak tiga kali (contohnya, sarapan pagi, snek pagi, makan tengah hari, snek petang, makan malam dan pencuci mulut yang sihat).
- Galakkan anak anda untuk sekurang-kurangnya makan sedikit. Cuba gabungkan pelbagai makanan supaya mereka mempunyai pelbagai sensasi rasa. Berikan beberapa keping epal dengan anggur dengan sedikit yogurt atau mentega kacang.
- Pastikan makanan yang anda berikan kaya dengan nutrien. Jika anak anda menghadapi masalah untuk mengekalkan atau menambah berat badan, tambah lemak yang sihat seperti minyak zaitun dan avokado untuk meningkatkan kandungan kalori.
- Beri perhatian kepada pengambilan kalsium.
- Dapatkan nasihat doktor atau pakar diet berdaftar untuk menentukan sama ada anak anda boleh mendapat manfaat daripada makanan tambahan.

### SELERA MAKAN YANG TINGGI

- Galakkan anak anda untuk memenuhi sekurang-kurangnya separuh daripada pinggan mereka dengan buah-buahan dan sayur-sayuran. Buah-buahan dan

sayur-sayuran rendah kalori dan tinggi serat, yang membantu kanak-kanak berasa lebih kenyang dengan kalori yang kurang.

- Kehausan kadangkala boleh terkeliru dengan kelaparan. Pastikan anak anda terhidrat boleh membantu untuk menormalkan selera makan mereka.
- Galakkan anak anda minum air dan menghadkan minuman bergula seperti coke, pepsi, sprite dan lain-lain.
- Sertakan protein dan buah-buahan atau sayur-sayuran dalam setiap makanan ringan (ketulan soya dengan lobak merah kecil, epal dengan keju rendah lemak, yogurt rendah lemak dan buah-buahan, tauhu dengan lada benggala dihiris, telur dengan timun, salad dan salad tomato) untuk membantu anak anda berasa kenyang tanpa kalori yang berlebihan.
- Tidak menggalakkan makan tanpa mengira masa (membiarkan anak-anak makan apa sahaja dan pada bila-bila masa yang mereka mahu sepanjang hari). Ini boleh membawa kepada diet yang tidak seimbang dan/atau berkalori tinggi.



## SOKONGAN PSIKOLOGI

Sesetengah kanak-kanak yang disahkan menghidap JIA mungkin mempunyai gangguan dalam menyesuaikan diri dan seterusnya membawa kepada keyakinan diri yang rendah. Ahli psikologi dan psikiatri boleh membantu anak-anak dan keluarga mereka menguruskan perasaan mereka mengenai JIA, dan menangani kesakitan.

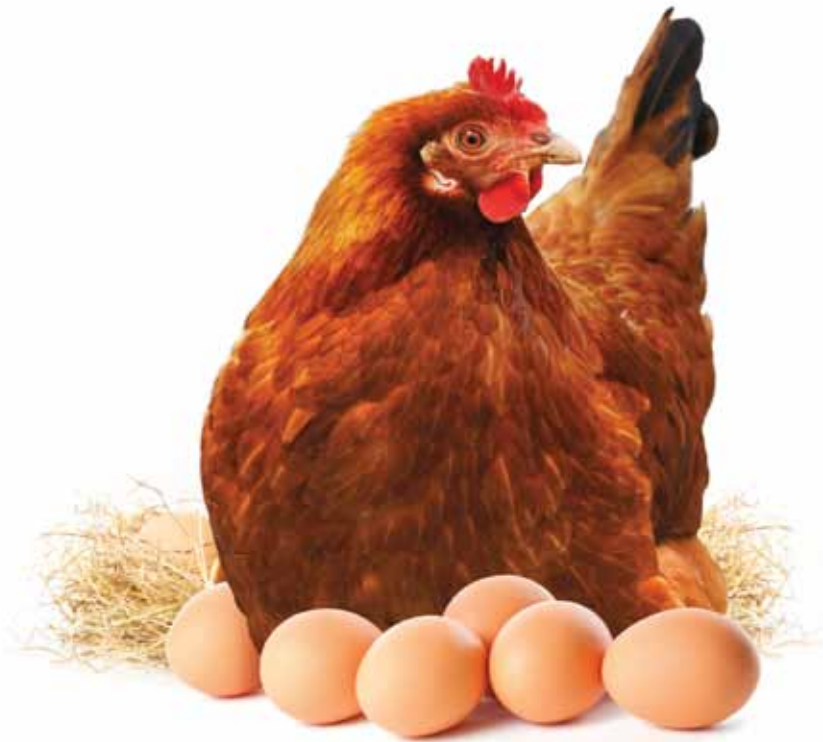
## KUMPULAN SOKONGAN

Menemukan kanak-kanak yang menghidap JIA dan membuat kawan antara mereka adalah sesuatu yang baik. Yayasan Arthritis Malaysia menyokong pesakit-pesakit kecil ini dengan mengadakan hari aktiviti yang menyeronokkan dan kem untuk kanak-kanak yang menghidap JIA supaya mereka belajar daripada usia muda tentang penyakit mereka dan diberi kuasa untuk menguruskan diri mereka sendiri apabila mereka membesar.

Bertemu keluarga lain yang mempunyai anak dengan JIA boleh menjadi pengalaman yang berharga untuk seisi keluarga. Ia boleh membantu untuk berkongsi idea dan pengalaman dengan keluarga lain dalam keadaan yang sama.

Jadi kekal berhubung dengan doktor anda, teruskan penglibatan anda bersama AFM dan sertai pelbagai aktiviti mereka dan memperkasakan diri anda dan anak anda dengan maklumat untuk menghadapi pelbagai aspek keadaan mereka dengan cara yang terbaik. Yang paling penting, libatkan seluruh keluarga untuk kekal aktif dan positif.

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**Kordel's**



一旦得知自己的孩子患上关节炎，父母心里的难受简直非笔墨所能形容。确定孩子每天按时吃药，也定时带孩子复诊，是不是就足够了？为了给孩子全面的照护，还有些什么是父母可以做的？

# 少年自发性关节炎 你应当怎样扶持孩子？

## 何谓少年自发性关节炎？

少年自发性关节炎（英文简称JIA），是指有关孩童在16岁之前就开始患上的关节炎。自发的意思是指病发原因不明，关节炎是指单个或多个关节已经发炎至少6个星期之久。

## 什么引起少年自发性关节炎？

人体里有一道免疫系统，能够打击入侵人体的细菌，维持人体健康。但是，当这免疫系统发生错乱，误把正常的身体部位当成外来物（比如细菌）的时候，就会开始行动，攻击有关部位。在少年自发性关节炎的情形里，是免疫系统在攻击关节。这就是自身免疫现象，我们至今仍不知道它发生的原因。

## 父母应该具备些什么知识？

士拉央医院小儿风湿科顾问医师邓瑞冰医生说：“监督孩子服药以及定期带孩子复诊固然重要。在此之余，父母在协助孩子管理这个疾病的时候，还需要注意到一些其他的方面。”

## 物理治疗

通晓关节和肌肉运作的情形，是物理治疗师的专长。他们会教导你的孩子做一些保持关节灵活以及增强肌肉的运动，尤其是专门为受影响关节所设计的运动。物理治疗师也会教导你其他舒缓疼痛的方法，在治疗上与药物互补互助。

- 用冰袋敷在红肿、发热的关节上会有舒缓作用。
- 热敷则能够使紧绷、疲惫的肌肉放松。
- 当自发性少年关节炎复发时，以副木夹着肿胀或疼痛的关节会有帮助。
- 经常运动也会刺激身体制造天然的舒缓疼痛荷尔蒙（内啡肽）。
- 他们会为你的孩子制定进阶式的运动计划，让孩子由简单的动作开始，慢慢提高难度。他们也会在特定器材的使用上给你指导，或告诉你该做些什么特别训练。
- 物理治疗师也会安排你的孩子到水浮力治疗池，让他可以在温水里做运动。孩童本性喜欢在水里活动；温暖的水会舒缓疼痛，水的浮力能支撑孩子的体重，那么他们就能够能够在关节不觉吃力的情形下活动关节和肌肉。

## 职能治疗

职能治疗师会为你的孩子定制副木夹板或支撑物，帮助减少疼痛关节的负担，避免关节变形。他们也会教导你的孩子怎样通过改变一贯做事情的方式，来保护关节。例如双手并用或使用辅助器具。

他们也能够提供辅助器具，让孩子可以轻松做到日常生活上有难度的动作，例如自己穿衣服、书写、甚至进食。为了要让患者可以尽量正常活动，家居或学校环境需要作一些改良的时候，职能治疗师也能够在这方面提供相关意见；学校方面可以提供的辅助之一，是上课时让无法做到手写的患者使用电脑来取代。通过使用辅助器具，患者安全参与活动的的能力得以提高，他们的生活品质也随之改善。

## 做预防葡萄膜炎检验

葡萄膜炎是指眼睛内多处发炎，发炎处包括虹膜(眼睛颜色部分)以及负责眼睛定焦的肌肉和组织。发炎的情况是因为自身免疫造成，就跟关节的情形一样。如果不加以治疗，葡萄膜炎会导致视线模糊。父母必须知道，有些孩子不大可能会察觉自己的视力正在渐渐模糊的事实，其结果是眼睛会失明。所以，定期带孩子给眼科医生做检验，看看眼睛可有发炎，是很重要的第一件事。



## 牙齿保健

颞下颌位于双耳前方、下颚与头颅骨下方连接的地方。少年自发性关节炎或许也会侵袭这个关节，引起颞部疼痛和僵硬；更甚者还会改变颞部的发育，造成两颞发育不一致，一边比另一边大。在颞部疼痛和僵硬情形之下，刷牙及使用牙线清理牙缝就会很难了。

为了避免这种情形发生，有关的孩童需要做点颞部运动。牙医也会建议使用一些专门牙刷握柄，或使用电动牙刷，或使用牙线器，来维持牙齿及牙龈健康。

你孩子的牙医对以下事情应该要了解：

- 孩子的病情以及所服用的药物，因为这些都会影响孩子的口腔健康。例子：如果孩子曾做过关节置换，牙医在做任何牙科手术之前，都需要先给孩子一些抗生素做准备。
- 孩子很难长时间张开口，所以将原本较冗长的检查，分作几次简短检查会比较合适。

## 心理上的扶持

有些确诊患上少年自发性关节炎的孩童会对自己的情况难于适应，结果变得缺乏信心。心理医师及精神科医师能够帮助这些孩子与家人调节心情，适应患病后的生活，以及教导他们如何处理疼痛。

## 营养

### 食欲不振

- 在固定的时间间隔里让孩子小量进食。对孩子来说，这会比三餐大量进食来得容易(比如分成早餐、上午小点心、午餐、下午小点心、晚餐、健康甜点)。
- 鼓励孩子每一餐至少吃上几口。为孩子准备不同种类的食物，让他尝尝不同的口味。例如吃优格乳时可以加入几片苹果、几粒葡萄，还有一点点的花生酱。
- 确定自己给孩子吃营养丰富的食物。如果孩子老是不长肉或容易消瘦，那就在饮食中加入健康脂肪，如橄榄油或酪梨，来提高饮食热量。
- 要注意饮食中的钙质含量。
- 给孩子服用营养补品之前，可以先向医生或合格营养师咨询，确定有帮助才进行。

### 胃口奇佳

- 鼓励孩子多吃水果和蔬菜，因为它们高纤维、低热量。如果用餐时餐碟上有一半是水果蔬菜，孩子就容易饱足且不会吃下太多热量。
- 孩子很容易将口渴和饥饿混淆。确定孩子每天喝足够的水，可以帮助他的食欲恢复正常。
- 鼓励孩子多喝水的同时，也限制他喝含糖饮料，比如果汁和可乐等汽水。
- 每次吃的小餐点里头，都要包含蛋白质和水果蔬菜(例如：豆筋配小红萝卜、苹果配低脂乳酪、低脂优格乳配水果、豆腐配灯笼椒片、鸡蛋黄瓜、生菜番茄沙拉)，帮助孩子容易饱足，同时不会吃下太多热量。
- 不放任孩子胡乱吃东西(随时随刻想吃什么就吃什么)，这会导致营养失衡及/或吃下太多热量。

## 互助小组

让同样是患上少年自发性关节炎的孩童们聚在一起互相玩乐，建立感情，对他们非常有益。大马关节炎基金会定期为这群孩子举办康乐活动日以及生活营，帮助他们从小就了解自己的疾病，随着年龄的增长学会懂得怎样管理病情。

有机会跟其他病童的家人见面共处，是难得的机会，也会给自己家庭带来正面作用。家里同样有关节炎孩子的家人们，可以借此机会互相交换面对此疾病的心得和经验。

经常和孩子的医生保持联系，经常参与大马关节炎基金会的各项活动，让自己和孩子共同吸取相关资讯，学习更加有效面对患病的各种情况。说到底，全家人共同参与，一起保持活跃和维持积极心态，才是最为重要的。



# Noshini's story: One family's journey with JIA

Being diagnosed with arthritis at any point is challenging, but to have a child diagnosed at a tender age of 3 turned one family's life around into a testament of dedication and determination.

**N**oshini was only 3 years old when she was first diagnosed with arthritis. Her mother Rajamah recalls, "She had been having fever intermittently for about two weeks. My mother, who was looking after her at that time, also noticed that she had some discomfort in one knee as when she woke up in the morning, she would drag her leg as she walked. On closer examination we realized that there was some swelling in her knee." But they were still not prepared when the pediatrician, after doing a blood test and X-ray, said she had juvenile arthritis. Her father, Saravanan says, "We were shocked as nobody in our family, including Noshini's grandparents had arthritis. In fact, Noshini's great-grandmother is 95

years old and still very healthy! Was it something we ate? Medication? Air? How could this happen?"

The pediatrician immediately referred them to Dr. Tang Swee Ping at Hospital Selayang, who at that time was the only trained pediatric rheumatologist in the country. It has been a long journey since that fateful diagnosis. Today, almost a decade later, Noshini, 13, is a bright, cheerful and active child whose arthritis is well controlled. In fact, at her last reading, her blood level readings were normal. And the credit goes completely to her dedicated parents and committed team of doctors who have stood by her every step of the way.

## THE DEDICATED APPROACH

**FAITH IN THE DOCTORS:** In my conversation with Noshini and her parents several aspects stood out. First, that they had complete faith in their doctors and followed their instructions to the tee.

**LOG BOOK:** Another aspect that stands out was their meticulous approach to Noshini's treatment plan. Saravanan proudly displayed his "log book" where every single doctor's visit; from the very first visit ten years ago, to the last one a week before our interview and every single medication prescribed, has not just

been noted in detail but also signed and attested by the doctors at the end of each visit!

**EYE HEALTH:** As there is always the risk of developing uveitis (eye inflammation), and in Noshini's case cataracts (a clouding of the eye's natural lens), due to long term steroid usage, she has an eye check-up scheduled every year.

**PHYSICAL ACTIVITY:** From the age of 7, Noshini has been having a physiotherapy session every month as initially she had trouble bending the affected knee to squat. Her parents encouraged her to be active and play sport. Says Saravanan, "When she cycles, I jog alongside her. Whenever she has no tuition or other activities, I encourage her to be active. Besides cycling she also plays badminton once a week. She also has a session with the occupational therapist once a month where she works with soft balls, terra band etc.

**NUTRITION:** On the doctor's advice, she has a diet with lots of fruits and vegetables every day and her junk food intake is monitored. Because of her medication, Noshini had gained weight. So they had to be very particular about her diet and exercise to manage it.

**MEDICATION:** For many years Noshini was on Methotrexate and steroids. She had to cope with the side effects of that which included weight gain, nausea and tiredness. She also had to deal with taking her injections every two weeks. Two years ago she shifted to biologics, which is also administered through an injection every two weeks. This has helped her tremendously. Her weight has normalized and her energy levels have improved as her tiredness and pain has reduced.

Concludes Saravanan, "We are very proud that despite having to take strong medication everyday and cope with its side-effects, she got 5A's in her UPSR exams. We would like to express our deepest gratitude to Dr. Tang Swee Ping, Dr. Lim Sern Chin and Dr. Cham Weng Tarn for their dedicated care all these years. Their support has been invaluable." 📍



"There were many people who offered us unsolicited advice; from drinking energy juices to taking vitamins and supplements that boosted immunity to trying alternative therapies like ayurveda and other massage treatments. But we stubbornly stuck with our doctor's advice and always referred back to her when we came across any information." Saravanan, Noshini's father





## Living with JIA

“I worry about whether they would treat me differently if they knew about my condition. I worry about having a boyfriend in the future. Will I find a man who will love me enough to accept my condition? Are marriage and children on the cards for me? I guess only time will tell.”

While for most young girls, sixteen is a carefree and fun age, it was when Alice experienced the chilling early symptoms of arthritis. Several years later now, she is still struggling to come to terms with the ramifications of being diagnosed with rheumatoid arthritis.

**A**lice 23, was diagnosed with JIA when she was 16. One morning she found her wrist very painful and swollen. Alice says, “I found that I could not do simple things like brush my teeth and open doors. It was very bewildering and scary.” The next day she went to see the doctor to do a blood test and X-ray. She was given medication to reduce her inflammation and a painkiller. It helped her and the pain gradually eased.

A year later, at the age of 17, the symptoms reappeared. This time, she was referred to a rheumatologist and she was diagnosed with rheumatoid arthritis. Though her rheumatoid factor was negative, her diagnosis was based on her symptoms and tests like the MRI and ultrasound that showed slight erosion in her wrist joints. She recalls, “At that time, I didn’t really understand what it meant; that it was a lifetime condition and that at this point there is no cure. So I was naively positive. **But with time, when I understood that it was chronic, that it could actually get worse, my spirits began to drop. There were many days when I would be anxiety-ridden and worry endlessly about the future but then I would pick myself up and remind myself to take it day by day.**”

She has been on Methotrexate since and goes for regular check-ups every three months. She feels an occasional slight swelling on her ankles and worries whether the RA is spreading. She’s been going for physiotherapy too; where they use ultrasound and then exercise her wrists by working with weights and bands. This helps to reduce inflammation, strengthen and keep them mobile.

During college, she did have some flare-ups and she noticed that stress was actually a huge trigger. She says, “While in college, there was this one subject that I didn’t like, and before that exam I always had a flare-up of pain! Also drinking coke and some other aerated drinks causes a flare-up. Slowly I became more sensitive to what caused flare-ups and learnt to manage my condition.”

### FINANCIAL CHALLENGES


As a young adult now, there are challenges that she faces on many fronts, the most pressing being financial. All these years, her medical bills at a private hospital were covered by her mother’s company. But not being a child anymore, she is not covered any longer. On the work front, as she was applying for jobs, the dilemma she faced was whether to reveal her condition to her prospective employers. The hesitancy

was because she was concerned that revealing her condition would actually work against her favor in landing a job. Ultimately, being her first job, she chose not to disclose her condition. But only a few weeks into the job now, she is already worried about being able to juggle her doctor’s appointments with work schedules and manage her pain if it flares up due to work pressure without support and understanding of the company.

She is also very concerned whether she can get any medical insurance to cover her bills as her condition started so early. Says her mom, who was also with her at the time of this interview, “As a parent, you are always worried about your child, especially as this is a condition that could get worse with time. You want them to have access to good medical care.”

### SOCIAL RAMIFICATIONS

Then there are the social ramifications. So far, she has not discussed her condition except with a very close friend as, says Alice, “I did not want to be seen and treated differently among my peers because of my condition.”

Though there are some days when she feels overwhelmed, Alice focuses on staying positive and doing the best she can under the circumstances. Says Alice, “I really hope they will find a cure for arthritis in the future.” 

*\* The name has been changed to protect the privacy of the person.*

# Alkaline Water Relieves Gout

In this age of connectivity that we live in, there is no shortage of information that flows towards us, solicited or otherwise, from both well-meaning family and friends and strangers on the internet. The challenge, according to Consultant Rheumatologist Dr. Amir Azlan Zain, “Is to intelligently sift through the information, separate fact from fiction and seek information that is clearly backed by scientific evidence as opposed to mere hearsay.”

Some of you must have come across marketing claims from either friends or the internet that alkaline water can increase your energy, hydrate you better than regular water, prevent digestive issues, slow aging and eliminate pain associated with gout! But before you run out to buy anything, it is important to know that such claims have not been

properly tested in controlled scientific studies, and some even run counter to what science tells us about the body.

## WHAT IS GOUT?

Gout is a type of arthritis. It is caused by a build-up of a substance called uric acid in the blood. If your body produces too much uric acid or your kidneys don't filter enough out, it can build up and cause tiny sharp crystals to form in and around joints. These crystals can cause the joint to become inflamed (red and swollen) and painful.

Gout is usually treated with medications such as non-steroidal anti-inflammatory drugs (NSAIDs), colchicine or corticosteroids. Lifestyle changes, such as losing weight or changing your diet, and taking medication that lowers uric acid levels, such as allopurinol are recommended.

## WHAT IS PH?

pH stands for power of hydrogen, which is a measurement of the hydrogen ion concentration in the body. The total pH scale ranges from 1 to 14, with 7 considered to be neutral. A pH less than 7 is said to be acidic and solutions with a pH greater than 7 are basic or alkaline.

## Air Alkali Meringankan Gout

Dalam dunia yang sentiasa terhubung seperti sekarang, kita menerima pelbagai jenis maklumat melalui internet, sama ada yang diminta atau sebaliknya, daripada ahli keluarga, sahabat handai malah orang yang tidak dikenali. Cabaran kita, menurut, Pakar Perunding Reumatik Dr. Amir Azlan Zain, “Adalah untuk menapis maklumat secara bijak, memisahkan fakta daripada fiksi dan mendapatkan maklumat yang jelas disokong oleh bukti saintifik, dan bukannya oleh khabar angin semata-mata.”

Mungkin ada antara kita yang pernah mendengar dakwaan pemasaran sama ada daripada rakan-rakan atau melalui internet bahawa air yang beralkali boleh meningkatkan tenaga, menghidratkan dengan lebih baik berbanding air biasa, mengelakkan masalah pencernaan, melambatkan proses penuaan dan menghapuskan kesakitan yang dikaitkan dengan gout! Tetapi sebelum anda membuat keputusan untuk membeli apa-apa, anda perlu tahu bahawa tuntutan ini masih belum diuji dengan betul dalam kajian saintifik yang terkawal, malah ada dakwaan yang bertentangan dengan apa yang sains memberitahu kita tentang badan.

## APAKAH GOUT?

Gout adalah sejenis arthritis. Ia disebabkan oleh pengumpulan bahan yang dipanggil asid urik dalam darah. Jika badan anda menghasilkan terlalu banyak asid urik atau buah pinggang anda tidak menapisnya dengan cukup, ia boleh terkumpul dan menyebabkan kristal kecil yang tajam terbentuk di dalam dan sekitar sendi. Kristal ini boleh menyebabkan sendi menjadi radang (merah dan bengkak) dan menyakitkan.

Gout biasanya dirawat dengan ubat-ubatan seperti ubat anti-radang bukan steroid (NSAID), colchicine dan kortikosteroid. Perubahan gaya hidup seperti mengurangkan berat badan atau menukar diet anda, dan mengambil ubat-ubatan yang merendahkan tahap asid urik, seperti allopurinol adalah disyorkan.

## APAKAH PH?

pH bermaksud kuasa hidrogen atau power of hydrogen, yang merupakan ukuran kepekatan ion hidrogen dalam badan. Jumlah skala pH adalah antara 1 hingga 14, dengan 7 dianggap sebagai neutral. pH kurang daripada 7 dikatakan berasid dan larutan dengan pH lebih daripada 7 adalah beralkali.

**Menurut Dr. Amir Azlan Zain, “Minum air alkali tidak melegakan gout. Sebabnya mudah. Perut mengandungi cecair gastrik berasid kuat**



According to Dr. Amir Azlan Zain, "Drinking alkaline water does not relieve gout. The reason is simple. The stomach contains strong acidic gastric fluid that neutralises any alkaline that enters it. In any case, the regulation of the body pH is very tightly controlled and there is no physiological mechanism by which drinking alkaline water would make the blood more alkaline."

The idea that 'uric acid' is therefore 'neutralised' by alkaline ingested is an extremely simplistic view of human physiology. The only way to reduce blood uric acid is to either eat less purines or take medications.

What we must know is that unless we have certain conditions such as kidney or respiratory disease, our body maintains a healthy pH balance on its own. Our bodies are wonderful machines and can correct imbalances naturally. For example, if our blood becomes too acidic, we breathe out more carbon dioxide to bring down the levels. But hydration is crucial for health. However, stick with plain water.

***The pH range that our bodies operate on is extremely narrow; pH 7.35-7.45 and anything outside of this range very quickly kills people. Thus the mechanism for neutralising anything can potentially cause harm to the body.***

**yang meneutralkan apa-apa bahan alkali yang memasukinya. Tambahan lagi, pH badan dikawal selia secara ketat dan tidak ada mekanisme fisiologi seperti meminum air alkali boleh membuat darah lebih alkali.**

Idea bahawa 'asid urik' boleh 'dineutralkan' oleh alkali adalah satu pandangan fisiologi manusia yang amat mudah. Satu-satunya cara untuk mengurangkan asid urik dalam darah adalah sama ada mengurangkan memakan purina atau dengan mengambil ubat-ubatan.

Apa yang kita perlu tahu ialah bahawa jika kita tidak mempunyai keadaan tertentu seperti sakit buah pinggang atau pernafasan, badan kita akan mengekalkan keseimbangan pH yang sihat dengan sendiri. Badan kita adalah mesin yang indah dan boleh membetulkan ketidakseimbangan secara semula jadi. Sebagai contoh, jika darah kita menjadi terlalu berasid, kita bernafas keluar lebih banyak karbon dioksida untuk menurunkan tahap ini. Tetapi penghidratan adalah penting untuk kesihatan. Walau bagaimanapun, teruskanlah dengan meminum air kosong.

***Julat pH tubuh kita adalah amat sempit; pH 7.35-7.45 dan apa-apa di luar julat ini membunuh manusia dengan. Oleh itu sebarang mekanisme untuk meneutralkan tubuh boleh mendatangkan mudarat.***

## 碱性水能够缓和痛风

**在**今天这个通讯发达的时代，资讯随处可得，每天接收的讯息不会少，来源有自己搜索的，或来自亲朋好友，甚至网上善意的陌生人不等。风湿科顾问医师阿米尔医生指出，面对大量资讯时的最大挑战就是“该如何利用智慧好好将资讯过滤，区分真实与虚构，只相信有科学根据的事实，不轻信人云亦云者。”

来自朋友或网上的不少行销诉求都说碱性水能够增加你的能量，比普通水更加能够滋润人体，能预防消化问题，能减缓老化，还有能够消除痛风的疼痛！在你决定购买任何水机之前，你必须知道这类说法都没有真正经过受管控的科学研究来证明，当中有些说法甚至跟科学事实天差地别。

### 什么是痛风？

痛风是一种关节炎，它由血液内累积的尿酸所引起。当身体制造了过多尿酸，而肾脏又无法有效将它们过滤出去时，它们就会累积并在关节内部和周边形成细小尖锐的晶体。这些晶体会引起关节炎（红肿）和疼痛。

痛风一般是经由药物来治疗，如非类固醇消炎药、秋水仙碱或可的松类固醇，医生也建议患者调整生活习惯，例如减重或改变饮食、服用降低尿酸的药物，例如别嘌醇。

### pH是什么？

pH代表氢的强度，是用来显示人体内氢离子浓度的指标，亦称为酸碱值。pH或酸碱值的级别排列由1至14，7为中性。低于7的是酸性，高于7者为碱性。

**阿米尔医生指出：“饮用硷性水并不会缓和痛风。理由很简单，人的胃里有很强的胃酸，任何硷性物质进入其内都会被它中和。无论如何，人体有管控严密的酸碱平衡机制，通过饮用硷性水这样的生理作用，是不会令血液变得更硷性的。”**

喝下碱性水就可以中和尿酸的说法，是对人体生理很表面的看法。减少血液里尿酸含量的唯一法子就是服用具备以下功能的药物。

我们必须明白，除非我们患有某些疾病，例如肾脏疾病或呼吸道疾病，不然身体是会自行保持在一个健康的酸碱值的。人体是一台奇妙的机器，它会自然而然的进行调和，改正失衡。举个例子，如果血液酸性太高，我们会呼出较多二氧化碳，降低酸度。

吸取足够水分对维持健康身体很重要，在这一点上，喝普通的水就可以了。

**人体正常操作时的pH酸碱值区限很狭窄：pH 处于7.35至7.45之间，任何超出此范围的酸碱值会很快使人丧命。有鉴于此，凡是欲硷化人体的动作都会给人体带来潜在的伤害。**

# Take Charge Of Your Diet

**W**hat is inflammation? Do you know that eliminating certain foods

from your diet can reduce inflammation in your body? Dr. Shyama Nair, a yoga teacher and a passionate advocate of healthy eating based in the US, shares why our gut is so important and hence the food we eat.

## WHAT IS INFLAMMATION?

Inflammation is part of the body's natural defense system. Pain, swelling, redness, and heat classically signify inflammation. When our bodies sense foreign invaders, a specific cascade of events is set off in which our white blood cells and some special chemicals called cytokines mobilize to protect us. However, when the immune system shifts

out of balance, inflammation can run rampant causing a chronic condition in the body that could lead to disease and weight gain.

## SO WHAT CAUSES INFLAMMATION?

According to Dr. Mark Hyman, "The sugar you eat, high doses of the wrong oils and fats in your diet, hidden food allergens, lack of exercise, chronic stress, and hidden infections all trigger a raging, unseen inflammation deep in your cells and tissues.

While everyone is different, there are some foods that irritate the immune system more than others. They are gluten (wheat, barley, rye, oats, spelt, kamut), dairy (milk, cheese, butter, yogurt), corn, eggs, soy, nuts, nightshades (tomatoes, bell peppers, potatoes, eggplant), citrus, and yeast (baker's yeast, brewer's yeast, and fermented products)."

## FOODS THAT FUEL INFLAMMATION

Dr. Shyama, explains that eliminating certain foods from our diet can help reduce inflammation in our bodies.

- Processed foods
- Adulterated, refined, diluted, sweetened, salted
- Dairy is considered

very inflammatory as cows are fed with growth hormone and antibiotics to keep healthy

- Sugar and any forms of artificial sweetener
- Vegetable oils like corn, canola and soy are high in Omega 6's and convert into trans fats when heated at high temps
- Tropical fruits too are high in sugars that convert into pure fructose
- Refined grains like GMO wheat and corn are inflammatory

## SO WHAT CAN WE EAT?

- Anti-inflammatory foods include grass fed meats, organic dairy and poultry and non farmed fish
- Good oils like coconut oils, unheated olive oil and avocados
- Vegetables, beans and legumes, mushrooms
- Fruits like berries, apples, pears and nectarine are recommended as they have a low-glycemic index. Pears, apples and nectarines are now considered inflammatory because unless organic they contain high concentration of pesticides!
- Nuts (in limited portions) and seeds
- Organic eggs

So why should we reduce inflammation?

Dr. Mark Hyman, Director of Functional Medicine Clinic at Cleveland Clinic and an eight-time #1 New York Times bestselling author says, nearly every modern disease - from autoimmune diseases, heart disease, and cancer to obesity, diabetes, and dementia - is caused by inflammation!

## SOME GUT FACTS: THE NEXT BIG THING: MICROBIOME

Did you know that

# 70%

of our immune system resides in our gut. We have 10x's the no of microbes as cells in our body which live in communities that live in symbiosis with us and are collectively called the microbiome.

The microbiome has

# 100x's

more DNA than we have cells and the DNA of the microbiome and our cells talk to each other.

The microbiome consists of

# 3<sup>1</sup>/<sub>2</sub>-4<sup>1</sup>/<sub>2</sub> lbs

of bacteria that are responsible for our immune functions.

The gut is referred to as the

# 2nd Brain

because even if the vagus nerve is cut it can still function on its own through the enteric nervous system.

# 80-90%

of serotonin is manufactured by the gut.

## MY STORY-RELIEF FROM RA PAIN

I am a 57 year old woman suffering from Rheumatoid Arthritis for the past 26 years. My first symptoms appeared when I was only 31 years old. Pain, stiffness, swelling, redness in the joints were part of my daily life. In time the pain spread to my shoulders, fingers, knees and ankles. I was on potent allopathic medications. Biologics were very new at the time, but I took methotrexate and liquid gold injections, both of which did not suit me. I reacted with a bad rash.

In April 2014, while on a holiday to my sister's place in North Carolina, I happened to meet her friend, Shyama; a health advocate, and a yoga teacher. When I told her my story, she suggested I try 4 things:

- A gluten-free diet;
- A dairy-free diet;
- A diet free of refined sugars; and
- A diet free of processed foods.

I thought about it for a few days and decided to give it a try. What did I have to lose? My pain level on a scale of 1 to 10 was constantly between 8 and 10 in spite of being on Celebrex, Prednisone (a steroid), Ultracet, Gabapentin, Methotrexate and Cymbalta (an anti-depressant). At that point, my fingers were a bit deformed, my ankles had turned away from each other, my gait was hugely affected, my back stooped as my shoulder joints hurt if I sat straight, and my hips were slowly being affected too.

I came home to Phoenix on May 1st and started my gluten-free diet right away. Although I greatly missed my pasta and breads, I persisted on my diet. By mid-July, I noticed a tremendous reduction of pain in my joints. I was able to go for walks, use my hands to pursue my crafting hobbies, and generally had more energy to do chores around the house. I went from being a couch potato to an active human being. And best of all, my pain level was down to 3 to 5 on a constant basis!

At this point I started to introduce a dairy-free regimen to my diet. After a couple of weeks, I started to feel even better. I was able to grocery-shop, stand for a long time while cooking, and clean without any pain. Generally I avoid buying processed food. Getting off refined sugars is a challenge for me but I have greatly reduced the sweets I consume.

### Daily Diet

My diet consists of a lot of vegetables and fruit. I make smoothies with almond or soy milk and drink them in between meals if I feel hungry. My breakfast consists of gluten-free cereal with banana and a cup of tea with almond milk. For lunch I make rice or quinoa, some lentils and a vegetable curry. For dinner, I just have a bowl of fruit mostly berries during the season. If I crave dessert, I have a couple of dates with walnuts or almonds, or some figs.

My life has changed so much for the better. It is such a relief that I'm not going to be in a wheelchair and dependant on others. I am still on some medication (disease modifying anti rheumatic drugs- DMARDs), but no biologics or steroids.

If you are suffering from severe pain, whether it is RA or OA, Gout, or Crohns, or any form of auto-immune disease, I would urge you to try a gluten-free diet for at least six months. PLEASE give it a shot what do you have to lose, but PAIN!

# Kids Get Arthritis Too!



**Dr. Vim** at Physio Plus shares expert advice and valuable information on dealing with kids with arthritis.



**P**hysiotherapy helps treat the physical effects of JIA; such as pain, weakness, limited range of motion, or reduced physical ability.

Exercise routines improve muscle strength and flexibility, reduce joint stiffness and boosts overall fitness.

## SPLINTS AND ORTHOSES

If your child complains of painful joints and swelling, there is most likely inflammation and the joint needs to be rested. A splint or orthosis to support and rest the part is beneficial. Orthoses are usually custom made and can provide great relief from pain. However, they need to be removed periodically to perform passive exercises to ensure that muscle length is maintained. Otherwise the child will develop stiffness due to shortening of tissue structures.

## STRETCHING

Applying heat treatment before exercises, especially stretching exercises, will increase the efficiency of the exercises. Stretching involves gently assisting the muscles and ligaments reach their maximum possible length by way of passive and assisted active movements. It is of utmost importance that your physiotherapist is sensitive to the child's needs and is able to create a working relationship with him/her.

## EXERCISES – YES, THEY CAN!

Perhaps the most important thing to know about exercise for children

*The heart gladdening news is that studies have demonstrated that these conditions improve with exercises. Aerobic and anaerobic capacity can be enhanced with exercises. Allowing your child to train with weights can increase muscle strength and endurance. Children with JIA also respond better to exercise therapy compared to adults with arthritis.*

with JIA is that it does no harm. They can exercise and they should. Exercise has benefits for adults and this is a well-researched fact. However the benefits can be even greater for children with arthritis and it is very important for them to keep moving.

## CHILDREN WITH JIA HAVE THE FOLLOWING PHYSICAL ISSUES:

- 1. Decreased muscle strength and muscle endurance.** This is the capacity of the muscle to maintain its performance for a longer period. So they tend to tire easily.
- 2. Reduced aerobic capacity when doing aerobic activity.** An aerobic activity is one that requires

oxygen exchange in the blood to a greater degree than other activities. For example; running and dancing. So their ability to maintain a certain level of aerobic activity for a prolonged length of time is compromised.

### **3. Decrease in anaerobic capacity.**

Anaerobic capacity is required for children to perform intense bursts of activity. Most daily activities performed by children are anaerobic in nature. Physical skills required in anaerobic activity like batting, throwing a ball, short runs are some examples that require anaerobic capacity.

All these effects can be felt even when the disease is inactive.

## SOME RECOMMENDED ACTIVITIES FOR CHILDREN WITH JIA



### SWIMMING & AQUATIC THERAPY

Performing exercises in a warm swimming pool helps to increase muscle tone. It can be done either individually or in a group environment and it is safe, fun and beneficial for children and teens. Water buoyancy helps support the body and joints and can be used for assistive and resistive therapy movements.



### TAI CHI

Tai Chi involves a number of movements in a flowing sequence.

They are performed slowly and gracefully with smooth transitions in between movements. The movements have a calming effect and can also help the child or teen to relieve stress and improve inner harmony. Tai chi is a good alternative to competitive sport.

Children who are daunted by these challenges can be drawn to the gentle movements of tai chi which deliver similar benefits in exercise and health without the challenge of competition.



### YOGA

Yoga postures help to strengthen their muscles, makes them more flexible, builds coordination and balance in the bodies and improves their sleep. Breathing practices enable them to be more focussed and attentive, relieves the tension in their minds and thus helps manage their stress. It also boosts their self-esteem and confidence.

## STRATEGIES THAT HELP MANAGE PAIN FROM JIA



### KEEP YOUR CHILD MOVING

- Everyone gets stiff when they stay in one position for a prolonged period of time. Remind your child to change position frequently during quiet activities like watching television or studying. This may mean getting up and moving around 2-3 times per hour for a few minutes, or simply changing activities briefly.

### BUILD-IN REST BREAKS

- Remind your child to take regular short breaks during physical activities.
- This eases joint pains so that children can continue to participate. Playing until your child is worn out may cause further pain and make them too tired to attempt other activities.

### USE HOT OR COLD PACKS

- Heat or cold pack can ease joint pain.
- Use a hot water bottle, or a hot or cold pack wrapped in a towel. Cold treatment is used for analgesic and vasoconstriction purposes in acutely inflamed joints during the acute period. It can be applied for 10 to 15 minutes, but needs to be monitored

closely for adverse reactions. When applying a cold pack, preferably apply some moisturising lotion/oil to make therapy comfortable.

- Some redness called a hyperemic reaction due to increased blood flow can be seen on the skin which is normal.

### CONTRAST THERAPY

- Some children may not prefer cold so you can alternate between warmth and cold therapy. This results in a fluctuation in blood supply to the affected joints. Increasing and decreasing the blood supply helps reduce pain and inflammation

### GENTLE SOFT TISSUE MASSAGE

- Massage can relieve pain and prevent adhesions in the subcutaneous tissues. It is applied with heat treatment generally before stretching exercises. It has been shown to reduce anxiety levels in the child, reduce pain and induce better sleep.

### ELECTRICAL MUSCLE STIMULATION

- Short-term electrical stimulation is useful in children with excessive muscle atrophy and in whom muscles have a very feeble contraction. The low frequency currents helps retrain muscle movement.

### MAINTAIN A HEALTHY WEIGHT

- It is important to keep the child or teen within the normal limits of height/weight ratio and reduce the stress on weight-bearing joints.

**I have come across parents who are anxious that their kids do well at school, or at play. Despite the child having fever and joint pains, they insist that the child walk "like the other kids of your age", or say things like "you are just being lazy".**

**As parents, we can get stressed by the needs of the system and the challenges of this competitive world. We must understand that children do not really know what it is to be lazy. They run, rush about, tumble and stumble in their haste to explore and learn life itself. Every day is a new discovery. So when a child says, "Mummy I am tired", he or she actually means it. Take the child seriously. Give them a break, cuddle them and offer words of comfort.**

By Dr. Sargunan Sockalingam

## HOW MUCH DO YOU KNOW ABOUT ARTHRITIS? TAKE THIS QUIZ AND CHALLENGE YOURSELF.



**1. Kathleen Turner, Lucille Ball, James Coburn, Edith Piaf and Paul Auguste Renoir are famous personalities who were all diagnosed with**

- A. Autism
- B. Lactose Intolerance
- C. Excessive happiness
- D. Rheumatoid Arthritis

**2. The hospital designed by Patch Adams is called**

- A. Hospital Happy
- B. General Hospital
- C. Institute of 1 Medical Doctors' Board
- D. The Gesundheit Institute

**3. Dr Christiaan Barnard of South Africa had Rheumatoid Arthritis. He is credited with**

- A. Generous donations to Malaysia
- B. Banning news portals in South Africa
- C. Performing the world's first heart transplant
- D. Rejuvenating Batman as a movie franchise

**4. One of the following is rumored to have curative properties in arthritis**

- A. Turmeric
- B. QuPutih
- C. Bauxite
- D. Oil palm leaf

**5. This important drug for treatment of RA was recently out of stock in Malaysia**

- A. Marijuana
- B. Methotrexate
- C. Mesenchymal stem cell
- D. Magic Vape

**6. \_\_\_\_\_ is the best medicine**

- A. Theocracy
- B. Public caning
- C. Laughter
- D. A large donation

**7. The latest medicine for RA that has reached Malaysia is known as**

- A. Spectre
- B. Moolah
- C. Small Molecule
- D. Biologic

**8. Experts in movement and function, who work in partnership with their patients to overcome movement disorders are called**

- A. Politicians
- B. Physiotherapists
- C. Religious enforcement officers
- D. Hypnotherapists

**9. A flowing current is what the Greeks call**

- A. Cardio
- B. Nephron
- C. Artho
- D. Rheuma

**10. The official magazine of the Arthritis Foundation Malaysia is called**

- A. Utusan Malaysia
- B. The Malaysian Outsider
- C. The Sabah Report
- D. Joint Efforts

## ANSWERS

**1 D** Rheumatoid arthritis. It is an autoimmune disease that causes inflammation in your joints. The main symptoms are joint pain and swelling.

**2 D** The Gesundheit Institute. It is a non-profit healthcare organization that was started by American physician Patch Adams, best known for his work as a medical doctor, social activist and a clown.

**3 C** On 3rd December 1967, South African doctor, Dr. Christiaan Barnard, performed the world's first human

to human heart transplant in Grootte Schuur Hospital, Cape Town.

**4 A** Turmeric. The main active ingredient in turmeric, curcumin, is supposed to have powerful anti-inflammatory effects and be a very strong antioxidant.

**5 B** Methotrexate. It is one of the most effective and widely used medications for treating rheumatoid arthritis (RA) and other inflammatory types of arthritis.

**6 C** Laughter. But we also accept D A large donation

**7 C** Small Molecule. Development in drugs has more recently included the area of small molecules; of small molecular weight that share highly potent biological action targeting cellular structures and intracellular signalling proteins.

**8 B** Physiotherapists

**9 D** Rheuma. Rheumatology is a subspecialty devoted to diagnosis and therapy of rheumatic diseases.

**10 D** Joint Efforts



# Cost Burden of Rheumatoid Arthritis & The Role of Biosimilars

RHEUMATOID ARTHRITIS (RA) IS A CHRONIC PROGRESSIVE ILLNESS THAT IS ASSOCIATED WITH SIGNIFICANT DISABILITY AND LONG-TERM TREATMENT. RECENTLY, WE MET UP WITH DR. CHOW SOOK KHUAN, A CONSULTANT RHEUMATOLOGIST FROM SUNWAY MEDICAL CENTRE, TO TALK TO US ABOUT THE ECONOMIC IMPLICATION OF THE DISEASE AND HOW BIOSIMILAR DRUGS CAN BE A POTENTIAL COST-SAVING ALTERNATIVE FOR PATIENTS IN NEED OF BIOLOGICAL THERAPY.



Dr Chow Sook Khuan  
Consultant Rheumatologist  
Sunway Medical Centre  
Selangor

This article is  
contributed by

**LF** ASIA

## BURDEN OF DISEASE

RA places a significant financial burden on the patient, family, society and the healthcare system. This burden can be measured in terms of direct and indirect costs.

Direct costs refer to the amount of money spent for medical care, such as outpatient visits, laboratory tests, medication, surgical procedures, hospitalisations etc. Indirect costs refer to reduced productivity at work, absenteeism or unemployment due to disease-related disability. Other sources of indirect costs include pain, anxiety and depression which can negatively affect a person's quality of life.

## TREATMENT COSTS

The standard treatment for RA includes disease-modifying anti-rheumatic drugs (DMARDs), such as methotrexate, sulphasalazine and hydroxychloroquine. Biological therapies are introduced when the patient fails to respond adequately to two or more conventional DMARDs. Because of the complexity of biological molecules and the manufacturing process, the cost of treatment using a biologic agent is extremely expensive compared to conventional, chemically synthesised DMARDs.

"For example, a patient will only need to pay RM670-RM720 for a year's supply of methotrexate compared to RM2,500 for a single vial of infliximab," shared Dr Chow.

"Depending on body weight, a patient may need two vials of infliximab per infusion and eight infusions for the first year. This would bring the cost of treatment to approximately RM40,000 per patient."

As a result, many patients have limited or no access to this type of treatment.

"Some patients have medical insurance but find that they only have enough for maybe 6 infusions per year," said Dr. Chow. "They will try stretching out the intervals between infusions to save cost, or fall back on conventional DMARDs and pain relievers to manage their symptoms."

## HOPE FOR AFFORDABLE TREATMENT

Biosimilars are highly comparable versions of original biological therapies (also called originator drugs) that are now available at a lower price.

One such biosimilar product recently approved for the treatment of RA in Malaysia is Remsima®, a monoclonal antibody that contains infliximab as its active ingredient.

Remsima® is 20-25% cheaper than the originator drug for infliximab and almost half the price of other biological therapies. This would translate to considerable savings that will ease the financial burden of individual patients, and free up valuable resources in government hospitals to provide biological therapy to a wider group of patients.

## PATIENT ASSISTANCE PROGRAMME

If you need help paying for biological therapy, pharmaceutical companies sometimes offer financial support in terms of discounts or reimbursements to eligible patients.

The Remsima® Patient Assistance Programme is a special collaborative programme established by the manufacturer (Celltrion Inc. Korea) and distributor (LF Asia Malaysia) for Remsima® to help patients who are underinsured or have limited income to obtain the proper treatment they need.

RA patients who are prescribed biological therapy for the first time routinely require three loading doses at the beginning of the course of their treatment, followed by a maintenance dose once every 8 weeks. Those who are enrolled in the Remsima® Patient Assistance Programme will be given their first maintenance dose free of charge.

If you are already on biological therapy but would like to reduce your medical expenses, discuss with your doctor whether switching to a biosimilar is suitable for you.

# JIA Independence Camp



Exercise sessions.

By Dr Tang Swee Ping, Chairman AFM Junior Club

**T**he AFM Junior Club held its JIA Independence Camp at the Agrotek Eco Resort at Sungai Semunggis, Hulu Langat. Led by Dr Tang Swee Ping and Miss Chan Li Jin, 12 Junior Club members made it to this small cozy resort; nestled in a valley with a small sparkling river flowing through it, surrounded by lush greenery and hills. Sister Fatimah Abdullah from Hospital Selayang, an ever-willing volunteer with the AFM Junior Club assisted in the camp. This year, we were also very fortunate to have two occupational therapists; Miss Eunice Yap and Miss Charlie Tan who generously imparted their knowledge.

On the 11th of December 2015, a huge crowd gathered at the lobby of Selayang Hospital to wait anxiously for the bus. The participants were going to spend 2 nights away from their families and for many, it was the first time ever. Nurul Farhana binti Hamidi, a veteran at the JIA Independence camp trudged in alone all the way from her college in Shah Alam with confidence. The participants were soon transported in a 1.5 hour journey, away from the hustle and bustle of Kuala Lumpur city to a completely different landscape of nature, quiet and peace.

Over the next 3 days, the participants were kept busy with a myriad of educational and fun activities. The overarching principle of the camp was empowerment through knowledge and recognition of their abilities and talents. They learnt about Juvenile Idiopathic Arthritis through a series of interactive lectures like "What is JIA?" by Dr Tang, as well as "Joint Protection" and "Coping With School And Work" by Miss Eunice Yap and Ms Charlie Tan respectively. The participations also had great fun learning about their medications through a competitive quiz organised by Dr Tang, and the winning group was rewarded.

The highlight of this year's fun activities was T-shirt painting led by Miss Chan Li Jin. Talent was abound and it was amazing to see dull plain white T-shirts rapidly transformed over two hours into designer patterns. The participants were given the theme to draw about the camp and they enjoyed the opportunity to express themselves. The plan was initially to award a prize to the best T-shirt design but this proved to be an extremely difficult and uphill task for the judges, and finally 3 prizes had to be awarded!

Another highlight was the group sharing session. This year's group sharing session was one of the best ever with a very positive feel to it. Nurul Farhana shared her long 15-year journey with JIA; from the time of diagnosis at the age of 5 years till today where she is in remission and off all medications. She shared stories of how she coped with the various obstacles throughout her journey to motivate and encourage the rest of our more junior participants. Another participant Nur Hazirah, although new to the camp, shared how she took on the challenges of being different, especially in a boarding school. It was great to see them encouraging one another with various



Working as a team.



Role Play.



Group sharing sessions.



Morning exercise by the river – led by Li Jin.



Learning massage by Eunice to soothe the aches and pains.

suggestions and reassuring words and knowing that they are not alone in their battles.

Miss Eunice Yap, an occupational therapist, devoted a morning to teaching appropriate stretching exercises. The participants excitedly tried on their new donated terra bands and stretched those stiff muscles and joints. They had the opportunity to learn simple massaging techniques which can be used to soothe achy muscles and joints, and they also had the hands-on opportunity to practise on each other.

Another empowering and highly anticipated activity was jungle trekking. Most participants were slightly apprehensive and had reservations if they would be able to make the 1.5km hike. They went up and down a small hill, crossed a small river (some had to be carried!) and were finally rewarded with a lovely waterfall. The smiles on their faces and the pride in their eyes said it all.

The final highlight of the camp was the Flying Fox. The boys had been waiting eagerly for this highlight which was kept for the last day. The flying fox at this camp was very high and participants had to climb up a small hill and up a 4m platform. The climb was a challenge for those wobbly knees but they made it with encouragement from one another – ‘don’t give up’, ‘we are almost there’ and especially ‘not to look back!’ The view from the platform was spectacular, but looking down towards the camp was certainly a stomach-churning experience and definitely not for the faint-hearted. The boys took it in their stride and volunteered to ‘test the



T shirt painting.



A dip in the icy cold river.

waters’ first and had a great time zapping down. The girls were initially apprehensive but as there was no other way down apart from the long arduous climb, many were eventually coaxed ‘to just close your eyes and jump’ and felt exhilarated and empowered by the experience.

The group also got to know their inner selves better through a session using Origami and made really cute giraffes. Throughout the camp, the participants made new friends, relaxed and played in the icy cold river and shared gossip and stories during meal times. The 3 days spent together fostered strong bonds of friendship, left them not only with precious memories but armed them with valuable knowledge to forge ahead.



Sharing smiles with friends.



Dr. Tang and her team of kids.

# RASG CNY GATHERING

By Annie Hay

The RASG had its CNY gathering on the 27th of February 2016. The members gathered in enthusiasm to listen to the two invited speakers. The first speaker, Ms Lydia Phua, is a certified nutritionist who has worked with clients with various health conditions; including diabetes, post stroke patients and those with weight management issues.

She creates different types of nutrition plans and programs that are tailored to fit every client's individual health needs and goals. She also educates them about food and how it affects their body. She strongly believes in weight management through better eating habits and that eating healthy doesn't have to be boring!

Her message was that good nutrition is the key to good mental and physical health as it affects the way one feels and how one's body works. As patients with RA are always seeking to ease its symptoms with diet and supplements, she says; "The best approach for people with RA –for everyone– is a well-balanced diet which, according to the U.S. Food and Drug Administration, should be centered on plant-based foods. Approximately two-thirds of one's diet should come from fruits, vegetables and whole grains. The other third should include low-fat dairy products and lean sources of protein."

The next speaker, Dr Samantha Ong is an associate chiropractor specialising in scoliosis stabilization



and pediatrics. She uses precise spinal manipulation techniques to reduce pain, enhance flexibility, and restore mobility to the back and body. She educated the audience on many aspects of chiropractic.

Members were also invited to a free consultation with Dr Samantha Ong or Ms Lydia Phua or both. The Q & A session that followed was interactive with members asking questions that pertained to their illness. The members adjourned to lunch at 1pm. 37 members attended the event.

## WHAT IS CHIROPRACTIC?

Chiropractic comes from the Greek word which means "Done By Hand". Chiropractic treatment is meant to keep joints mobile and the blood flowing to the cartilage around the joints.

## WHO IS A CHIROPRACTOR?

A chiropractor specialises in diagnosis and treatment of neuro-muscular-skeletal conditions. Chiropractors are not interested in the symptoms rather the cause of the pain.

## CHIROPRACTIC AND ARTHRITIS

Arthritis presents itself as:

- Persistent fatigue
- Stiffness, especially in the morning or after sitting for a long time
- Increased weakness
- Decreased range of motion
- Increased joint swelling (inflammatory arthritis: RA, PA, etc)
- Degeneration and deterioration of cartilage between joints

## CHIROPRACTIC TREATMENT BENEFITS

- Reduces stiffness and pain
- Removes muscle tenderness and spasm
- Helps strengthens the joints and reduce weakness
- Prevents degeneration

## CHIROPRACTIC TREATMENT OPTIONS

- Spinal manipulation
- Trigger point therapy
- Soft tissue therapy
- Exercise and mobilization

Spinal manipulation should not be carried out with arthritis patients during flare-ups however there is no contraindication to the other forms of chiropractic treatments.

# GENTING ANG POW

In a glittering event at Genting International Convention Centre, on the occasion of Chinese New Year, Genting Malaysia Berhad distributed a very generous amount of RM500,000 to the less fortunate and disabled. AFM was one of the 50 charity organizations chosen to receive a donation of RM10,000. The event was held on 21st of February 2016 from 11.30am to 3pm. More than 850 guests attended the luncheon hosted by chairman and chief executive officer of Genting Group, Tan Sri Lim Kok Thay. Guest of honour, transport minister Datuk Seri Liow Tiong Lai, presented the cheques to representatives from the charities.

AFM was represented by Madam Patricia Ho, Asst. Hon. Secretary and Madam Shanta from the Secretariat.

This New Year contribution is part of their annual drive to give back to society and bring good cheer to the needy and underprivileged. They do this by supporting charity organizations in carrying out their programmes and also help them meet their day-to-day operational costs.

AFM expresses its gratitude and says “thank you” to Genting Malaysia Berhad for this magnanimous gesture. We hope AFM will continue to receive support in the years to come.



Madam Patricia Ho, Asst. Hon. Secretary receiving the cheque on behalf of AFM.

## ARTHRITIS FUND

AFM subsidises the cost of joint replacements for eligible persons. The aim of treatment is to control arthritis and prevent joint deterioration. However, occasionally, when arthritis is severe or progressive or the patient presents for treatment late, the joint affected by arthritis can be damaged irreparably. This will result in pain and loss of mobility. In selected cases, the damaged joint can be replaced by an artificial one by undergoing joint replacement surgery. This procedure can relieve pain, restore mobility and normalise joint function.

The cost of implant for the knee surgery is generally above RM8,000. Many patients forego surgery and continue to deteriorate and suffer pain because they are unable to afford the implant.

Arthritis Foundation Malaysia (AFM) appreciates this area of need and has set up a fund to assist those who require a joint replacement but lack the means to purchase the prosthesis.

For further details please contact AFM. You can check out our website too for more details at [www.afm.org.my](http://www.afm.org.my)



Dr. Sargunan Sockalingam, President of AFM shares his insights and thoughts on data collection and research practices.

**T**he last two months have been fascinating. Instead of the usual task of reviewing journal articles to enhance my knowledge and keep up-to-date with current practice, I went headlong into data collection. I am currently involved in two large projects. Both involve collecting as much information as possible about Rheumatoid Arthritis, Psoriatic Arthropathy and Ankylosing Spondylitis profiles of patients. I am also gathering data on patients with Lupus.

### RESEARCH MODALITIES

Much of the information we have today is derived from research, more specifically, clinical research. However, research is not limited to clinical practice alone. There are many branches of research, starting from basic sciences, genetic and applied genetics to sophisticated immune modification studies. These are just the tip of the iceberg. You are probably aware that mice and other animals are used for research, and I can tell you, it is best to ignore any compassionate thoughts you may have with regards to the eventual outcome for these creatures. To improve the “quality of life” of human beings, sacrifices are necessary.

### VARIABLES


But the other important element of research is the collection of clinical data to better understand the disease process. The unfortunate thing about

all this is that it is painstaking and backbreaking work. As I take a break, from typing in data, it dawned on me that a lot depends on the accurate description and interpretation of the information that we punch in. It is simply astounding, how one disease can behave so differently in a single individual over time. Sometimes, perfect strangers can have identical manifestations of the same disease, yet other times, siblings can have completely opposite findings, with regard to the same illness.

Pain tolerance, anticipation of progress and attitudes towards disease are also vastly different among individuals. There are sufferers who seem to take it all lightly and not be disturbed by intense disease activity, and there are those who feel that their disease is debilitating, even though they have the mildest form of the disease.

How does one interpret this variation? And what is more fascinating is the discovery that we are at the mercy of people who enter the data. What if there are errors that have not been corrected? Interpretations of events, such as mild, moderate or severe disease flare, may differ among different investigators. In order to overcome this, there are audits, standardizations and scoring systems, but assessors leave me bewildered by the varied deviations that have been recorded. I suppose this is why we have statisticians. Such is the nature of the human body and disease. Investigators have

very difficult tasks. Gathering and punching in data, is by no means a task for a single individual.

Over the years there will be leaps and bounds in information technology. Software and digital applications are being designed to collect as much information, some even in real-time from a single patient. Perhaps the future of data collection and analysis lies in getting real time data from patients and care-givers themselves. But what will we do with all this information, once we have it? It may not be so different from what is being done now, which is the design of therapeutic agents and interpretation. For now, this is the realm of the big pharmaceutical companies, who as we know, are quite happy to set the price of medications at astronomical rates. 

Perhaps, it is time patients and care-givers put a price on the information that is gathered from them for a change!

In a few weeks from now, a meeting of healthcare professionals and IT experts will take place in Kuala Lumpur, to discuss the future of how medicine is practiced in this challenging new world. I certainly hope they recognize the value of the largest source of crucial information in understanding the mechanism of disease; our patients and their care-givers.

# FIND A RHEUMATOLOGIST

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

## WILAYAH PERSEKUTUAN

- 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
- KPJ Tawakkal Specialist Hospital, Kuala Lumpur
- Pusat Perubatan Universiti Malaya, Kuala Lumpur\*\*

## SELANGOR

- KPJ Ampang Puteri Specialist Hospital, 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\*
- Columbia Asia Hospital, Bukit Rimau, Shah Alam
- Ara Damansara Medical Centre, Shah Alam

## KEDAH

- Hospital Sultanah Bahiyah, Alor Setar\*

\* 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.

\*\* The hospital also has a private wing, University Malaya Specialist Centre

## PULAU PINANG

- Hospital Pulau Pinang, Pulau Pinang\*
- Bone, Joint & Pain Specialist Centre, Sunway Perdana, Pusat Bandar Seberang Jaya, Seberang Perai

## PERAK

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

## MELAKA

- Hospital Melaka\*

## JOHOR

- Hospital Sultan Ismail, Pandan, Johor Bahru\*
- Columbia Asia Hospital, Nusajaya, Johor
- Hospital Pakar Sultanah Fatimah, Muar

## NEGERI SEMBILAN

- Hospital Tuanku Jaafar, Seremban\*

## KELANTAN

- Hospital Raja Perempuan Zainab II, Kota Bharu\*

## TERENGGANU

- Hospital Sultanah Nur Zahirah, Kuala Terengganu\*

## SABAH

- Hospital Queen Elizabeth, Kota Kinabalu\*

## SARAWAK

- Hospital Kuching, Kuching\*

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<b>TRUSTEES</b>	Tan Sri Dato' G. Hari Narayanan Tan Sri Dato' Dr. Abu Bakar Suleiman

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## ARTHRITIS FOUNDATION, MALAYSIA MEMBERSHIP APPLICATION / RENEWAL FORM

NAME:I/C NO: \_\_\_\_\_ DATE OF BIRTH: \_\_\_\_\_ GENDER: \_\_\_\_\_

OCCUPATION: \_\_\_\_\_ MARITAL STATUS: \_\_\_\_\_

E-MAIL: \_\_\_\_\_ MEMBERSHIP NUMBER (IF RENEWAL) \_\_\_\_\_

HOME ADDRESS: \_\_\_\_\_

TEL NO: \_\_\_\_\_ MOBILE NO: \_\_\_\_\_ FAX NO: \_\_\_\_\_

OFFICE ADDRESS: \_\_\_\_\_

TEL NO: \_\_\_\_\_ MOBILE NO: \_\_\_\_\_ FAX NO: \_\_\_\_\_

I enclose herewith payment of RM \_\_\_\_\_ Cheque/Money order no. \_\_\_\_\_  
BEING PAYMENT FOR:-

### NEW MEMBER:

- Ordinary Member (RM35) (Registration Fee: RM20, Annual Subscription: RM15)  Life Member (RM200)  Corporate Member (RM1,500) (Registration Fee: RM1,000, Annual Subscription: RM500)

### MEMBERSHIP RENEWAL

- Ordinary Member (Annual Subscription: RM15)  Corporate Member (Annual Subscription: RM500)

Please cross your cheque and make it payable to:

### ARTHRITIS FOUNDATION MALAYSIA

Peti Surat 10, Tingkat Bawah, Bangunan Sultan Salahuddin,  
Abdul Aziz Shah, 16, Jalan Utara, 46200 Petaling Jaya, Selangor Darul Ehsan.

Signature of Applicant

Date

For patients who need to control their RA symptoms,  
but cannot continue with MTX...

# #MyLifeWithoutMTX



## Are You One of Them ?

- Forgot to take your MTX?
- Not fully adhering to your MTX?
- Experience moderately to extremely severe side-effects?

## Did not receive a change to your treatment regimen?

### What Can Be Done ?

- Recognizing and acting on treatment challenges can have positive outcomes
- **ACT NOW...** Talk to your doctors if you are experiencing side-effects with your current treatment regimen

*Please consult your healthcare professional*