



# AStRETCH

WINTER 2019

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## ANKYLOSING SPONDYLITIS AUSTRALIA



### The European Map of Axial Spondyloarthritis by Annie McPherson & Greg Johnson

*The European Map of AS (EMAS) project was originated by CEADE (Coordination Española de Asociaciones de Espondiloartritis), Prof. Marco Garrido-Cumbrera, Health and Territory Research, Spain's University of Seville and is sponsored globally by Novartis. In October, 2018 in Guangzhou, China at our ASIF Council Meeting, Marco and the President of the CEADE, Pedro Plazuelo presented an overview and outline of the EMAS project. Subsequently, at the EULAR, June conference in Madrid, this project results were released.*

*With the assistance of the ASIF member societies from China and Russia, the project is now the [International Map of AS \(IMAS\)](#). The purpose of the IMAS project is to understand the patient perspective of living with Axial Spondyloarthritis (AxSpA). ASstretch has provided a precis of the EMAS project results.*

#### The European Map of Axial Spondyloarthritis: Capturing the Patient Perspective—an Analysis of 2846 Patients Across 13 Countries

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#### Abstract

Even though scientific research in axial spondyloarthritis (axSpA) has grown significantly, more exploration from the patient perspective is required. A recent

cross-sectional survey of 2846 patients, the European Map of Axial Spondyloarthritis (EMAS), describes how patients who live with axSpA experience the physical, psychological and social impacts of their disease.

EMAS results showed a substantial physical and psychological burden. The mean delay to patient diagnosis was 7.4 years, a mean BASDAI score was 5.5 and 75.7% of participants reported moderate to severe spinal stiffness throughout the day. 74.1% reported difficulties finding a job due to the disease, and 61.5% reported psychological distress.

#### Introduction

Axial spondyloarthritis (axSpA) is a chronic inflammatory disease leading to chronic pain, structural damage, and disability. axSpA encompasses radiographic (ankylosing spondylitis [AS]) and non-radiographic (nr-axSpA) forms.

Periods of apparent disease inactivity can be periods of great pain, stiffness and fatigue for patients thus masking the insidious nature of the disease. EMAS aimed to generate evidence on axSpA using a patient reported questionnaire developed by the Ankylosing Spondylitis International Federation (ASIF) and clinical experts.

#### Methods

EMAS was a cross-sectional survey of patients self-reporting as axSpA from Austria, Belgium, France, Germany, Italy, the Netherlands, Norway, Russia, Slo-

*The information contained in this newsletter should not take the place of advice and guidance from your own health-care providers.*

*Be sure to check with your doctor about changes in your treatment plan.*

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## The European Map of Axial Spondyloarthritis *continued from Page 1*

venia, Sweden, Switzerland, the UK, and Spain. Patients in participating countries were asked to assess questions related to 12 different items: socio-demographic and anthropometric characteristics, disability assessment, work life, daily life, lifestyle habits, diagnostic journey, healthcare resource use, treatment, comorbidities (including extra-articular manifestations), psychological health, disease outcomes, and patient disease-related attitudes and treatment goals. A range of supplementary indices were also collected: Bath Ankylosing Spondylitis Disease Activity Index (BASDAI); General Stiffness Index; Global Limitation Index; General Health Questionnaire (GHQ-12). Participants were recruited between July 2017 and March 2018.

### Results

A total of 2846 people with self-reported axSpa participated in the survey. The largest sample sizes were found in Spain (23.9%), France (22.4%), Norway (17.9%), Russia (8.2%) and Italy (4.7%). The average age of participants was 44 years with females making up over half (61.4%) of the sample.

The majority of participants had been diagnosed with AS (79.2%). The average age of symptom onset was 26.2 years with the mean disease duration of 17.2 years. For those who reported their HLA-B27 status, 71% were positive. Around 20% of participants reported a diagnosis of uveitis or inflammatory bowel disease. A majority (75.7%) report moderate to severe spinal stiffness whilst half (50.1%) reported medium to high functional limitation during disease flares.

Fear of suffering pain (30.5%), loss of mobility (30%), and disease progression (32.9%) were commonly reported. Most participants were concerned about stopping the disease progression (32.5%), eliminating pain (30.7%) or finding ef-

fective treatments (23.3%). The most common goals were to eliminate or reduce pain (28.5%), improve mobility (19.3%) and improve quality of life (8.3%).

### Discussion

The data indicates long diagnostic delays, deterioration of quality of life and a high burden of disease for axSpa patients. Patients on average visited two health care professionals, mainly GP's followed by orthopaedic specialists, physios and osteopaths but not rheumatologists prior to receiving a diagnosis.

The EMAS sample showed a high prevalence of mental health difficulties e.g. psychological distress (61.5%) with some reporting depression (33.8%) and/or anxiety (38.6%).

Limitations of the report were acknowledged including reliance on self-reported data and some non-validated scales or indices. However, the sample characteristics were consistent with previous cohorts including patients with confirmed axSpa.

### Conclusions

EMAS emphasizes the need to take urgent measures to reduce the burden of disease associated with axSpA including reducing diagnostic delay; ensuring patients are optimally and holistically managed with access to exercise programs, psychological, and physiotherapeutic care; incorporate the patients perspective into clinical practice by facilitating the shared decision-making between patients and physicians; and increasing patient participation in their care to generate better physical and psychological health outcomes.

*Please refer to Page 3 for an infographic on axSpa and its prevalence in men and women. The study results can be read in full here:*

[The European Map of Axial Spondyloarthritis](#)

## What is axSpa *kindly reprinted from ASIF*

# What is Axial Spondyloarthritis?

axSpA is a painful chronic inflammatory disease that primarily affects the spine and sacroiliac joints (SIJs)<sup>1</sup>

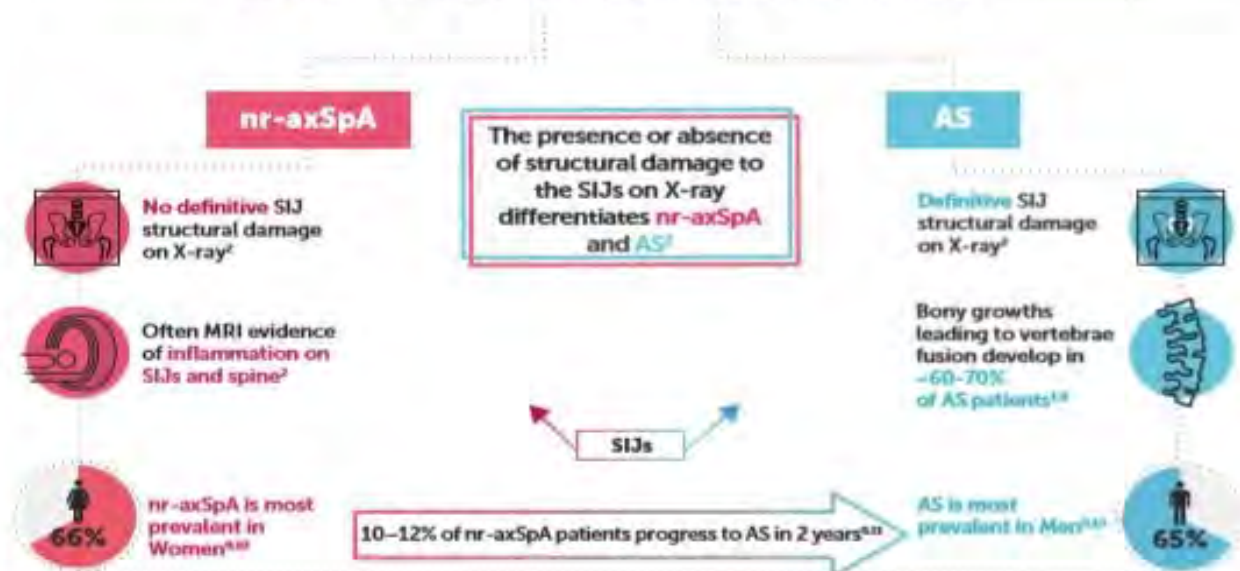
axSpA is an umbrella term for non-radiographic axSpA (nr-axSpA) and radiographic axSpA also known as Ankylosing Spondylitis (AS)<sup>2</sup>

**Leading symptom:**  
Inflammatory back pain  
that improves with exercise,  
but not with rest<sup>1</sup>

**Disease onset:**  
Usually before the  
age of 45, often  
in the 20s<sup>3,4</sup>

**Prevalence:**  
Similar to Rheumatoid  
Arthritis, 0.2-1.4% of adults  
have axSpA<sup>5,6</sup>

axSpA is equally prevalent in both Men and Women<sup>4,7</sup>



**Patients with nr-axSpA and AS share common clinical features<sup>2,8,11-13</sup> ...**

**... and experience a significant and similar disease burden<sup>2</sup>**

**Uveitis:** Eye inflammation

**Enthesitis:** Inflammation of the points of insertion of tendons and ligaments into bone

**Peripheral arthritis**

**Psoriasis:** Skin disease

**Inflammatory bowel disease:** Chronic inflammation of the digestive tract

**Dactylitis:** Inflammation of the fingers or toes



... Inflammatory back pain

... Severe stiffness & reduced mobility

... Fatigue & difficulty sleeping

... Decreased quality of life

... Impaired social participation

... Impaired work & home productivity

Abbreviations: axSpA, Axial Spondyloarthritis; nr-axSpA, non-radiographic axSpA; AS, Ankylosing Spondylitis; MRI, magnetic resonance imaging; SIJ, sacroiliac joint

References: 1. Sieper J and van der Heijde D. Arthritis Rheum. 2015;65(5):543-51. 2. Diebold J et al. Arthritis Rheumatol. 2016;68(7):1649-76. 3. Sorella J et al. Arthritis Care Res. 2012;64(9):905-10. 4. Radwanski M et al. Ann Rheum Dis. 2009;68(9):777-83. 5. Hamilton L et al. BMC Musculoskelet Disord. 2015;16(Suppl 3):S2. 6. Sieper J. Rheum Dis Clin North Am. 1999;15(9):515-37. 7. Mease P and Khan M. J Intern Med. 2010;267(5):480-1. 8. Sieper J et al. Nat Rev Dis Prim. 2015;9(1):150-15. 9. Radwanski M and Sieper J. J Intern Med. 2015;267(5):480-1. 10. Sieper J et al. Semin Arthritis Rheum. 2015;44(6):556-62. 11. Wallace J et al. Arthritis Res Ther. 2015;17(Suppl 2):S20. 12. de Winter J et al. Arthritis Res Ther. 2016;18(Suppl 3):S20. 13. Strand V and Singh J. Mayo Clin Proc. 2017;92(6):555-64.



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## Australia Pacific League Against Rheumatism Annual Scientific Meeting: April 2019 by Annie McPherson

At the Australia Pacific League Against Rheumatism and Australia Rheumatology Association (APLAR & ARA) workshops and Annual Scientific Meeting (ASM) conference in Brisbane April 2019, Spondyloarthritis (SpA) featured in many presentations and workshops. Here are some of the main themes from these events:



Anne Lloyd, Ornella Clavisi & Annie McPherson

The new Axial Spondyloarthritis (axSpA) terminology was used widely in presentations and workshops. It has become very apparent the relationship between spondyloarthritis (SpA) family of conditions are quite strong and now being acknowledged by rheumatologists worldwide. In the early stages of diagnosing a patient's condition, it is important that the clinician/rheumatologist works closely with the patient to identify all the related symptoms in his/her history. The conditions commonly identified under the SpA family are: Axial Spondyloarthritis (axSpA or Ankylosing Spondylitis- AS), Non-radiographic Axial Spondyloarthritis (nr-axSpA); Reactive arthritis (ReA); Psoriatic Arthritis (PsA); Juvenile Idiopathic Arthritis (JSpA); Enteropathic Arthritis (EnA) and Undifferentiated Arthritis (USpA). [Refer also to our AStretch Spring

2018 edition for a full explanation of how these conditions are connected.] Most interesting to note was the extensive pathway clinicians need to traverse, sometimes between these conditions to arrive at the correct diagnosis and thus treatment path for a patient.

There was a great emphasis on identifying changes for SpA patients on imaging including X-Ray and Magnetic Resonance Imaging (MRI) along with the standard techniques of physical examination, patient history and blood tests. When a patient has back pain but shows no changes in the X-ray lower back (Sacroiliac) -SI joint, an MRI maybe requested to show any inflammation around these joints and the spine.

The goals in these learnings was to assist the clinicians to diagnose SpA patients at an earlier than the presently common 7-8 years. An earlier diagnosis would potentially lead to more informed decisions for appropriate earlier treatment pathways, and management options for the clinicians and the patient.

Other attendees we met at the conference along with the rheumatologists, were Physiotherapists, Occupational therapists, and Rheumatology Nurses. Several sessions were focused on the roles of these Health Professionals in a complete Management plan for the patient. A presentation on the very successful, Fracture Liaison Nurses program, highlighted the importance of these services, in assisting with follow-up management for patients in the public hospitals system, who have osteoporosis and have had a fracture. Rheumatology Health Professionals Translational Practice

Workshop was specifically structured to provide examples of how these medical teams could enhance a patient's treatment programs to maximise their benefits in a clinical setting. Many of the examples provided by the speakers included patient involvement/engagement in the research programs and studies, and how the success rate was much higher, its implementation and translation into clinical practice."

Several times during research presentations, acknowledgement in managing patients with chronic inflammatory arthritis was highlighted. As a result, patient advocates and representatives were often involved in the research teams indicating there is a stronger trend to



Naomi Creek & Rosemary Ainley

include them in the MSK research community. Both Musculoskeletal Australia and Arthritis Australia management and staff were represented at the conference, along with state based Arthritis organisations.

Annie McPherson



## Reducing Chronic Daily Stress Is Anti-inflammatory *by Jen Hall*

I was diagnosed officially with AS in 2013 at 52 years of age after a long history since childhood of back and hip pain, and mobility issues. I have suffered chronic bilateral Uveitis since the age of 17, resulting in blindness in one eye.

In 2015 as part of my undergraduate degree in Psychological Science I was lucky enough to complete a unit of study in Positive Psychology at Maastricht University in The Netherlands. I'm sure you can imagine how the opportunity to study overseas with a highly ranked university in this specific field was a positive experience in itself: possibly related to the curriculum related compulsory excursions to a Belgian chocolatier, and well known Belgian brewers Stella Artois with "mandatory" sampling in both instances.

As part of the assessments for the course we had to design a research study relating to the field of positive psychology. Mindfulness and meditation fall neatly under the Positive Psychology umbrella as well as CBT and other cognitive therapy models. This area of psychology appealed to me after many years of life changing experiences relating to different forms of meditation, and understanding through experience of the impact of "realistic" positive thinking. I had been engaging in practices of optimism, positive thinking, and meditation methods for many years before I studied mainstream psychology.

The study I designed was related to measuring the impact of regular

mindfulness meditation practice on circulating inflammatory markers in the blood stream. In the course of designing this research study I read many research articles that indicated significant results of the impact of stress on physical well-being, as well as the impact of taking positive action in working with stress through meditation, increasing healthy lifestyle habits, and increasing optimism.

One study stood out to me as acknowledging a powerful contributor to decreased mental health resulting in decreased physical health, specifically from increased inflammation. In this 2012 study by Gouin et al., it was noted that naturally occurring daily stressors increased levels of inflammatory markers IL-6 and CRP. It was also noted that exposure to multiple stressors was associated with elevated inflammatory markers. This study quoted similar findings from previous studies. So these findings beg the questions "what are our daily stressors unique to our circumstances?" and "how do we sustainably reduce chronic daily stress?"

When people are living with chronic illness there is naturally daily stress: whether it's physical issues like mobility, feeling unwell, coping with daily tasks of house work or caring for families, side effects from medication, adhering to special diets and exercise; or practical, mental and emotional issues like navigating medical appointments, worries about the future, just to name a few. Navigating these issues can create feelings of being under pres-

sure at times, which according to the research, literally inflames the health condition, and a vicious cycle ensues. How can we introduce positive action and optimism on a daily basis without creating yet another pressure filled "must do"?

There have been many studies about the impact of different forms of meditation on physical and mental health, literally changing the brain, increasing grey and white matter. More studies have shown a positive impact on pain levels and associated stress that naturally accompanies chronic pain experience: this includes positive impact on experiences of anxiety and depression. Mindfulness Based Stress Reduction (MBSR) was introduced to medicine via the introduction into pain clinics in 1979 by Nobel Laureate Jon Kabat-Zinn. Transcendental Meditation as structured by Maharishi Mahesh Yogi is another form of meditation that has been extensively researched by the scientific community with significant results in improvements in physical and mental health. Other simple methods of enhancing physical and mental well-being have been studied and widely embraced in the professional health community.

Studies indicate strong connections between improved mental and physical health by spending time outdoors during the daylight hours and where possible in sunshine (with care around sun exposure), and in natural settings. Visiting local parks, rivers, lakes, the beach, walking in the bush, are all great ways to improve well-being for those of us who are quite mobile. Spending 30

## Reducing Chronic Daily Stress Is Anti-inflammatory *continued from Page 4*

to 60 minutes out in the fresh air in nature, moving your body within your capacity, is a great recipe for mood enhancement. For those less mobile finding a space outdoors where you can do some stretches, enjoy sitting in a garden or balcony, cultivating and caring for some pot plants, can be simple ways to connect with nature. As you read these suggestions what comes to mind that you could experiment with in your world?

Often people embark on healthy eating as a healing option. Great idea. However, if you're like me, sticking to a rigid eating plan that removes lots of favourite foods or drink can feel highly stressful; the stress outweighing the proposed health benefits. Often there can be prescriptive exercises that are important to do but motivation can be low when you're already feeling unwell and in pain. So how do we change from habits that could prove detrimental, to healthy life enhancing habits, without creating another daily stressor?

I found ways to incorporate changes in small ways over time. Experimentation to see what worked, what I was actually willing to do depending on how I felt, was my method. I made changes in my diet gradually through finding out basic healthy diet information that would apply to anyone and making small adjustments through experimentation. I found it much easier to introduce small changes, especially when catering for a family who had eclectic taste buds.

Yoga was a practice I found helpful: incorporating breath work and stretch poses in a most basic form helped me to increase my chest expansion from half of what it should have been back to a normal range over about two years. The impact on my mobility and my mental well-being when exercising with care helped get me back on to a road of preventative care.

I learned to incorporate some stretches into my daily showering routine and when moisturising my skin. I raised my rotary clothes line to its highest level to make every bend and stretch count. On the days where life is more physically challenging I practice acceptance and move within my ability that day with an attitude of acceptance. But I do keep moving.

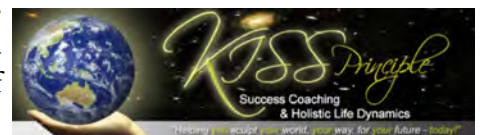
I learned to practice meditation with a teacher to learn how to focus, to sit with, and build a tolerance, to pain. Meditating with pain often led me to need less pain medication without detriment to my well-being. The body scan meditation as taught in many mindfulness practices including the MBSR is a practice of restful observation of body sensations, including pain.

It's important to note an underlying theme that over time I was able to embody throughout this day by day journey. Self-compassion incorporating kindness and often humour towards my self was a key attribute and attitude that I learned over time to bring into just about every experience of pain, change, stagnation, and difficulty. The above journey I have described took time to devel-

op. It took many trials and some errors in judgment. It took support from the medical profession and searching until I could find medical professionals who were willing to work with me in my own experience rather than group me into a general label.

Conditions like AS and autoimmune challenges take time to understand. Our own experience, circumstances, thoughts, and feelings about our condition needs our own care and attention to help us understand our own needs to live with the best quality of life that we can. Finding ways to minimise stress appears to be an important option that we can experiment with as part of our health and wellbeing on a daily basis; one moment at a time.

If you would like to try mindfulness meditation, I have two free audio downloads and some information sheets available on my website: Mindfulness of Breath, and a Body Scan meditation. These two exercises are the foundation for developing a mindfulness practice.



[KISSPrinciple.com.au](http://KISSPrinciple.com.au)

*If you look for the "free downloads" under Services you will find the free tools. There are also links to other provider's related resources on the website. You can also contact me for more information on 0437640053.*

Jen Hall BPsycSc(ACU) GradCert-Gestalt(GTB) DipCouns(ACAP)



## AS Exercises *by Margaret Lewington (Physiotherapist)*

Last month the Spondylitis Association of America (SAA) held a seminar which was live streamed. They had three presenters: Rheumatologist, Occupational Therapist and Certified Yoga Instructor. I was inspired by the presentation by the yoga therapist, Nancy O'Brien C-IAYT I felt it gave a good example of active relaxation, mindfulness, and gentle movements.

Her talk was titled “The Power of the Breath: The Mind-Body Connection”. She spoke of “mindful breathing”. Be kind to yourself and accept yourself as you are at this moment with compassion. There is a connection between stress, inflammation and discomfort or pain. Mindful breathing and movement can help to de-stress which may help reduce inflammation, pain and discomfort. Breath is always available to us, wherever we are. We just need to bring our focus to that breath. “Say to yourself ‘I am breathing in. I am breathing out.’. Your mind will wander, but gently bring it back and try to be as present in this moment as possible.”

She describes a 3 part basic breath. Firstly, support yourself in a comfortable position. (Lying, sitting, standing)



1. Gently expand the belly as you begin to inhale.
2. Gently expand the lower ribs. (Feel them with your hands to be sure they move.)
3. Gently expand the upper chest, lengthening, opening.

Then to breathe out:

1. Bring in the upper ribs.
2. Then bring in the lower ribs.
3. Then finally bring the belly towards the spine like a sit up.

Try to make the breath out longer than the breath in. You may like to focus on a thought or intention and hold this in your mind and heart as you breathe in and release it as you breathe out.

She also suggests adding a little movement. With your hands resting on your knees, slide them back towards your hips as you breathe in. Draw your shoulders and elbows back and lift your heart. Breathe out as you slide your hands back to your knees. Gently fold forward and lower your chin. Repeat a few times.

You can also add breath to other movements and everyday tasks. To add breath to a routine twist, start in a comfortable seated position. Begin your twist with your lower torso, turning gently to one side with a breath in. Pause for a moment and then breathe out. But keep in the same position. With another breath in, add the lower ribs to the turn, breathe out, then breath in again while adding the upper chest and head to the turn.—no straining— just gentle turning of each part with each breath in. Take a few mindful breaths in and out, maybe going a little further, then come back to the front and repeat to the other side.

“Because both movement and good alignment are key, mindful breathing and mindful movement practices can be ideal supports for those living with the challenges of Spondyloarthritis. Because the practices usually feel good and create a sense of ease and pleasure, they can fairly easily become a part of everyday routines, potentially helping to minimize pain, and help with the emotional impact of chronic illness. Yoga in the moment—always there for you. It’s free!!”



A Tai Chi based movement sequence which you could add mindful breathing to: Stand with feet comfortably apart, knees slightly bent, chest up, shoulders relaxed. “Hold a ball” in front. Gently turn from side to side. As you turn to the left, have your left hand on top and then reverse to Right hand on top to turn to the right. After several repeats, reach your top arm up and over your head as you turn to the other side. Do 2 repeats of the ball across the front and then one high arm over your head. You may like to do the ball turn a little faster and the overhead slow. Breathe, Turn, Stretch.



## Ankylosing Spondylitis Victoria Inc Report *by Annie McPherson*

### AS Victoria Activities:

Welcome to new members Jeannie and Jeremy. We have a number of new ASers who are liking our Facebook site, many are Interstate and International. As a result, we have added PayPal to provide for them in our membership finance services. Now we are well into July, please remember to renew your annual memberships as soon as possible. The funds collected help us to provide resources and services to people newly diagnosed with Axial Spondyloarthritis SpA (Ankylosing Spondylitis).

The World Spondylitis Day celebration Saturday 04 May, was held at our usual Berwick Inn restaurant in Berwick, where a small group of AS Vic committee, family, friends and regular ASers enjoyed a very Aussie pub lunch.



*Lunch at Berwick Inn*

Our winter, Christmas in July social event will be on by the time this newsletter comes out, so we hope to see you there. Later in September we have our Annual General Meeting at Austin Health, followed by a dinner in Heidelberg, so look to our Events page on the AS Victoria web site for details. [www.asvictoria.org](http://www.asvictoria.org)

### MSK Australia Activities:

As chair of the newly formed Musculoskeletal Australia's (MSK Aust.) Consumer Advisory Council, I attended the Australia Pacific League Against Rheumatism (APLAR) and Australian Rheumatology Association (ARA) An-

nual Scientific Meeting (ASM) and conference at the Brisbane Convention Centre with MSK Aust. management and staff. I would like to thank MSK Aust. and Janssen Australia for sponsoring and supporting me to attend. This is a rare opportunity to attend talks and presentations by leading expert researchers in the MSK field.

During this ASM, Arthritis Australia (Arth.Aust.) posted on their Facebook page,

[www.facebook.com/arthritisaustralia/](http://www.facebook.com/arthritisaustralia/)

their video by Sydney based rheumatologist Dr. Paul Bird, on explaining the Spondyloarthritis (SpA). SpA is the new terminology incorporating AS (axial Spondyloarthritis axSpA) and its family of diseases.

[www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

Our readers may have noticed we have included a number of articles on SpA from NASS, the UK AS patient society, in previous editions of AStretch, Spring 2018. The term is now used widely in Europe, the Americas and Asia/Pacific by clinicians, health professionals and patients and was extensively featured in the sessions at the conference. SpA conditions, symptoms, features, and different diagnostic imaging (X-ray and Machine Resonance Imaging – MRI) techniques all came under intense discussion at the ASM, to encourage the MSK clinician audience to look for SpA symptoms in potential patients and to try and obtain an earlier diagnosis.

Our associates, Creaky Joints Australia (CJA), Rosemary Ainley, Naomi Creek and Seth Ginsberg (from CJ USA) also attended the ASM and we shared many discussions on the sessions.

During the conference the ARA Rheumatology Health Professionals Association held a workshop on various sub-

jects including Lower Back Pain, Rheumatology in Paediatric patients and the Arthritis Aust. National Arthritis Strategy from earlier in April, 2019, specifically around consumer participation and community involvement.

A number of our Patient Advocate and Health Professionals Associates have joined this newly formed Special Interest Group (SIG) to focus on a range of Rheumatology inter-related topics and Allied Health treatments.

The MSK Aust. Consumer Advisory Council (CAC) met in April to review a number of ongoing projects and later in April I was invited to attend the MSK Aust. AGM. Having the opportunity to present to the board of MSK Aust. where there were many new members, was an exciting chance to explain some of our peer support group and CAC activities. Understandably, they were very interested in our AS Victoria group community activities and on this occasion to highlight the obstacles faced by young people with axSpA in particular, in the wider community and Healthcare sector was generated great interest. The Chair, Dipak Sanghvi has requested Ornella Clavisi, MSK Aust. General Manager, Consumer Services and I provide updates and reports directly at future Board Meetings.

### ASIF Activities:

The Axial Spondyloarthritis International Federation patient society (ASIF) council members, attended the European Union League Against Rheumatism EULAR ASM in Madrid, Spain in June 2019. Prior to this meeting the ASIF Council, newly elected at the Guangzhou China meeting in Oct.2018, elected to update the name of the patient society to "Axial Spondyloarthritis International Federation - ASIF". The matter had been raised as an issue by ASIF member country representatives to comply with the new



## Ankylosing Spondylitis Victoria Inc Report *continued from Page 8*

trend by Health Professionals and Clinicians at the EULAR ASM. A new Axial Spondyloarthritis axSpA infographic “*What is Axial Spondyloarthritis*” is now available on the web site [www.asif.info](http://www.asif.info) to help explain to patients and is reproduced here in this edition of ASTretch.

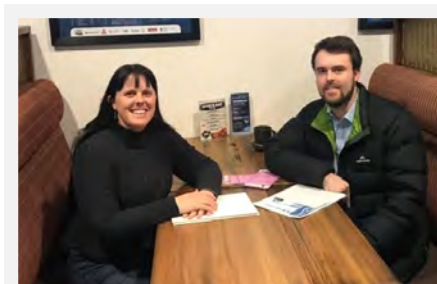
Annie McPherson

### A Bendigo Update

In July I had the absolute pleasure of sitting down with Jontee Brown in Bendigo to discuss how his life was completely turned around from a minor injury to his leg when he was 17 years old.

Jontee fell over during a Year 12 school trip to Philippines in 2015 causing a cut to his leg. On returning home the injured knee became infected and he soon found himself in the Royal Children’s Hospital in Melbourne with

Reactive Arthritis (ReA). Unexplained back pain soon followed resulting in Ankylosing Spondylitis (AS). During all his hospital visits, treatment and surgeries on his infected leg (11 surgeries over the years!), Jontee was also able to complete Year 12 in Bendigo and be accepted in to Latrobe University to studying teaching.



*Dionne & Jontee*

After finding himself as an able bodied high school student to relying on crutches for daily mobility (a wheelchair on bad days), he began touring

local schools to promote disability awareness and how to maintain a positive attitude when you suddenly find yourself in the position of having a visible disability. In 2018 this community awareness resulted in Jontee being awarded the Bendigo Young Citizen of the Year!

He has been able to continue his passion for sports and is now a star wheelchair basketball player for Kilsyth Cobras in Melbourne and is the All Abilities Coordinator at the Bendigo Basketball Stadium. In 2018, Jontee accepted a contract to play professional wheelchair basketball in Germany with his sights set for further opportunities to play overseas in the near future. Maybe we can keep an eye out for Jontee in the Tokyo Paralympics in 2020!

Dionne Lynch

## AS Group of Queensland Report *by Graham Collins*

It’s all fairly quiet in Qld at the moment and that has nothing to do with Qld losing the State of Origin to the Nsw Blues last Wed night. Ah well there is always next year as they say.

It is a bit like A.S. I suppose, you have to keep bouncing back. No use in feeling sorry for yourself, you are in charge of your own destiny, and you always get back what you put in.

Tuesday evening hydro sessions with Margaret Lewington at RBWH are still going well and it is always encouraging to see a new face, as well as those we might not have seen for a while.

We had another pizza night last Tues after hydro and thirteen people attended and had some good discussions along with good food. I believe this one was even instigated by someone we have not seen at the pool for some

time, so it just goes to show the social interaction is an important part of the group, as well as the exercise component.

Margaret Lewington gave a talk recently to 50+ Physios at RBWH to keep

### Ankylosing Spondylitis Clinic

#### Princess Alexandra Hospital, BRISBANE

Matthew Brown will be leaving Brisbane to take up a position at King's College London as Director of their National Institutes of Health Research Biomedical Research Centre. The clinic that he has run since 2006 at the Princess Alexandra Hospital for axial spondyloarthritis patients will close. Metro South HHS patients attending the clinic will be seen in rheumatology outpatients at Princess Alexandra Hospital, but those living out of MSHHS's catchment will need to be seen in their own health service district. Patients will be notified about this change.

AS Qld would like to thank Matthew Brown and the clinic team for all the research, diagnosis and disease management work that they have done.

We wish Matt all the best in his future endeavours.

them up to date on A.S. and Ax Spa. Thanks Marg for helping to keep A.S. in the focus for as many Physios as possible. Keep exercising and hope to see you in the pool.

Graham Collins

## Calendar of Events

### VICTORIA

Refer to [www.asvictoria.org](http://www.asvictoria.org) for details or Annie McPherson mob: 0408 343 104

#### September

Mon 2: Coffee and Chat @ Leongatha RSL 6 to 8 pm.

Tue 3: Coffee and Chat @ Korumburra Rec Centre 2 to 4pm

Tue 10: Annual General Meeting @ Austin hospital 6:30 to 7pm then dinner at Old England Hotel, Heidelberg

Sun 15: Coffee and Chat @ Alphington Community Centre Meeting room 1 to 3pm

#### October

Tue 1: Coffee and Chat @ Korumburra Rec Centre 2 to 4pm

Mon 7: Coffee and Chat @ Leongatha RSL 6 to 8 pm.

Tue 8: Committee Meeting @ Austin Hospital 6 to 8pm

Tue 15: Coffee and Chat Alphington Community Centre Meeting room 1 to 3pm

## Hydrotherapy Classes

### BRISBANE (QLD)

Sessions supervised by **Margaret Lewington** (Physiotherapist).

**When:** Tuesday evenings.

**Time:** 6:30 - 7:30pm

**Where:** Hydrotherapy Pool

Lvl 2, Ned Hanlon Building

Royal Brisbane & Women's Hospital

Butterfield St, HERSTON.

**Cost:** \$15 or 10 classes for \$140

**Enquiries:** Margaret on

0404 414 501 or 07 3376 6889



### PERTH (WA)

Sessions supervised by experienced Physiotherapists.

**When:** Monday evenings (Public holidays excepted).

**Time:** Two sessions.

Hydrotherapy pool 5:45 or 6:45pm.

Gymnasium & pool 5:45 & 6:45pm.

For those current group members and those who have recently participated in an AS program with the Hospital or the Arthritis Foundation.

**Where:** Arthritis Wyllie Centre,

17 Lemnos St, SHENTON PARK.

**Cost:** \$12

**Enquiries:** (08) 9388 2199

[www.arthritiswa](http://www.arthritiswa)



### Facebook Groups

[AS Brisbane](#)

[AS Sunshine Coast](#)

[AS Group VIC](#)

## General Information

Ankylosing Spondylitis Groups of Australia

[www.asaustralia.org](http://www.asaustralia.org)

Ankylosing Spondylitis Victoria Inc

[www.asvictoria.org](http://www.asvictoria.org)

Arthritis Australia

[www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au)

Spondylitis Association of America (SAA)

[www.spondylitis.org](http://www.spondylitis.org)

*Contains message boards, online chat forums, and a members only section for resources*

Ankylosing Spondylitis International Federation (ASIF)

[www.spondylitis-international.org](http://www.spondylitis-international.org)

The National Ankylosing Spondylitis Society (NASS - United Kingdom)

[www.nass.co.uk](http://www.nass.co.uk)

*Contains an excellent questions and answers section and downloadable guidebook - A Positive Response to Ankylosing Spondylitis-Answer and practical advice.*

# Ankylosing Spondylitis Victoria Inc

## Membership Form

*AS Victoria Inc is a Move muscle bone & joint health Peer Support Group*



### Who we are and what we do....

AS Victoria is an organisation of people with Ankylosing Spondylitis who wish to improve knowledge and ability to manage the condition. Our group shares a number of goals and objectives for people and families living with Ankylosing Spondylitis.

### We aim to provide the following:

- Provide a forum for the exchange of ideas and experiences.
- Distribute information to patients and medical professionals on AS.
- Provide and co-ordinate educational information, events, workshops and seminars on AS.
- Co-operate and interact with local, interstate, international Arthritis and peer support groups including participation in their events and activities.
- Arrange social events and activities for our group members, their families and friends

### Some of the benefits of belonging to our group:

- AStretch newsletter
- Seminar evenings with excellent guest speakers
- Improved awareness of AS and the AS community
- Opportunities for interaction with other members at social gatherings and activities
- Land exercise DVD for people with AS

### Membership Details

First Name: \_\_\_\_\_ Surname: \_\_\_\_\_

Mobile: \_\_\_\_\_ Home: \_\_\_\_\_

Email: \_\_\_\_\_

Address: \_\_\_\_\_

I wish to become a member of AS Victoria Inc support the purposes of the organisation and agree to comply with the rules for an incorporated association under section 46 of the Associations Incorporation Reform Act 2012.

Signed: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Send to:

AS Victoria Inc

PO Box 3166

Burnley North 3121

asvicweb@gmail.com

www.asvictoria.org

Ankylosing Spondylitis Victoria Inc complies with the Privacy Amendment (Private Sector) Act 2000 and will not sell your personal information to another organisation. You may be notified of AS Victoria Inc events, services and ways of assisting us to maintain these services. If you wish your name to be removed from our data base at any time please write to us. AS Victoria Inc passes on to members a variety of information on health and medical issues only for general, educational and informative purposes. AS Victoria Inc is not diagnostic or prescriptive and does not replace the services or advice of a qualified health care professional or purport to do so.



**Membership Type**☐ New ☐ Renewal (annual 30<sup>th</sup> June)☐ Mail out# membership (\$25.00)☐ Concession\* Mail out# membership (\$20.00)☐ Email member ship (\$20.00)☐ Concession\* email membership (\$15.00)

Donation: \$ \_\_\_\_\_ (Donations over \$2 are tax deductible)

**Total:** \$ \_\_\_\_\_

Cheque, money order or direct deposit -

AS Victoria Inc NAB BSB : 083 399 Account : 154321878

#Mail out membership all correspondence will be sent by Australia Post

\*\*Concession rate available for pensioners, unemployed with health benefit card  
and full time students with student card.***Statistical Information (Optional):-***

1. Are you a member of Arthritis Victoria? Y / N

2. Can we pass on your contact details to other members of the group in your area? Y / N

3. Gender M / F

4. Year of Birth: \_\_\_\_\_ 5. Preferred Language: \_\_\_\_\_

6. Do you suffer from A S Y / N 7. Do you know someone who suffers from A S Y / N

**Do you have any other conditions?**

.....

**Are there any specific activities you would like us to organise?**

.....

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