

# ASTRETCH

SUMMER 2014

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## ANKYLOSING SPONDYLITIS AUSTRALIA

### A gut feeling about AS by Mary-Ellen Costello (PhD student, Prof Matt Brown's Lab)

**WARNING:** Best not read whilst eating lunch, contains traces of microbes.



So it turns out we're not alone. We are covered and inhabited by trillions of microbes living in and on our body. They live in our mouths, on our skin and especially in our gut. For as long as we've known

about bacteria they've been divided into 2 categories – harmful pathogens causing infection like golden Staph, E. coli and Salmonella, and not so harmful boring 'normal flora'. Normal flora consists of all the bacteria that live with us every day that don't make us sick. It's this normal flora living in our gut that has become the subject of some serious attention and investigation recently. As it turns out, these bacteria are not so boring and may have more to offer than we've given them credit for. The new name for all the microbes, or bacteria, that live in our gut is the microbiome. Microbiome refers to all the bacteria and their genes that inhabit all the parts of the human body.

There is a close relationship between the gut and spondyloarthropathy (SpA), for example patients with reactive arthritis experience flare-ups after gastrointestinal infection with *Campylobacter*, *Salmonella*, *Shigella* or *Yersinia*, or urogenital infection with *Chlamydia*. Microbial involvement has been suggested in AS, however, no definitive link has been established. On average, up to 70% of patients with AS have some form of gut disease with about 10% going on to develop



Crohn's disease (CD). Recently, it's been shown that many genes associated with AS also play a role in microbial recognition and gut immunity; such as genes involved in the IL-23 pathway, which are important regulators of intestinal 'health'. Also, there is significant overlap in the number of genes associated with CD that are also associated with AS suggesting that the gut microbiome plays a role in disease.

In recent years, only a few studies have examined the make up, diversity and function of the human gut microbiome. Studies comparing the gut microbiota of lean and obese twins have shed light on the importance of intestinal microbes and how a change in microbiome composition can affect food metabolism in the gut. A study in 2009 showed that even with a similar genetic make-up, twins that were obese had substantial differences in both the number and type of bacteria in their gut flora, with a dominance of Gram Positive bacteria from the phylum Firmicutes (1). This shift in gut flora composition changed how food was broken down and processed in the gut, leading to increased body mass index and obesity (2). This shows us how changes in the gut microbiome have consequences that affect health.

When our normal gut microbes get out of whack, the result isn't always just a few extra kilos. After a few courses of antibiotics, sometimes the result can be a stubborn and recurrent bacterial infection known as *Clostridium difficile* or C.diff for short. The main symptom is nearly constant and debilitating diarrhoea, and this particular bacteria is resistant to almost all antibiotics we have and is very difficult to get rid of.

*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.*

## A gut feeling about AS *continued from Page 1*

### Contents

A gut feeling about AS	1
Top 10 Tips for AS	3
AS Exercises	5
AS Vic Inc Report	6
AS Group of Qld Report	8
Calendar of Events	9

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Recently, one of the most successful therapies for C.diff is to re-populate the intestine with healthy bacteria to keep C.diff in check. There's been only one way to do this, get rid of the old gut flora and swap it for a new and healthy one... in other words, a faecal transplant! (3) This involves taking faeces from a healthy donor (a close family member or very, very good friend) filtering, and then reintroducing the new faeces to the gut either through a nasogastric tube into the stomach or directly to the gut during a colonoscopy. However, the screening of the donor faeces is minimal and not consistent between centres. We all carry different bacteria, viruses and parasites at any given moment and while they might not do the donor any harm, this means we may be introducing potential pathogens as well as the healthy flora to the transplant recipient. This kind of therapy is still in its infancy although results for patients with C.diff have been very promising and therapy is currently being trialled in patients with Crohn's disease. However, we still don't really know exactly what a healthy gut microbiome should consist of, or the long-term effects of a faecal transplant. It may not be as simple as taking microbes from one person and giving them to another, just as you can't just take blood or a kidney from one person and give it to another. We know that everybody has their own combination of microbes in their gut and a healthy flora for one person may not be healthy for another. Very little is known about this and research is on-going. Currently several laboratories in the US are working on patient screening on how to best regulate faecal transplants to ensure the bacteria that are being transplanted will do what we think they should. This is so we don't have any unexpected consequences, with the goal of eventually not having to use a donor for the transplant at all, but tailoring the combination of microbes grown in the lab for each individual patient.

This work is currently on-going and while much more research needs to be done, it is clear that we can't ignore

the bacteria in our gut. Researching the gut microbiome opens the door to better understanding the role of the gut in AS, as well as the possibility of new treatments – and it might be as simple as changing our gut flora.

Now, let's talk lunch options....

Further reading:

On gut bacteria making us fat:

<http://www.bbc.com/news/health-23970219>

Faecal transplants:

<http://www.abc.net.au/news/2014-03-18/sydney-doctor-claims-poo-transplants-curing-diseases/5329836>

<http://www.huffingtonpost.com/leonard-smith/clostridium-difficile-b-2818740.html>

<http://www.nature.com/news/policy-how-to-regulate-faecal-transplants-1.14720>

ABC's Catalyst 2 part series on gut flora:

<http://www.abc.net.au/catalyst/stories/4067184.htm>

References:

1. Turnbaugh PJ, Hamady M, Yatsunencko T, Cantarel BL, Duncan A, Ley RE, et al. A core gut microbiome in obese and lean twins. *Nature*. 2009;457(7228):480-4.
2. Ridaura VK, Faith JJ, Rey FE, Cheng J, Duncan AE, Kau AL, et al. Gut Microbiota from Twins Discordant for Obesity Modulate Metabolism in Mice. *Science*. 2013;341(6150).
3. Petrof E, Gloor G, Vanner S, Weese S, Carter D, Daigneault M, et al. Stool substitute transplant therapy for the eradication of *Clostridium difficile* infection: 'RePOOPulating' the gut. *Microbiome*. 2013;1(1):1-12.

Mary-Ellen Costello is a PhD student in Prof Matthew Brown's laboratory based at the University of Queensland Diamantina Institute.

## TOP TEN TIPS for managing AS *by Brisa France and Ingrid Hill—Senior Physiotherapists, RNHRD.* Reprinted with the kind permission from NASS.

We are two Senior Physiotherapists working at the RNHRD in Bath, England. We have devised these top tips for managing an AS flare from our experiences of working with people with AS over the last 15 years.

### 1. Understand your Condition

Educating yourself about AS empowers you to manage your condition more effectively. Get good, well-informed information and always ask questions at your appointments. Don't forget the NASS website [www.nass.co.uk](http://www.nass.co.uk). Write down the information you are given and keep it in a safe place so you can refer to it when needed. Listen to your body and keep a mental note of how your AS changes, what helps and what seems to make it worse. Try the "Talking AS" website if you want to monitor how your AS affects you over a few months [www.talkingas.co.uk](http://www.talkingas.co.uk).

AS seems to have times when it will flare and episodes when it is more manageable or settled. A flare can include pain, stiffness and fatigue. Understanding all these features can help you to manage them.

**PAIN** can be due to:

Active inflammation in the tissues around the joints and tendons. This can be a very intense / raw type of pain.

Shortening / tightening of muscles or tendons around inflamed areas. This can lead to a dull, achy type of pain.

Protective muscle spasms pulling on inflamed sites. This pain can be intense and sharp.

**STIFFNESS** can be due to:

Joints fusing or formation of bony bridges restricting movement.

Muscles and tendons shortening and tightening, as part of the inflammation and healing cycle.

**FATIGUE** can be due to:

The inflammation and healing cycle using energy.

Muscle spasms as a response to pain using energy.

Poor quality of sleep due to pain.

Loss of deep sleep so energy levels are not adequately replenished.

Stress from living with a chronic inflammatory condition.

### 2. Medication

You need the help of medicine to live with a chronic, inflammatory, and painful condition and to help deal with a flare. These include anti-inflammatories and painkillers. We advise you take your medication, especially painkillers, as soon as you wake up and realise that you're having a flare. The whole procedure of getting out of bed can be painful - so get help from painkillers as soon as possible. Keep an emergency pack of your medication, water, and a biscuit next to your bed. Remember it takes 20 minutes for your medication to start to work.

It's important to know the maximum dosage you can take in 24 hours for all your medications. It is easy to lose track of the number of doses taken, especially if you are feeling "muzzy-headed" and sleep-deprived. Remember to replace your emergency pack of medicine ready for the next time it is needed.

### 3. Breathing Techniques

During the 20 minutes that you are waiting for your medication to work, the best and most effective thing to do to alleviate the flare symptoms is to BREATHE.

Research shows that just three good diaphragmatic breaths correctly learned when you are not experiencing a flare can greatly reduce pain levels by:

Relaxing muscles.

Controlling feelings of panic.

Lowering your stress hormone levels.

Giving you a feeling of being in control.

Slowing your breathing techniques avoids the fast panicky upper chest breathing associated with flares and will help to flood your system with oxygen and nutrients which in turn will help to break the build-up of pain resulting in a constant cycle of pain.

### 4. Mind/Body Link

Never underestimate the strong relationship between your mind and body. Your head will always influence your pain and conversely your pain will always affect your head and mind. Your pain signals are received in your brain and that is what controls your response. So:

PLAN a strategy where you make sure that you are in control of your AS and not the other way around. Your aim at this stage is to not allow the pain to build up to a level where it takes over your life; this is what is known as the cycle of pain.

During a flare people can sometimes feel panicky tearful and out of control. AS feeds off this stress.

### 5. Gentle Stretches in Bed

Whilst you are waiting in bed for your medication to take effect, don't forget that your bed is a soft, safe and gentle environment. Your spine, joints and muscles are feeling warm and unaffected by the pull of gravity. The worst thing to do is to keep still, even though it is the one thing that you most want to do. The key word here is GENTLE, do a few simple stretches that you know well without aggravating your pain.

### 6. Get Out of Bed

Wait for the painkillers to take effect before getting out of bed. If you know



## TOP TEN TIPS for managing AS *continued from Page 3*

it is going to be painful getting out of bed, then:

Try to move in stages so you do not pull on muscles that are already in spasm.

Move on the out breath - do not hold your breath while bracing yourself.

Let your body adjust to each position before moving to the next one.

### 7. Shower/Bath

Warm water helps to relax tight muscles and release the stiffness in joints. It is also pain relieving. You may find the jet of warm water from a power shower helps TO soothe sore areas, like a massaging effect. Soaking in a bath can also be soothing — if you can get in and out safely without causing more pain.

### 8. Stretches and Movement

The important thing to remember is that you won't hurt yourself if you have been taught the correct stretches by your physio. Gently stretch the areas that stiffen up and tighten up with your AS even if this feels as though it might be harmful and counterproductive. It is one of the main strategies for limiting the duration and intensity of

your flare. Try to go out for a short walk; natural daylight helps to lift the mood by releasing endorphins which in turn help you to cope with your pain.

### 9. Pain Relieving Techniques

During a flare it is useful to sit quietly and take stock of the situation. Then try some of these recommendations in combination with your medication.

**HEAT:** Wheat or cherry stone packs or thermal heat stick-on packs, (useful if you need to be on the move). Sometimes an alternating combination of heat and ice can stimulate blood supply locally to the painful area.

**HOT BATH/SNOWER:** A combination of Epsom salts and/or your favourite aromatherapy oils can relax and help to lift your mood.

**TENS MACHINE/PAIN PEN:** Learn the correct way to use them, the pulsed programme of impulses is better.

Learn **ACUPRESSURE POINTS** and then use them on yourself.

Learn **RELAXATION AND OR MEDITATION** techniques.

Don't forget that even when you are in flare it is safe to attend your local

NASS group especially if there is access to a hydrotherapy pool where you can do some gentle stretches.

### 10. Educating Family, Friends and Colleagues

It is best to explain your condition when you are feeling well. There is nothing worse than having to explain AS when you are feeling unwell, miserable, grumpy and tearful. People close to you can become anxious and worried when they see you in pain; it can help to reassure them if they understand your condition. Some people have a code word for a bad AS day so the whole family can understand how they are feeling, and this helps to decrease tension for everyone. You can get extra guidebooks from NASS and a guide to managing AS at work which gives advice on talking to your managers and work colleagues.

**FINALLY if your flares increase in number or intensity, seek advice from your rheumatology team or GP as your medication or its dosage might need changing.**

**DO NOT SUFFER IN SILENCE.**

**There is help out there.**

## Paracetamol - may not be as safe and gentle as you might think!

Paracetamol - may not be as safe and gentle as you might think.

A recent article in the Courier Mail QWeekend July 2014, posed this question. Following are a few points made in this article. This information is not complete, and any further information or clarification should be obtained from your health professionals - GP, Rheumatologist and pharmacists.

Paracetamol was discovered in the late 19th century. It has been used in Australia to relieve pain and fever since the 1950's. It is available in many forms with common brand names. At the recommended dose, it is assumed safe and effective, and encouraged as the preferred choice for relief, especially with Osteoarthritis (OA). Use of it took off in the 1960's in response to emerging concerns about the long

term side effects of aspirin and the other NSAIDS, which can irritate the stomach lining and cause bleeding.

If too much paracetamol is taken, it can seriously damage your liver. The assumption that in the recommended dose, all is fine, is now being challenged. In 2011 Michael Doherty of England's Nottingham City Hospital published a study that followed the progress of 892 men and women with knee pain. Some were given paracetamol, other ibuprofen, while a third and fourth group took either high- or low- dose combination of the two. The blood results of the people taking the paracetamol indicated that they were losing blood internally, at the same amount as those taking ibuprofen - only the ibuprofen group reported feeling less pain.

The article also mentions a review of research

that looked at people taking paracetamol to relieve chronic joint pain found seven studies that compared the drug with a placebo. Five of these found it to be marginally more effective, but two found no difference. They state that in March, the Osteoarthritis research Society International changed its paracetamol guidelines to "uncertain" to reflect growing safety concerns.

Most experts believe it's still useful for fevers, headaches, sore muscles and acute pain. However, for chronic pain, it could be time to rethink. Also, some drugs work better for some people than others. It is important to think about all drugs that you take, and if they are working for you.

**Seek medical advice for any further information.**

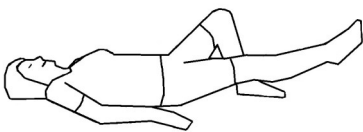
## AS Exercises by Margaret Lewington (Physiotherapist)

The exercises in this newsletter focus on 'core' strength - control of the trunk and abdomen, while doing another movement. They are Pilates type exercises. Good control of the 'core' muscles is important for back health, especially if you are still quite mobile.

For most of them, start in the relaxation position with your core activated - ie start on your back, knees bent, arms by your sides, palms up. Hips, knees and feet in line. Rock your pelvis back and forward (arch and flatten) to find mid range - and rest here - neutral spine. Draw your low tummy gently in, hold, and keep breathing. (activate the core)

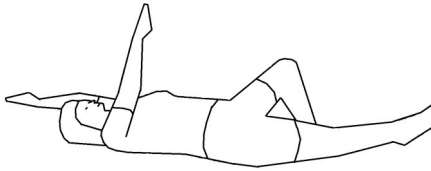
Keep your chin tucked in and neck long, shoulders and body relaxed. BREATHE - slowly throughout, expanding the lower ribs. They demand some general and specific strength. Take care, progress slowly, technique is critical. Some may not suit everybody. Gradually increase repetitions to 10 each side.

### 1. LEG LIFT AND SLIDE



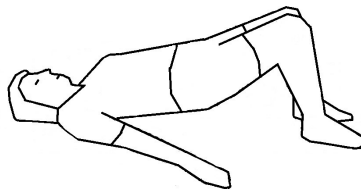
Lie on your back, as described above. Now lift one leg and bring the knee towards your chest until your thigh is vertical. Pause. Slowly straighten out knee keeping leg just off the mat. Pause. Return by bending up again and place your foot back on the mat. Repeat with the other leg.

### 2. DEAD BUG!



Lift both arms to the ceiling, elbows straight, palms facing. Lift leg same as exercise 1 and at the same time take the opposite arm overhead - to just off the mat. Pause and keep the neutral spine position. Return to start position as you repeat with the opposite arm and leg. Now slowly alternate. BREATHE.

### 3. BRIDGE



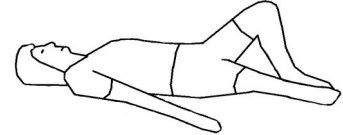
Flatten your spine to the floor by tilting your pelvis back. Slowly scoop your bottom off the mat, vertebra by vertebra, until your shoulders, hips and knees are in a straight line. Hold for a moment then relax back to start position vertebra by vertebra.

For extra challenge, while holding the bridge position

a) Lift your arms to the ceiling, with straight elbows and palms facing, slowly take arms overhead to just above the mat. Then take them around to shoulder height and then back to the start.

b) Extend one knee to straighten leg. Keep knees at the same level but not touching. Then bend back to start position.

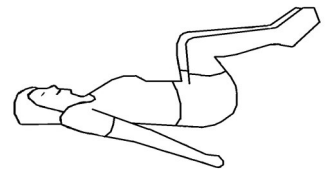
### 4. BENT KNEE FALL OUT



Gently and slowly lower one leg out to the side as far as you can control, then return. Keep the other leg still. Do not allow your pelvis to roll. Keep the movement smooth throughout.

### 5. TABLE TOP

Raise one leg until the knee is vertically over your hip



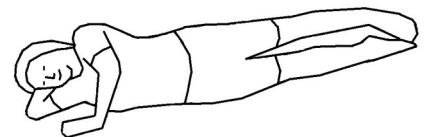
and the shin is horizontal. Lift your other leg to the same position (progress to 5 sec holds) Lower one leg at a time, keeping spine in neutral all the time.

For extra challenge, while holding the table top position

a) Raise your arms just off the mat, curl chin to chest reaching past your hips and perform a small abdominal curl until shoulder blades are off the mat.

b) Slowly roll legs in the table top position from side to side, about 30-40 degrees. Ensure good control throughout.

### 6. SIDE DOUBLE LEG LIFT



Lie on your side, legs straight, arm under head. Top hand on mat for support. Activate your core. Keep feet together, raise both legs off the mat and hold a moment and return. Gradually increase to 5 sec holds.

## Ankylosing Spondylitis Victoria Inc Report *by Annie McPherson and Allan Davidson*

Welcome to new members Lyn, Kaye, Dionne, Dale and June.

### Our Fairfield RSL Coffee and Chat

meetings have swapped over to the evenings (the second Tuesday in the month) for the summer. Now we are on daylight saving time come and join in the chat.

**AS Victoria Inc's annual AS Information Seminar** was again held at Austin Health. Over 30 people with AS attended, along with their family and friends. This year we had attendees and members from all around Victoria, many from Melbourne's eastern suburbs.

Annie opened the proceedings then introduced Simon Von Saldern, Arthritis & Osteoporosis Victoria's (A&O Vic) General Manager of Development and Services as our MC. Simon's group at A&O Vic manages the finance, information technology, administration, communications, marketing and fund raising services which includes our AS Vic Peer Support Group. Simon provided a brief talk on the A&O Vic "Make-A-Move" campaign, to raise Victorian Government awareness of the need adequately fund for MSK conditions.

Dr Christopher Mack, FRACP a Rheumatologist, with practices in Ringwood, Lilydale and Wantirna and also a consultant at Eastern Health at Box Hill was the next speaker. Dr Mack's presentation "Bath to Bedside" covered his experience in Bath, UK as a registrar and then consultant working with AS patients. The Bath AS course promotes self-management, teaching patients how to optimize their health and the best exercise program. This program and the simultaneous development of the warm water exercise program continue today and are qualified by the stories of success that regularly emerge from the UK AS Society, NASS. Dr. Mack continued with an interesting profile of Spondyloarthropathies (SPA) and correlations of back pain across the different conditions. A number of tools rheumatologists have today for example BASDAI, to gauge the level of progress of



AS and its impact on a patients life were developed by the physiotherapists working in Bath.

Belinda Coulter, physiotherapist then lead the audience in a brief stretch exercise routine prior to the refreshment break. Many participants took the opportunity to meet with others to exchange ideas about day-to-day management and exercise routines over a sandwich and cup of tea.

After the break, Simon had the pleasant duty of presenting Maria Makris with her A&O Vic, Five Year's Service award for volunteering with a Peer Support Group. Well done Maria!

Belinda Coulter returned to the speaker's platform to present a summary of the activities at Caulfield Community Health Services Physiotherapy AS Program. The program has been held twice a year, for over 20 years and is loosely modelled on the Bath AS program, with a strong emphasis on warm water exercise. In recent years self-management such as meditation and relaxation techniques have been added. To demonstrate participant progress Ms Coulter prepares a pre and post program report including a BASDAI, for each persons specialist.

Dr Lionel Schachna, Consultant Rheumatologist Austin Health, who is well known to many AS Victoria Inc members, then proceeded with a Question and Answer



*Dr. Lionel Schachna presenting*

session, joined by Dr. Mack and Ms Coulter covering areas of: Use of NSAIDS treatment long term and slow down in spinal fusion; Medication suitable for peripheral joint disease; 10 years history in Australia of AS and Anti-Inflammatory biologics medication; Biologics and exercises combination; Health professionals

now detecting and diagnosing AS earlier and treatment alternatives available; AS responds best to Biologics out of all the SPA's.

Follow up comments from the participants included: "Well done AS Vic. - An excellent selection of speakers this year", "Thank you to AS Vic for providing an educative forum on AS", "Thank you for helping me and my family to understand this complex condition and learning new ideas to help with management"

As President I thank our committee and volunteers, they have done an excellent job of organising a very successful event. The committee thanks the speakers for their excellent presentations and continued support for those with AS. Our thanks also for support from: Austin Health, Education Precinct and Spondylitis Clinic, Aust Café, MBE Kew and AbbVie Aust.

The Festive Season is almost upon us, the Committee of AS Victoria Inc wishes to extend Seasons Greetings to all our members, supporters and associates.

Regards **Annie McPherson**

### Arthritis & Osteoporosis Victoria:

Late in August, our AS Vic PSG committee members, Vicky Genius and Adam Collard joined me in attending the **Peer Support Group (PSG) network** of Arthritis & Osteoporosis Vic. (A&O Vic) **Leader training** at their conference rooms in Elsternwick. In all over 30 representatives from Melbourne and regional Victoria PSG groups participated. Ideas and practices were exchanged as well as a chance to catch up over lunch. Subjects discussed included A&O

Vic membership fees and services, public liability insurance cover, consumer advocacy and engagement work, group promotions to increase awareness of musculoskeletal (MSK) conditions in our communities.

In early October Vicky Genius and I assisted John Catchpole of the Men's Health



## Ankylosing Spondylitis Victoria Inc Report *continued from page 6*

Group, with an **Arthritis & AS Information Table at the Whitehorse and U3A Nunawading "Positive Ageing Expo"** in the Whitehorse Centre, as part of their 2014 Whitehorse Seniors Festival. The Expo and lectures were very busy, with over 30 enquiries at our stand. We provided information from A&O Vic, AS Vic, Astretch newsletters and many fact sheets

**Cycling Victoria event, 117th Austral Carnival / Australian Madison Championship** The world's top cyclists will be lighting up the boards at Hisense Arena on Saturday 20 December. Five time Olympian Shane Kelly will be riding to help raise awareness of MSK health in Australia. Joining Shane on the back of a tandem bike is Mike McKenzie (see following article)



### Make A Move Ride 2015

Mike McKenzie and Stan Proctor will be cycling the 3,750km from Melbourne to Darwin next September to raise awareness about the prevalence of musculoskeletal conditions in Australia, and to raise funds for Arthritis and Osteoporosis Victoria. Both seasoned veterans in long distance cycling – Mike and Stan have ridden from Melbourne to Sydney together and Mike has also tackled the long road from Mel-

bourne to Perth. The inspiration behind taking on such a challenge came about after Mike's 29 year old son Bradley was diagnosed with Ankylosing Spondylitis earlier this year. They aim to raise \$50,000 and will be supported by Arthritis and Osteoporosis Victoria and AS Victoria in their fundraising efforts leading up to the big event. If you would like to support Mike & Stan please contact :-

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or Annie 0408 343 104

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Belinda Coulter physiotherapist, advised the **Caulfield Community Health Service** Physiotherapy AS program, which ran from late August, into early October was fully booked and again very successful. Dr Lionel Schachna from Austin Health Spondylitis Clinic, Anne Lloyd from A&O Vic's MKS Helpline and myself contributed sessions to the program. The first session for 2015 program is due to commence in late March. Please contact me directly if you require more information on my mob. 0408 343 104.

Regards

**Annie McPherson**

**President AS Victoria Inc**

Merry.  
Christmas

### A new TNF for AS now listed on the PBS

From 1st September, 2014, Cimzia (Certolizumab pegol) became an authority required listing on the Pharmaceutical Benefits Scheme for the treatment of adults with active Ankylosing spondylitis who meet certain criteria. Cimzia has been indicated for the treatment of Rheumatoid Arthritis, and this year the indications for use of Cimzia were extended to include Ankylosing Spondylitis and Psoriatic Arthritis.

The active ingredient in Cimzia is a humanised monoclonal antibody produced by cultured cells. Monoclonal antibodies are proteins that recognise and bind to other unique proteins.

Overproduction of the naturally occurring protein, Tumor Necrosis Factor, TNF, is thought to cause RA, PsA and AS. Cimzia works by binding to a specific protein, TNF and blocking its action.

### Golf Clinic

In September we headed to **Albert Park Golf Driving Range** to Kevin Webster's Golf Clinic held especially for our members. We all had a successful day and learnt something valuable for our pursuit of the perfect golfer. Tamara was a little awed by



*Some great form at our members golf clinic!*

the amount that needs to be learnt, but it was a good introduction for her. Paul had good instruction from Kevin and is following up on what he has learnt. Overall good advice for us golfers and a fun day. Kevin was delighted with the interest shown on the day and has offered to make it an annual event.



*Allan, Tamara and Paul*

**Allan Davidson**

**Committee Member AS Victoria Inc**

Cimzia is injected under the skin. (subcutaneously) After the loading dose, the recommended dose of Cimzia for adult patients with Ankylosing Spondylitis is 200mg every 2 weeks or 400mg every 4 weeks.

*NOTE: This information is a brief comment only. It does not represent the entire body of information on this topic. Further information should be obtained from your Medical professionals - Rheumatologist and Pharmacist.*

## AS Group of Queensland Report *by Ross Wilson*

It's been a quiet few months for the Group since the last Newsletter, with just the one event, which was a picnic at Bribie Island. Unfortunately I was away on holidays and missed it but I am told it was a great day with a number of the Sunshine Coast members attending, which was great to see. The weather was perfect, as usual.



*Some of the AS Qld Group at Bribie*

On the subject of holidays and life in general, my wife and I came to a decision awhile back while on an overseas holiday in Cambodia and Vietnam. After watching so many of our group miss some of the best bits of the tour because they either weren't physically capable or didn't want to put in the effort, we decided that we would go to and do all of the things that in later years we may not be able to do.

AS has affected my life, there is no denying it, but I will not let it take over. I work hard at staying active and continue to do most of the things I have always done. I can't work as hard and long in the garden as I used to but getting older could have something to do with that as well. Riding my Ducati and mountain bike is still a passion, I just find I have to stop for a break a bit more often than I used to.

We both enjoy exploring new places and meeting new people and we have drawn up a long list of places

we want to visit and things we want to do in the coming years. I love to challenge myself and see what I'm capable of. On our recent trip to Carnarvon Gorge we trekked over 50 kms during the four days we were there and saw everything there was to see. Although we were pretty buggered by the end, it was very satisfying.

I still remember the feeling I got when I was finally diagnosed. It was a feeling of relief, finally knowing why I was feeling like I was. For over 15 years I didn't know what was happening. Was it all those years racing motorcycles and the crashes that went with it? Or was it the aftermath of the other silly things I had done in my youth? Finally knowing enabled me to take charge of my condition and with the help and guidance from my Rheumatologist, Physiotherapist and the meeting and talking to others with AS, put me on the right track to tackle this condition. Warm water exercise plays a big part in keeping me flexible and I thoroughly recommend it. AS affects everyone differently, but the most important thing is to have a positive attitude. It has certainly helped me over the years.



In other news, Helene Frayne, the CEO of Arthritis QLD has tendered her resignation, effective at the end of November. This should not have any impact on our Group and we wish her all the best in her future endeavours.



*Ross just hanging around after a long*

Margaret Lewington has once again travelled to the ASIF Conference, which was held in Bulgaria this year. We are very thankful to have Margaret representing us and the Australian Groups at such an important event.

Christmas is fast approaching and our Christmas Dinner is on again, so please check the calendar for info and please consider coming along. It always is a good night to celebrate friendships and enjoy the festive season.

I would like to take this opportunity to wish everyone a very Merry Christmas and a safe and free moving New Year.

**Ross Wilson**

**President**





## Calendar of Events

### VICTORIA

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

**Tuesday 10th Feb 2015: Coffee & Chat** meeting at Fairfield RSL

**Tuesday 17th Feb 2015: Committee Meeting** and Social dinner following.

Please also check Arthritis & Osteoporosis Vic. website for events [www.arthritisvic.org](http://www.arthritisvic.org)

### QUEENSLAND

Refer to [www.asaustralia.org/qld/](http://www.asaustralia.org/qld/) for details or Mark Robinson mob: 0407 425 750

**Saturday 6th December - Christmas Dinner** at 6:30pm.

Asian House Chinese Restaurant - Shop 3, 82 Meadowlands Road, Carina.

Cost: \$35 per head plus \$3 corkage for BYO.

RSVP: 29th November by [email](#), Phone or at Hydro.

## 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:** \$10 or 10 classes for \$90

**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 5:30 - 6:30pm.

Gymnasium & pool 5:45 - 7:45pm.

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

**Where:** Arthritis WA,

17 Lemnos St, SHENTON PARK.

**Cost:** \$8

**Enquiries:** [Lindsay](#)

[lindsay.dutton@health.wa.gov.au](mailto:lindsay.dutton@health.wa.gov.au)



### 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)

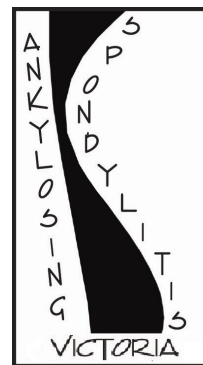
[www.nass.co.uk](http://www.nass.co.uk)

*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 an Arthritis and Osteoporosis Victoria 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.au

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: \$ \_\_\_\_\_

**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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