

WINTER 2013
NEWSLETTER

AStretch

ANKYLOSING SPONDYLITIS AUSTRALIA

www.asaustralia.org



The gut, the bad and the friendly

by Tony Kenna

The immune system protects us from all sorts of nasties – bacteria, viruses, fungi, tumours to name but a few. In order to do this the immune system has developed vastly complex and intricate ways of distinguishing good from bad, or harmless from harmful. Generally this works well but in the case of infection or cancer or widespread inflammation and autoimmunity the immune system goes wrong. In AS, the immune system attacks the body's own cells and tissues. We know this involves components of the immune system called cytokines. Cytokines are like mass-messengers of the immune system, they allow one cell to communicate sets of instructions to thousands or millions of other cells. It's a bit like if you stand in front of a very large and noisy group of people and try to speak to them; you could either talk to each one individually and exhaust yourself and probably miss out on speaking to many, or you could use a microphone to carry your message a long way with little effort. So if one immune cell senses something is wrong it can release lots of cytokine molecules that float through the blood system to millions of other cells and alert them to what's happening.

Our genetic studies highlighted the importance of the cytokines IL-23 and IL-17 in AS. Inhibition of IL-17 has proven an effective therapy in early clinical trials, demonstrating that this is an important driver of inflammation in AS. Various studies have taught us lots about the cells producing and responding to these cytokines. But we still don't understand why they are produced in the first place. To investigate this we've turned our focus towards the gut.

While, at first glance, investigating the role the gut plays in AS may seem like a bit of a research tangent there's solid, clinical and scientific logic to justify it. The co-existence of AS and gut inflammation has been known for some time and between 5-10% of AS patients develop clinically diagnosed inflammatory bowel disease (IBD), and a further 70% of AS patients develop subclinical gut inflammation. In reactive arthritis (ReA), a member of the SpA family, inflammatory arthritis sometimes develops following gastrointestinal infection with particular bacteria, indicating that inflammation in the gut may influence

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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 gut, the bad and the friendly - continued from page 1

inflammation in joints. Recent advances in our understanding of the genetics of AS and IBD show us that AS and IBD share some important abnormalities, including abnormalities influencing IL-23 and IL-17.

Our TV screens and other media are filled with messages about the importance of a balance of good bacteria and bad bacteria in our diets. Incredibly, these ads are spinning us too tall a tale. In fact, there is mounting research evidence in many diseases that the bacteria in your gut can have a very important effect on your overall health. We are covered in and filled up with billions of bacteria, many of which are good for us. The good types help us digest food, produce nutrients we can't produce ourselves and even protect us somewhat from harmful bacteria. We live in a state of 'symbiosis' with these helpful bacteria and they don't cause disease. Bad bacteria do. Altering the balance of good and bad bacteria could then have a profound effect on health. It is doubtful that a single harmful bacteria is responsible for activating the inflammatory immune response in AS patients since 'outbreaks' of AS are not found. So the idea that a dodgy kebab could give you AS is unlikely. However, fairly subtle alterations to the composition of the bacterial flora, the collection of bacteria living naturally in and on us, may tip the balance of helpful and not-so-helpful bacteria against our favour.

To investigate this we have undertaken a study in Brisbane to compare the types of bacteria found in the gut of AS patients with healthy controls. Through our collaboration with Prof Giovanni Triolo and Dr Francesco Ciccia from the University of Palermo in Italy we are lucky enough to have access to gut biopsies from AS patients and healthy individuals. Lately, the news has been full of stories of horse meat being found in European 'beef' burgers. That was discovered through looking for horse DNA sequences in beef. Each species of bacteria have their unique DNA sequences and we use DNA sequencing techniques to determine what species are found in our gut biopsies. So far, we've looked in a fairly small number of samples because gut biopsies are not easy to come by (not surprisingly). Nonetheless, already we are starting to see differences in the microbes found in AS patients compared with healthy controls. No specific bacteria seem to dominate in AS patients but rather there is an alteration in the balance of normal bacteria. We believe genetics rather than diet or lifestyle is the main driving force behind these differences although we'd always advocate a healthy, balanced diet to maintain overall health.

As our studies progress we hope to learn about the 'microbial architecture' of AS and understand how the collection of microbes in AS gut may activate the immune response. Ultimately this will help us get to the heart of understanding inflammation in AS.

Tony Kenna

BSc (Hons), PhD

Research Fellow, UQ Diamantina Institute.

Health Professional Seminar by Margaret Lewington

The annual Health Professional Seminar run by Arthritis QLD in March was a great success, as usual. There was a very good attendance and an excellent programme with updates in many areas of rheumatology. Seven rheumatologists gave their time to give presentations as well as a podiatrist and pharmacist.

Topics covered practice in regional areas, osteoarthritis, paediatrics, polymyalgia rheumatica, osteoporosis, communication of benefits and risks of treatment and most importantly to us - 'Back Pain - a condition to be taken seriously'.

Dr Phil Robinson, who works at the AS Specialist Clinic at PAH (along with Prof. Matthew Brown) gave an excellent talk. His key messages were that we should consider Inflammatory Back Pain (IBP) in people presenting with back pain that has lasted at least 3 months. That we should look for and ask about the features of IBP and refer if we are suspicious.

He clearly identified the principles of mechanical and inflammatory back pain, highlighting the differences. He then outlined features of Spondyloarthropathy (SpA) and AS. He discussed back pain and sacroiliitis - Xray and MRI finding, as well as other diagnostic features such as Psoriasis, Peripheral arthritis, Inflammatory Bowel Disease, Iritis and uveitis, Enthesitis (Achilles), swollen digits and family history.

He presented figures that show SpA and AS are more common than often thought and highlighted the delay in diagnosis in most cases. He emphasized the need for early referral and treatment - outlining the values of early diagnosis. This included the patient having a correct diagnosis, hence being able to avoid inappropriate and/or harmful treatment, accessing good physiotherapy early as well as correct pharmacological management and decreasing complications of SpA.

He outlined treatment, including medical and pharmaceutical advances and current research findings. This was a helpful update.

He successfully increased the awareness of IBP, SpA and AS. He also showed that it is a condition that we can do something about. It can be well treated with both physical (physiotherapy) and pharmacologic therapies and the person can be helped and their life improved. Early diagnosis and referral is important.

Dr. Phil Robinson at this years annual Health Professional Seminar



Move to Improve

The benefits of regular physiotherapy

AS NEWS Autumn 2012

Reprinted with the kind permission from NASS

In last autumn's edition of AS News we let you know that Gareth, a very kind NASS member offered to pay for a year of private physiotherapy sessions for a NASS member who was unable to access physiotherapy either through a NASS group or the NHS. Thank you to everyone who applied to receive the physiotherapy. In the end, Gareth chose to fund physiotherapy for not just one but two NASS members! Thank you Gareth. Kelly and Adrian have written about how they have benefited from weekly physiotherapy.

Kelly's story

I am 27 years old and was diagnosed with AS two years ago. I first presented with symptoms at the age of 17 but like so many, went undiagnosed for years. My initial symptoms were quite unexpected and took both my family and myself by surprise. After several unsuccessful GP appointments and a MRI scan that came back 'normal', I was unable to get any answers as to why I was in so much discomfort. So I persisted for years, refusing as best as I could to not allow the pain to compromise my studies. As the years passed me by, my symptoms became increasingly intense and prolonged, so I decided to pay for a course of private physiotherapy to ease my pain and stiffness. This was a real turning point for me - it was here that my symptoms were immediately recognised and I was swiftly referred to a rheumatologist at my local hospital, who diagnosed me with AS. Getting diagnosed was, in so many ways a relief, as I finally had an answer as to why I was feeling so awful. However, it was also incredibly daunting, as being so young and leading such an active life as a singer, I was concerned about the impact AS would have on my life. After my diagnosis, I continued to have private physiotherapy as often as I could afford, and I also took up Pilates and swimming. Pilates has really helped to establish my core stability and I found that swimming loosened me up a great deal. Even though my physio sessions were few and far between, I looked forward to them immensely as I knew I would always leave feeling so much better. It was purely by chance last Christmas that I stumbled across the offer in AS News. I submitted my application and was lucky enough to be shortlisted and then selected for funding. I am currently four months into my treatment and I am feeling great - the benefits are profound. Each weekly session consists of mobilisation techniques to mobilise stiff joints, trigger point release to ease off a surrounding muscle that has gone into spasm, guidance on stretches relevant to the areas of pain and stiffness I am experiencing, and most recently acupuncture on the sore points on my spine, neck and shoulders. The relief is almost instant and I walk away eased of pain and stiffness. Combining physio with swimming and Pilates has allowed me to become less reliant on my medication and has really given me such comfort and support. Physiotherapy has played such an important role in my diagnosis and indeed my journey through AS. The private physio I have received has made a tremendous difference to my mobility and is instrumental in controlling the level of pain and stiffness I experience on a daily basis. AS wasn't part of my life plan, and to this day it doesn't shape my life choices. I have made an active decision to continue my journey without restriction, and physiotherapy has really made this possible. My sincere thanks to NASS for all of their support, Sandra Lamb at The Rainham Physiotherapy Centre and also a tremendous thank you to Gareth for his generosity and for giving me the

opportunity of receiving weekly physiotherapy – it really has made my life brighter.

Adrian's story

I was diagnosed with AS in 2005. I live and work in County Down, Northern Ireland. I am married with two children aged 11 and 8. I am a chef by profession. Before starting the physiotherapy sessions the effects of AS made my life very difficult to manage. The physical and mental demands of my work as a chef and the challenges of raising two young children, along with the constant pain and restricted mobility of AS made my life a real struggle. I had a constant need for medication to reduce the pain. My morale was low and I was left with little energy, when it came to interacting with my family after work. Whilst my work as a chef is rewarding, it is physically demanding, involving using the body in many different ways in a confined space in high temperatures. Before starting my physiotherapy sessions this work was quite overwhelming. My weekly physiotherapy sessions included a range of movement exercises, stretching, strengthening and endurance exercises, balance activities and core stability exercises. The physiotherapist looked at my posture and gait and gave me advice on improving both. She also gave me acupuncture to help with the pain. Finally, she gave me a home exercise programme to carry out between sessions. The benefits of the regular physio sessions have been very impressive. I have a reduced need for pain control, increased mobility and I feel much more relaxed. My morale is higher and I am much more enthusiastic about my work. I have more energy for engaging with my family. Overall, I now have a higher quality of life as a result of the physio sessions, which I have to say I initially approached with a degree of scepticism. My postural awareness and ability to self manage my condition and monitor symptoms have significantly improved.

View from the NASS physiotherapist

We can see from these two very fortunate NASS members, Kelly and Adrian, how regular one to one physiotherapy can really help target specific problem areas such as posture, tight muscles, reduced range of movement and pain, receiving treatment and advice and of course getting a personalised home exercise regime to carry on with the good work by themselves at home. This is why it is so important that you attend your annual review at the hospital or with your physiotherapist (even if you are feeling fine), so that any problems or deterioration in your posture or flexibility can be picked up and worked on straight away. It may be enough to alter your home exercise regime or else it may be appropriate for you to attend a course of physiotherapy at the hospital or your GP surgery depending where you're managed and looked after. If you are not under a rheumatologist or have not been to see him/her for some years it is worth asking your GP for a referral back to your rheumatologist for a medical and physio review. Of course don't forget that if you are lucky enough to live in an area where there is a NASS branch running then you too have access to regular physiotherapy. It may not be one to one but it will be run by a physiotherapist who has a special interest in AS and will always, I'm sure be very happy to talk to you after a session and offer advice on any problems you might have.

Claire Harris - Physiotherapist

Australian Rheumatology Association Database

A longitudinal study of the long-term effects of arthritis and its treatments in Australia

Australian Rheumatology Association Database (ARAD)

What is ARAD?

It is a national Australian database which collects important health information from individuals with inflammatory arthritis such as Rheumatoid arthritis, Ankylosing Spondylitis, Juvenile arthritis and Psoriatic arthritis. The aim of ARAD is to determine effectiveness and safety of new biological drugs used to treat inflammatory arthritis condition, such as Enbrel, Remicade, Humira, Kineret, MabThera and Orencia. ARAD collects information from patients every 6 months via questionnaires. Questions about medical history, medication history, responses to medication, physical functioning and quality of life are included. Patients and rheumatologists across Australia contribute to ARAD. **Participation in this patient study is completely voluntary.**

ARAD was established in 2003 as a national arthritis database to provide valid and reliable longitudinal clinical data of arthritis sufferers in Australia, with the ultimate aim of providing better care and improving outcomes for patients. ARAD looks at the long-term effects of different drug treatments, therefore the information we obtain may help us to better understand your condition and benefit arthritis patients in the future. ARAD is endorsed by the Australian Rheumatology Association (ARA) and is being conducted on behalf of its members. Rheumatologists are provided with a yearly report of their patients participating in ARAD. This report includes quality of life scores for each patient.

Recently, the Pharmaceutical Benefits Advisory Committee (PBAC) reviewed use of biologic medications. Data from the ARAD database was a very important resource for the review. The PBAC decided to amend the eligibility criteria for biologic medications. This amendment enables arthritis patients to receive biologic medications at an earlier stage.

ARAD has been fortunate to have Dr Alison Kydd from Canada undertaking an analysis of the ankylosing spondylitis patients in the ARAD database. The analysis focuses on long-term responses to biologic therapy and the influence of lifestyle factors such as smoking. As there are few large databases that collect long-term quality of life

measures in ankylosing spondylitis, the data from ARAD will help to examine how ankylosing spondylitis patients fare over time when treated with biologic agents. We noted from this analysis that patients with ankylosing spondylitis who were current smokers had poorer quality of life than non-smokers. (ARAD is also collaborating with another group based at University of Queensland to examine genetic aspects of Ankylosing Spondylitis.)

Prof Lyn March, current Chair of the Steering Committee for ARAD, says that the importance of collecting this long-term data from Australian patients with ankylosing spondylitis cannot be underestimated for examining long term safety. Further analyses are underway.

Visit the ARAD website for more information

www.arad.org.au

If you are interested in participating in ARAD please contact us:

Write to:

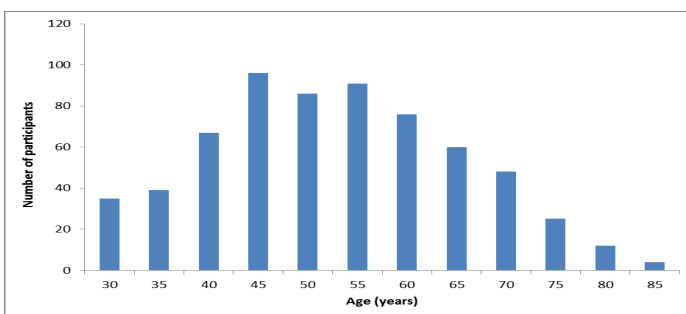
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ARAD is now in its eleventh year of operation with over 649 AS participants and over 4,000 completed questionnaires. The graph shows the age distribution of current AS participants, with the average age of current participants being 50 years.

Hydrotherapy in Brisbane

Supervised by Margaret Lewington
(B.Phty. Cert Hydro)

WHEN: Tuesday Nights

TIME: 6.30 – 7.30 pm

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 0404 414 501
or 07 3376 6889



Symposium



AS Group of Qld Symposium

This is the event of the year to look out for!

Planning is under way for a Symposium for people with AS, their partners, their carers and their families. It will be held later this year during either August or September depending on venue availability.

Several speakers have confirmed their attendance including a Rheumatologist, Ophthalmologist, Physiotherapist, Psychologist and other specialists and health care professionals. This is an excellent opportunity to learn about the latest research, drug therapies, treatments and services. It's also a great opportunity to catch up and chat with others who have AS. Lunch will be provided.

The date and venue is to be confirmed but please look out for further details on the website, via email or mailout. See you there!

Notice of AS Study

RHEUMATOLOGY RESEARCH UNIT, SUNSHINE COAST

Ankylosing Spondylitis Study

- Have you been diagnosed with Ankylosing Spondylitis?
- Are you wanting to start treatment or change your treatments because you have not had an adequate response?
- Are you interested in taking part in a research study looking at an oral medication to potentially relieve the signs and symptoms of Ankylosing Spondylitis?
- For more information please contact Lyndy Tolliday on 07 54431033 Monday, Tuesday, Thursday or Friday between 12 – 4 pm

Would our readers please note that this is a notice for a new drug trial.

Disclaimer:- The AS Group of QLD has no involvement with this research study. It would suggest you discuss any participation in this study with your own rheumatologist before proceeding.

AS Exercises

*By Margaret Lewington
Physiotherapist*

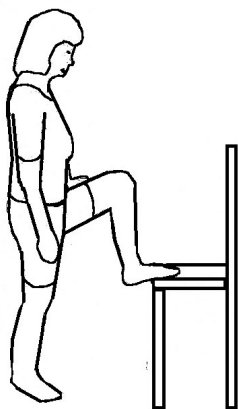
This series of exercises are simply done in standing - near a chair. This makes them easy to do at any time of the day. Grab a moment and do a few stretches. Little and often keeps you mobile, breaks up the day and helps you maintain good posture.

1 Chair taps

Firstly, warm up a bit by lifting alternate feet to the seat of a chair and tapping the chair. This is like walking on the spot or marching, but with a high knee lift. Watch your posture and balance - tummy in, chest tall, buttocks firm.

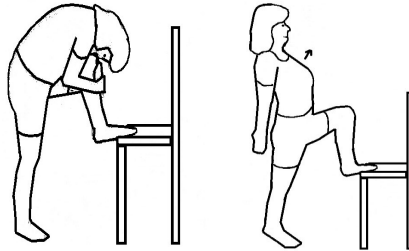
If you stand close to the chair you will need to lift your legs higher and it will take more effort.

You can do it slowly and steady - pausing with foot on the chair. Make sure you don't sway from side to side. You can also speed it up and turn it into a workout.



2. Forward curl - arch

With one foot on the chair, lean forward, curling you back. Hold your knee and pull yourself down - allow the low back to stretch and lengthen and the head relax down to stretch the back of the neck. Relax, breathe



and stretch. Now stand tall. Lift your chest up, palms to the front to open the chest and shoulders. (do not take your hands back too far as this will roll your shoulders forward). Lengthen through the front of the body - the tummy. Breathe in.

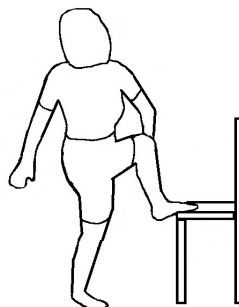
Repeat this several times on one leg and then change legs.

3. Trunk turn

With your left foot on the chair, place your right hand on the outside of your left knee. Turn to look around to the left behind you. Use your right hand to stabilise the left knee and keep it pointing to the front and also lever yourself around with this hand. Take your left arm around and turn and look behind.

Pause and hold. Repeat several times.

Now change legs and turn to the other side. You may also like to swap from leg to leg and repeat several times.



4. Hamstring (back of thigh) stretch.

Place one heel on the chair. Straighten your knee and push your heel away. Bend forwards towards your knee. Curl and round your back, but keep your leg as straight as possible. Hold and stretch for at least 10 sec. X 3 reps.

You may bend your standing leg a little if this is more comfortable.



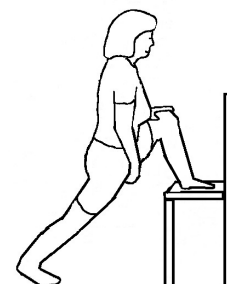
5. Hip Flexor (front of thigh) stretch

Place one foot on the chair - well forwards. Keep the back leg straight. Lean forwards onto the bent knee. Have your foot far enough forward that when you move forwards your knee is not in front of your ankle. Let your hip move forwards but avoid arching or rounding your back. Feel a stretch in the front of the thigh (hip).

Keep your heel down, and you will also feel a stretch in the back of the calf.

Hold and stretch for at least 10 sec. X 3 reps.

For a little extra stretch - raise the same arm as the back leg tall above your head.



Ankylosing Spondylitis Victoria Inc Report by Annie McPherson

Winter 31/05/2013

Winter mornings have certainly arrived here and we are reminded to rug up against the cold. However it was weird earlier in the month, when it gets to over 20 C. at midday and I have to shed a few layers for my midday walk!!

We would like to welcome new members over the past couple of months, Francis, Cameron, Dinar, Anthony and Jeff.

Over March and April we have continued with providing support and participating in the **Caulfield Community Health Services Physiotherapy Department's** exercises course for people with **Ankylosing Spondylitis**. **Belinda Coulter, physiotherapist and course leader has been thrilled with the attendance.** She has written an overview of the program, look for it at the end of this article. It is encouraging read their experiences and congratulations to Belinda and her team for an excellent program.

In mid May a small group of AS Victoria members shared a **coffee and chat** evening at the **Fairfield RSL** in Fairfield, where new members came along to meet others and exchange ideas. We are thinking of extending this idea to other RSL venues, so check one out in your district and let us know about it.

This month (May), we are busy with our **membership renewals, annual general meeting and committee nomination** notices going out to members. Please complete them as soon as you can and return to our AS Vic Inc. post box or online to our asvictreasurer@hotmail.com. If by chance we have missed your renewal or you may know of a past member who would like to rejoin, please let us know.

Annie McPherson

Annual General Meeting Ankylosing Spondylitis Victoria Inc

Date: Wed 26th June 2013

Time: 6:30 pm – 7:30pm

Venue: Austin Hospital

**Austin Towers, Education Precinct
4th Floor, Seminar Room No 4.2**

RSVP: Text Annie McPherson on 0408 343 104

OR email at: asvictreasurer@hotmail.com

BY Mon 24th June 2013

Members, family and friends are invited to attend the AGM which will be followed by our regular dinner at the "**Old England Hotel**" in Heidelberg.

See www.asvictoria.org/#!events/c1zyc for further details.

Caulfield Community Health Services: Ankylosing Spondylitis Course

April, 2013

I was very pleased when Belinda from CCHS Physiotherapy Department asked me to give a short presentation at the Ankylosing Spondylitis Course. I was asked to talk about Arthritis Victoria Services that would be of help for people with AS who were attending the course.

I talked about **The Arthritis Map of Victoria** which is a practical, interactive online tool that aims to help people living in Victoria manage chronic musculoskeletal conditions by helping them to locate the programs and services they need. The Map has been built on the Google Maps platform enabling consumers and Health Professionals to quickly locate local services and instantly retrieve door-to-door directions. The Arthritis Map can be accessed by going to the link www.arthritisvic.org.au

The Arthritis Victoria Website has a lot of valuable information about arthritis and other musculoskeletal conditions as well as links to other sources of information and resources to download. Members of Arthritis Victoria can also access the library catalogue by visiting the website www.arthritisvic.org.au and clicking on services and access the library page. Then when you find an item you would like to borrow, simply contact the librarian to have the item sent to you. Books and DVD's are sent to members all over Victoria free of charge and people just pay to return them or drop them in as they are passing.

People with AS can also phone **The Rheumatology Help Line** on **1800 263 265** and talk to a nurse with questions about medical information regarding MSK conditions, medications and treatments, assistance navigating the health system and information about support services available. The service is available to all Victorians via phone or email from **9am – 4pm, Monday to Friday**.

There is also a Telephone Information Service staffed by trained volunteers who can give people the opportunity to talk to someone else who also has a musculoskeletal condition as well as send information and refer people to **Peer Support Groups** and other Arthritis Victoria Services such as **Warm Water Exercise classes (WAVES)** **Tai Chi, Nordic Walking** and a range of self management programs.

People present at the course were most interested in the Arthritis Map as well as the library where they could access information on MSK conditions, pain management, exercise programs, complementary therapies and more. They were also very interested in the Rheumatology help Line and the support this service could offer them.

Anne Lloyd
Rheumatology Nurse
Arthritis Victoria

Arthritis Victoria Activities:

In early May we attended the Arthritis Victoria **regional seminar at San Remo**, a village near Phillip Island, Victoria. Our group met for morning tea, a coffee and catch-up chat and a short walk celebrating World Spondylitis Day. The Arthritis Vic. event was hosted by the local San Remo peer support group. The speakers included Dr. Mano Thevathasan, a rheumatologist who practices in the Frankston area, and he gave an excellent talk on arthritis conditions. Afterwards we met up with the Korumburra Arthritis peer support group folks for a chat. The Arthritis Vic. team provided a demonstration of Nordic Pole Walking, which Adam found most interesting, perhaps his line- dancing talents came in handy!!

Recently I attended a **patient centred care** session for at **La Trobe University**. The sessions are for **physiotherapy third year students**, where a consumer from Arthritis Vic presents a talk about their own experience in the Healthcare sector. We generally include the different doctors, physicians and the types of tests, procedures and medications we have experienced. There is always plenty of discussion about the group on all the topics.

This week we had the annual Arthritis Vic. **Volunteer Celebration** during Volunteer Week. Ellen, an inaugural member and committee volunteer of AS Vic Inc. and I attended. We met with other peer support group leaders and volunteers and discussed some of the activities and classes they conduct throughout the year. The service and outstanding achievement awards were presented this year by Linda Martin and a new board director Bernadette Dennis. Peter James and David Willams were awarded 15 years service medallions for their volunteer work as Waves Leaders for the Thursday night warm water exercises classes at Caulfield Community Health. This class has a group of folks with AS attending on a regular basis.

Annie McPherson

Caulfield Community Health Services: *continued*

Ankylosing Spondylitis exercise program, by Belinda Coulter, physiotherapist at Caulfield Community Health Service (CCHS) **Physiotherapy Department**, with assistance from Jen, exercise physiologist, has re-introduced the **Ankylosing Spondylitis (AS) exercise program**, after a couple of years break. Belinda led a group of 6 participants at the Elsternwick campus through the course incorporating various forms of exercise indicated for AS, in the gym and warm water exercise in the pool. The course, held on a Monday evening over eight weeks included sessions on: Mobilising the spine and other joints, muscle stretches, strength training, circuit/cardio exercises, Pilates-mat and fitball exercises, progressive muscle relaxation techniques and hydrotherapy/warm water exercises. There was an emphasis on establishing an exercise regime to continue

for a lifetime, once the course had finished.

Each week a short discussion about a topic related to AS preceded the exercises and the group had the opportunity to share their experiences. We were also fortunate enough to have a variety of speakers for question and answer sessions including: Dr Lionel Schachna, Rheumatologist, Austin Spondylitis Clinic; Anne Lloyd*, Rheumatology Nurse, Arthritis Victoria and Annie McPherson, President of AS Victoria Inc. peer support group. Feedback was extremely positive for all and we plan to run another course later this year. Here are some comments from the participants:

"I have a much more positive understanding of AS."

"I felt happy to share experiences and not feel so isolated with my AS and associated problems."

"The exercise are fantastic- some can be done subtly throughout the day at work and other more intense ones at home/gym."

"Very good balance of theory and practical advice, lots of good guidance."

"I look forward to going each week- enjoyed the small group and starting to feel more in control of my AS as I understand it better."

"I have really enjoyed the course and would highly recommend anyone with AS to do it - I feel very motivated after the session for the week ahead."

"Most helpful to realise the level of exercise that's OK-for me - knowing how to modify exercise routine if I'm having a flare up."

Belinda Coulter
Physiotherapist

New AS Vic Inc Website

We have recently upgraded our AS Vic Inc. **web site pages** which you can access via asaustralia.org or via asvictoria.org. We would very much like to hear your feed-back and comments. Note that everyone can peruse older AStretch editions and pick out exercises for areas of the body that may need attention or a re-fresher session. Please email your comments to asvicweb@gmail.com

Like us on Facebook:

Our committee member Adam Collard, has setup a Facebook page for our AS Vic Inc. peer support group.
<http://www.facebook.com/asgroupvic>

Adam's comments: I set up the Facebook page to help increase awareness of AS Vic Inc. peer support group and promote its benefits. We loaded up our AS Vic Inc. group information on the site. We check the site regularly for queries and comments. Members and individuals can "Like" our site, add comments, or pass on the information to their network of friends or colleagues. It's another great way to help raise awareness of AS.

AS Group Queensland Report by Ross Wilson

The **AGM** has been run and I was very pleased with the attendance. It is great when you receive good support from the members as it makes the efforts of the committee worthwhile. On the subject of the committee we have had some changes for the following year with our long standing Treasurer Lynn stepping down and Maritza swapping from Secretary to Treasurer and Michael putting up his hand to fill the Secretaries position.

The Committee is as follows:

President: Ross Wilson
Secretary: Michael Russell
Treasurer: Maritza Prada Sullavan
Newsletter Editor: Greg Johnson
Social Co-ordinator: Mark Robinson
General Committee: Graham Collins, Steve Fletcher,
Gai-Maree Sheperd,

PRESIDENT'S REPORT 2013 ANNUAL GENERAL MEETING

Hello and welcome everyone to the 2013 Annual General Meeting of the AS Group of Qld. I would like to thank you all for taking the time to attend.

I must first say thanks to my fellow Committee members for their ongoing support and as always a very big thank you to our Groups Physio, Margaret Lewington. Her tireless efforts for our Group, and the general AS population, are very much appreciated.

A special thank you to Lynn Adamson, our retiring Treasurer and long term Committee member. Thank you for all the hours you have spent looking after the affairs of the Group. You will be missed.

There were some changes during the year with Greg Johnson taking over the position of Newsletter Editor from Maritza. A big thank you to Maritza for doing such a great job and to Greg for taking on the position. It is greatly appreciated, as the Newsletter is our main contact with many of our members. We have had some great social events over the past year with a good mix and good attendances at all. Congratulations to Steve and our new Social Director Mark for organizing these great events. We will look forward to what you have in store for us in the coming year.

We are in the early planning stages for another Symposium, to be held in the third quarter of the year. So if anyone has suggestions of topics they would like to see covered, please let us know and we will endeavour to cover them.

Our aims for the following year, along with the Symposium will be, to continue the high standard of our Newsletter, organize a variety of social events, continue working on the web site and to support those living with AS wherever we can. Once again, thank you for attending.

Other News

Our two social events since the last newsletter have been well attended with the indoor rock climbing proving to be a great day with a lot of us surprising ourselves as to how much we were able to do. It just goes to show that even with AS you don't lose your competitive instinct. It's definitely something we all want to try again.

The other event was a supper after Hydro at Earth n Sea Pizza which again was well attended and it was good to catch up with Ex committee member Kelly who is back from Paris for a few months and enjoying the Hydro sessions while she's here.

Our next events are a BBQ at Roma Street Parklands and a dinner in June, so check out the Calender and come along.

Planning for the symposium is moving along well, so as soon as we nail down a date we will let everyone know.


Ross Wilson
President, AS Group of Qld


Rock climbing anyone?



Calendar of Events


Victoria

 **Wednesday, 26th June - Annual General Meeting** from 6:30pm to 7:30pm at the Austin Hospital. All members, family and friends are welcome. The AGM will be followed by a casual dinner held at the Old England Hotel in Heidelberg. See www.asvictoria.org/#!events/c1zyc or page 8 of this newsletter for further details.

 **The last week of July - Xmas Dinner** in July at Rosstown Hotel, Carnegie. Notices and details will be sent out in early July.

Queensland

 **Sunday, 26th May - BBQ at Roma St Parkland** from 11:30 am. A BBQ with salads is provided. BYO drinks and nibbles and be ready to have some fun. Parking from \$2 or take the train / bus and get dropped off at the gate. RSVP to Mark Robinson (suzemark@bigpond.net.au) or 0407 425 750, by the 24th of May.

 **Saturday, 29th June - Thai dinner** from 6.30pm at Mons Ban Sabai, 12 Martha St, Camp Hill, QLD 4152 www.monsbansabai.com RSVP to Mark Robinson (suzemark@bigpond.net.au) or 0407 425 750, by the 24th of June.
See www.asaustralia.org/qld/ for further details.

General Information on the web

Ankylosing Spondylitis Groups of Australia

www.asaustralia.org

Like Us on Facebook AS Brisbane

www.facebook.com/groups/271627319581232/

ASGroupVic

www.facebook.com/asgroupvic

Ankylosing Spondylitis Victoria Inc

www.asvictoria.org

Spondylitis Association of America (SAA)

www.spondylitis.org

Arthritis Australia

www.arthritisaustralia.com.au

Ankylosing Spondylitis International Federation (ASIF)

www.spondylitis-international.org

The National Ankylosing Spondylitis Society (NASS) (United Kingdom)

www.nass.co.uk Contains excellent information on AS, it's diagnosis and managing and living with AS.

Hydrotherapy in Western Australia (Perth)

WHERE: Royal Perth Rehabilitation Hospital
Shenton Park Annex Selby St Shenton Park

WHEN Every Monday evening
(Public Holidays excepted)

COST \$ 7.00

PHONE 08 9382 7307 Lindsay

TIMES:

Hydrotherapy Pool
5.30pm Hydrotherapy exercises

Gymnasium
5.45pm - Land Exercises

Note: All sessions are conducted by experienced Physiotherapists. Total Session time is two hours with groups changing over at the end of the first hour.

Also: Another AS/spinal mobility Pool Class is available at South Care, St John of God Hospital - for details: 08 9366 1730

Ankylosing Spondylitis Victoria Inc Membership Form

AS Victoria is a peer support group affiliated with Arthritis/Osteoporosis Victoria



Who we are and what we do....

The 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*

Signed: _____ Date: ____/____/____

Send to:
AS Victoria Inc
PO Box 3166
Burnley North 3121

*Concession rate available for pensioners, unemployed with health benefit card and full time students with student card.

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

** The rules are the model rules for an incorporated association under section 46 of the Associations Incorporation Reform Act 2012.

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 Ankylosing Spondylitis Victoria 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 Vic Inc passes on to members a variety of information on health and medical issues only for general, educational and informative purposes. AS Vic 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 30th June)
- ☐ Mailout* membership (\$25.00)
- ☐ Concession* Mailout* membership (\$20.00)
- ☐ Email member ship (\$20.00)
- ☐ Concession* email membership (\$15.00)

Donation: \$ _____

Total: \$ _____

Cheque, money order or direct deposit - Please contact our treasurer for our bank details:

asvictreasurer@hotmail.com

Statistical Information (Optional):-

1. Are you a member of Arthritis Victoria? Y / N
2. Are you happy for us to 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?

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

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