SUMMER 2011
NEWSLETTER

AStretch

ANKYLOSING SPONDYLITIS AUSTRALIA

www.asaustralia.org

TNF-inhibitor for Axial Spondyloarthritis

by Dr. Matthew Brown

Rheumatologist, Ankylosing Spondylitis Specialist Clinic, Princess Alexandra Hospital, Brisbane.

TNF-inhibitors (TNFi) have become the gold standard medical treatment for ankylosing spondylitis (AS). In our hands nearly all patients we have started on these medications with established AS have had meaningful responses, and most patients having minimal residual disease activity after two to three months of these medications. When used with care and with good support from our team, the safety of these medications has been high, with few patients having significant side-effects, these being infections or allergic reactions to the medications.

Current restrictions mean that public funding of TNFi for AS is restricted to patients with established xray changes in the pelvis. When patients first develop AS they typically experience pain and stiffness, usually in the back but sometimes in other joints, but have no xray changes visible. These changes take on average 10 years from onset of symptoms to develop. A proportion of patients with inflammatory spinal arthritis do not proceed to develop xray changes; at this stage we do not know how big a proportion that is. Nonetheless from this group of patients all our patients with established AS emerge, and this group can be hard to help, because they cannot access TNFi at affordable prices. We also know that patients with established AS continue to develop spinal fusion despite TNFi treatment, and it may be that by treating patients earlier before much joint damage has occurred, the treatment may be more effective at slowing or preventing the development of spinal fusion.

Part of the problem with extending access of TNFi to patients with early disease has been the difficulty of diagnosing inflammatory spinal arthritis and defining a group of patients who would benefit from TNFi treatment. The AS clinical community has now decided on a disease definition termed ‘axial spondyloarthritis’ which refers to patients with back pain and stiffness due to inflammation, and which meet certain criteria including clinical manifestations and either MRI evidence of inflammation in the pelvis and/or spine, or carriage of the HLA-B27 gene. Patients meeting this definition may have AS, or may have other conditions which may remit and not progress to AS, but having this definition means that a group of patients can be defined in whom response to treatment can be tested.

Clinical trials for patients with axial spondyloarthritis have now demonstrated that they do benefit TNFi. At this year’s American College of Rheumatology Annual

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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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TNF-inhibitor for Axial Spondyloarthritis - continued from page 1

Scientific Meeting, the findings of a trial of Humira (adalimumab) in patients with axial spondyloarthritis was reported (1). This was a large multinational trial in which some Australian centres including our own participated, and it showed that in patients meeting the axial spondyloarthritis disease definition, TNFi treatment is similarly effective as it is in patients with established AS. This confirmed earlier smaller studies that also showed a beneficial effect of TNFi in this patient group. TNFi was also safe in this group with no new risks identified that were not known from treatment of patients with established AS.

This is tremendously exciting news for patients with early AS, but there are still several hurdles to leap before TNFi become available for axial spondyloarthritis, particularly that it will need to be approved for funding by the Pharmaceutical Benefits Scheme. So please note: at this stage TNFi are still only available to AS patients with sacroiliac joint xray changes. Further research will also be required including determining what proportion of axial spondyloarthritis patients develop AS, whether TNFi treatment of axial spondyloarthritis can induce remission of the arthritis, and whether TNFi treatment slows or prevents joint damage in axial spondyloarthritis.

Also, as it currently takes on average 8 years or more from onset of symptoms before patients are being diagnosed with AS, clearly there will need to be an improvement in earlier diagnosis of the condition. This is going to require increased awareness of AS in the medical community, increased access to MRI scanning for low back pain, and possibly use of genetic screening to identify high risk individuals.

Nonetheless, the trial does show that in patients meeting an agreed disease definition, TNFi is a very effective treatment, with much potential to benefit patients with early AS for whom treatment options are now very limited.

Sieper et al, 'Efficacy and Safety of Adalimumab in Patients with Non-Radiographic Axial Spondyloarthritis – Results From a Phase 3 Study', S970, Arthritis Rheum, 63 (10, Supplement), 2011.

People's Experiences Travelling with TNF Medication!!

"I have been using TNF blocker "Remicaide" since September 2006. Remicaide is given as an infusion in hospital every 6 weeks and has kept me pain-free since beginning it. In this time we have travelled overseas once and interstate on a few occasions. I find that I can go for 7 weeks without any major pain issues and my specialist is happy to move the time frame around to suit any absence (say move one infusion forward a week or the next one back a week). Initially I could feel when the 6 weeks was up, but as time has gone by I seem to be able to go for longer without any discomfort.

As an aside, I had a Cardiac Artery Bypass Graft (double) in April 2010 and the doctors requested I miss one Remicaide infusion to ensure it didn't affect the healing process. On this occasion I went for 12 weeks without an infusion and my joints were beginning to feel a bit sore after about 10 weeks."

Bill

"I have done all of my travelling without taking my humira with me, as I have always worked around the time I go. I had 3 weeks in Thailand and took my needle the day that I left and I did not have any problems. Three months before I went to scaled back one day a fortnight on my humira to ensure I took it the day I left"

Steve

"My have travelled with TNF injections within Australia on flights from Brisbane to Perth and to Canberra.

My Rheumatologist told me the following:

1. I must carry a letter from him stating my condition and the medication that I was taking.
2. The TNF injection/s must be in the original packaging. (The original packaging has your name and other details on it.)
3. On the plane the crew will put the injections in a fridge to keep them cool.

Prior to our flight, I rang the airlines and was told that passengers carry injections regularly, especially diabetics. The letter from my Doctor and the packaged injections would be checked at the same time as my other carry-on luggage.

I arrived at the airport with the TNF injections inside an insulated bag with a cold pack to keep them cool. At Check-In, I was told that the bag would be checked with my other carry-on luggage. I was asked to show my Doctor's letter and the injection in its' packaging on only one occasion.

On board the plane, I was surprised when the attendants told me that the injections must stay with me because the crew were not allowed to put them in a fridge. The attendants gave me some ice to add to my insulated bag after some repeated prompting.

I can understand their reluctance to take responsibility for the injections but it was my first time travelling with the TNF medication and I was worried that it would not be kept cool enough."

Lynn

"I recently enjoyed a 6-week overseas holiday, the first overseas travel I've done since starting on TNFs (Humira) about 2 years ago. I took 3 pre-filled syringes with me along with a letter from my specialist and hope the following points might be useful for anyone doing the same:

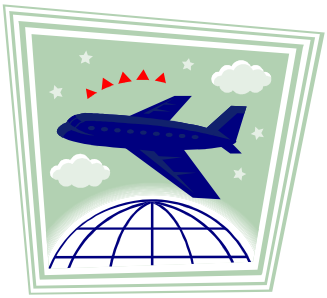
- *The only people who were interested in the fact I had syringes in my hand luggage were security as I was leaving Australia. Customs in neither London or Paris even queried it.*
- *I stayed mainly in self-contained accommodation so keeping the medication cool was easy. However on the odd occasion where I was in a motel, as most motel rooms in the UK don't have a fridge I had to rely on the staff at Reception to put my Humira in the fridge and gel packs in the freezer (<u>not</u> the other way around!)*
- *I found disposing of used syringes impossible as none of the airports, train stations, or pharmacies had disposal containers. I'd assumed I would be able to use the yellow Sharps bins which are in many of our loos in Australia but would highly recommend taking your own hard container with you.*

I was pleasantly surprised at how easy it was to travel overseas with TNFs. I was also relieved at how well my AS coped with the travel. As Ross had mentioned in an earlier article there is plenty of room on international flights to walk and even have a stretch during the flight, although for me a neck pillow is a must. The TNFs are keeping my AS under control really well so the only problems I had were neck and low back pain after either a big day of driving, or a couple of hours spent looking at the beautiful carved and painted ceilings which are in every cathedral art gallery grand house in Europe! As always though, a good night's sleep in a comfortable bed always helps."

Sharon

Travelling with AS and TNF Inhibition Medication

by Janelle McFarlane, Specialist Rheumatology Nurse.



At our Princess Alexandra Hospital Ankylosing Spondylitis Specialist Clinic, Brisbane, patients often ask us questions about travelling. Generally, it is great to hear our patients talking about going travelling because it usually means they are confident with their AS and are feeling well enough to enjoy active lifestyles.

Our physiotherapy team have some great advice about maintaining mobility whilst travelling, such as getting up and walking in flight to reduce "gelling" (the stiff feeling that can happen when you've sat for a long time) if that is a problem for you.

They also provide fabulous flexibility programs that can be done in a chair, so that there are no excuses even for busy executives that travel all the time! However sometimes patients need specialized information if they take injections called Tumor Necrosis Factor Inhibitors (TNF Inhibitors). Currently PBS approved forms of this medication (for AS) include: Adalimumab (HUMIRA), Etenercept (ENBREL), Infliximab (REMICADE) and Golilumab (SIMPONI) If you are taking these medications, or thinking you may need to start taking these medications there are extra things to consider, such as seeking vaccinations advice, medication storage and regulations regarding air travel and Medicare subsidized medicines.

Planning the trip – vaccinations:
Vaccinations are a complex area to consider and you will probably need to get the advice of a travel medicine expert (especially if you plan to go to more remote areas) and they can assist you with current information. Your rheumatologist may request that you have some tests to check if you have already been vaccinated against some infections or may even request that you receive certain vaccinations prior to starting TNF inhibition for the first time. This is because it is thought that TNF inhibition can affect your body's response to vaccination, so it could mean that you don't get the full effect of the vaccination. Also 'live' vaccinations should not be taken whilst being treated with TNF inhibition. Live vaccinations are vaccinations that are made from a modified form of the infection (microorganism or bug) so that your body creates its own immunity.

Most vaccinations are not live, and are therefore safe to have whilst taking TNF inhibition. It is important to consider the area that you are planning to travel to, for example, in some regions you must have a Yellow Fever Vaccination Certificate in order to get through that country's customs. The Yellow Fever Vaccination is a live vaccine which will mean that you will need to consult your rheumatologist prior to going.

Planning the trip – scheduling of medication:

If you are a frequent traveler, it may be that you could talk to your rheumatologist about changing your medication to a less frequently required medication. Your rheumatologist may even suggest that it is safe for you to take your injection a day early to avoid traveling with it, but this will need to be discussed because everybody has individual considerations. Alternatively, you can plan out when you are taking your injections and plan your trip around them.

Planning the trip – cold storage:

There are a number of cold storage devices commercially available and over the years, pharmaceutical companies have also provided cold storage bags. It is a good idea to thoroughly test your cold storage before using it – this will give you information about how long medications will stay within the 2 -8 ^{o}C range. Outside of this range, the medication becomes inactive. Recently we tested cold storage bags and although these tests were only quite basic, we were surprised to find that some of the cold storage bags actually contributed to freezing conditions. So it is really important to test the cold storage (with a thermometer or even a small amount of liquid packaged in a similar way to your TNF inhibitor injections) before you are planning to use in transit – there is no fun going away for a three week break and having a major flare of your AS because your medication had become inactive.. Remember when you are doing this testing, do not use your very expensive, publicly funded medications!

Flying there – CASA Regulations
Civil Aviation Safety Authority (CASA) has rules that airlines must abide by for the safe travel of all passengers, these effect travelling with cold storage and injection medications. The international limitation of 100ml of carry on liquid was implemented in response to the thwarted liquid explosive bomb plot in the United Kingdom in August 2006.

In order to get an exemption from these restrictions, you will be required to:

- have supporting documentation, including prescription and a letter from a doctor. The letter should also cover ice packs or gel packs which are required to regulate temperatures;
- have medicines ready for inspection; and
- make sure the name on the label of the prescription medication matches the name on the boarding pass.

It is a good idea to phone ahead to the airline, as various airlines have different rules for maintaining cold storage on long flights. Most will provide you with in-flight ice, but will not let you use refrigeration due to yet more CASA regulations. You will need a sealed container or bag for the ice and medication. If you decide to use an electrical device such as a thermometer or portable refrigerator, you will need to seek airline clearance first, as many of these are not allowed in the aero plane. Even the type of battery may be an issue.

Travelling with AS and TNF Inhibition Medication- continued from page 4

Other things to consider:

If you have limited mobility, it is a good idea to clarify mobility and medical equipment requested with the airline. Airlines have strict manual handling (lifting) rules and wheelchairs need to be arranged in advance eg if you need a wheelchair from the check-in desk to the aeroplane you will need to pre-book this. The airline will probably ask you to complete a mobility aid form.

Length of time away:

TNF Inhibition medications are very expensive and the government has a responsibility to Australian taxpayers to ensure appropriate usage. Therefore, there are limitations on how much PBS funded medicine can leave Australia at any one time.

The current limit is 6 months supply but to get up to date information it is worth checking the Medicare website: www.**medicare**australia.gov.au.

In summary, a useful tool might be to use this packing checklist:

- The original prescription
- Mobility aid form completed
- Letter from doctor (making sure it documents all the information required)
- Clear plastic bag for top up ice
- Thermometers
- The cold carry bag
- The medication

Hopefully, by working with your rheumatologist and having a clear understanding of the storage and regulatory requirements for safe travel with TNF inhibitor medications, you will have a fantastic time. Certainly, at the Princess Alexandra Hospital Ankylosing Spondylitis Specialist Clinic we enjoy a good travel story and seeing a couple of happy snaps!

Report of National Physiotherapy conference

by Margaret Lewington

Almost 2,000 physiotherapists gathered for our Biannual National Conference in Brisbane at the end of October. All areas of physiotherapy were represented in the program with our special interest groups organizing many concurrent sessions.

Abbott Pharmaceuticals was a gold sponsor of the event, and as such, had a trade display with booklets, exercise sheets, information about online learning and other relevant information to hand out. The stand was always busy, with many physio's showing interest. Danni Morley, a physio from Sydney, who also has AS, was at the stand to talk and answer questions as well.

As there have been several other events on AS, eg DVD's, seminars, which I have reported on in previous newsletters, it was pleasing to see that many physio's came with some knowledge and wanting more detailed information and resources.

As part of the level of sponsorship, a short presentation was given to the full conference audience at the beginning of one of the plenary sessions. Considering the number of special interest areas and the multitude of conditions, to have a talk on AS to the full audience is quite remarkable.

I was an invited speaker in the Aquatic program, presenting on the topic Aquatic Physiotherapy for AS.

Awareness of AS in the physiotherapy population has definitely made huge progress over recent times.

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

What the literature is saying!!

(Reference taken from the NASS website)

Smokers with early axial spondyloarthritis have earlier disease onset, more disease activity, inflammation and damage, and poorer function and health-related quality of life

This study was done in Leiden, The Netherlands and published in October 2011 in the Journal – Annals of Rheumatological Diseases

The purpose of this study was to look into what association smoking has with various clinical, functional and imaging outcomes in people with early axial (area of spine and neck) spondyloarthritis (SpA). 647 patients with early inflammatory back pain fulfilling at least one of the internationally accepted SpA criteria and with available smoking data were included in the analyses. Clinical, demographic and imaging parameters were compared between smokers and non-smokers at a cross-sectional level.
Results showed that smoking was independently associated with earlier onset of inflammatory back pain, higher disease activity, increased axial inflammation on MRI, increased axial structural damage on MRI and x-ray, poorer functional status and poorer quality of life.

Smoking increases levels of disease activity in patients with severe AS

(reference NASS website)

The largest study to date on the effects of smoking in patients with ankylosing spondylitis (AS) has shown that smoking increases disease severity.
The study was carried out on a large population of AS patients, from 10 rheumatology departments across the UK.
Results from the study found that associations with increased disease activity, decreased function and poor quality of life in smokers were independent of age, sex and disease duration.
Dr Mattey, author of the study said:

"This is the first study to show a dose-dependent relationship between smoking and disease outcome in AS. This suggests that cessation of smoking is likely to be beneficial in terms of functional outcome and long term quality of life in patients with AS".

The effects of combined spa therapy and rehabilitation on patients with ankylosing spondylitis being treated with TNF inhibitors.

Ciprian L, Lo Nigro A, Rizzo M, Gava A, Ramonda R, Punzi L, Cozzi F. Rheumatol Int 2011 sept 27

Source

Rheumatology Unit, Department of Clinical and Experimental Medicine, University of Padova, Padova, Italy.

Abstract

Despite advances in pharmacological therapy, physical treatment continues to be important in the management of ankylosing spondylitis (AS). The objective of the present study was to evaluate the effects and tolerability of combined spa therapy and rehabilitation in a group of AS patients being treated with TNF inhibitors. Thirty AS patients attending the Rheumatology Unit of the University of Padova being treated with TNF inhibitors for at least 3 months were randomized and assessed by an investigator independent from the spa staff: 15 were prescribed 10 sessions of spa therapy (mud packs and thermal baths) and rehabilitation (exercises in a thermal pool) and the other 15 were considered controls. The patients in both groups had been receiving anti-TNF agents for at least three months. The outcome measures utilized were BASFI, BASDAI, BASMI, VAS for back pain and HAQ. The evaluations were performed in all patients at the entry to the study, at the end of the spa treatment, and after 3 and 6 months. Most of the evaluation indices were significantly improved at the end of the spa treatment, as well as at the 3 and 6 months follow-up assessments. No significant alterations in the evaluation indices were found in the control group. Combined spa therapy and rehabilitation caused a clear, long-term clinical improvement in AS patients being treated with TNF inhibitors. Thermal treatment was found to be well tolerated and none of the patients had disease relapse.

Impact of home-based exercise therapy in patients with AS

This study was done by researchers in Istanbul, Turkey and is published in the June 2011 edition of Clinical Rheumatology.

It's simple and cheap to do your AS exercises at home. The aim of this study was to investigate the effects of home-based exercise therapy on pain, mobility, function, disease activity, quality of life, and respiratory function in patients with AS.
80 AS patients were included in the study. A home-based exercise program including range of motion, stretching, strengthening, posture, and respiratory exercises was practically demonstrated by a physiotherapist and a training and exercise booklet was given to all patients. The researchers then compared patients following the home-based exercise program five times a week for at least 30 minutes per session per session (exercise group) for 3 months with those exercising less than five times a week (control group).
The exercise group showed significant improvements in pain, mobility, respiration and quality of life over the control group after 3 months.
The researchers recommended that regular home-based exercise therapy should be a part of main therapy in patients with AS with patients exercising at least five times a week for at least 30 minutes per session. (summary from NASS website)

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.

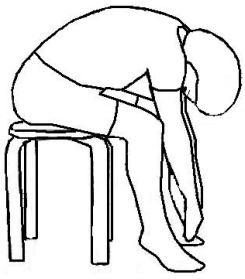
Also: *Another AS/spinal mobility Pool Class is available at South Care, St John of God Hospital - for details: 08 9366 1730*

AS Exercises
By Margaret Lewington Physiotherapist

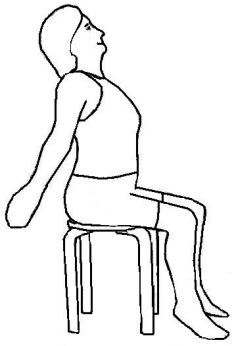
This issue features some exercises sitting in a chair. They will help to move your upper back and rib cage.

1. Sit tall and well supported. Lift your arms up above your head and reach as tall as you can. Try to take your arms back beside your ears.
Now look up at your hands, letting your head lean back.
Now also lean your body slightly back, letting your back arch. Come back to straight – reach and stretch up for an extra stretch, and now let your arms relax down.

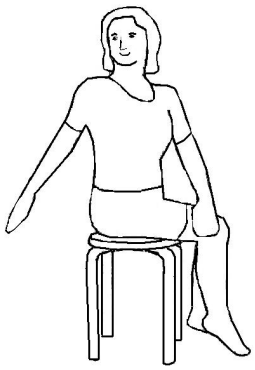
You can add deep breathing with this. Breathe in as you stretch up and as you do each new part. Remember to fully breathe out and relax, even if holding a stretched posture.



2. Lean forwards and reach to your feet. Let your back round. You may like to curl down – first head and then upper back, mid back and low back, or you may prefer to just reach down and hang and relax. Another alternative is to rest your elbows on your knees and curl as much as possible. Try to curl and round your low back the most.

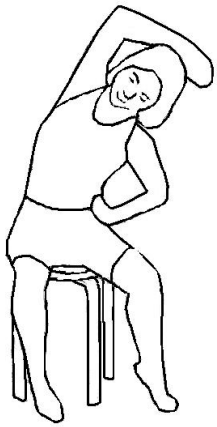


Now sit up – TALL – lift your chest, keep your chin down, back of neck long and gently arch your back. Turn your palms to the front to open across the front of your chest and shoulders.

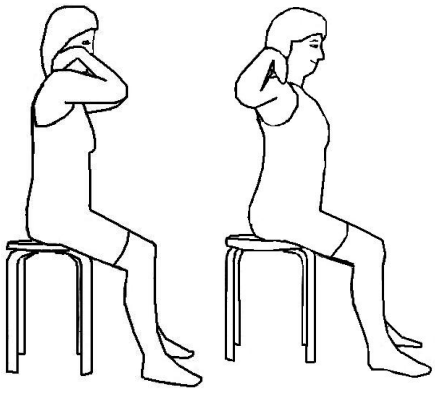


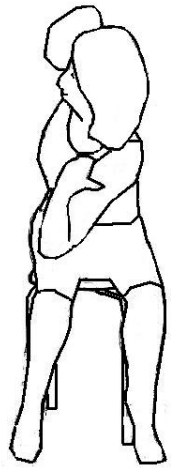
3. Place your left hand on the outside of your right knee and turn and look behind you to the right. Use the hand on your knee to hold your leg still to avoid lifting your hip and also to pull yourself around a little further.

You may use your other arm on the back of the chair to also pull yourself around further. Keep your chest up, feel your spine turning and look around as far as you can.



4. Place your left hand on your hip, to balance and prevent lifting your right hip as you lean your trunk over that hand to the left side. Lift your right arm up and over your head towards the left. Feel a stretch through your right side – at the top of your hip and waist and also along your chest and ribs. Repeat to the other side.





5. Sit tall and place your hands on your shoulders. Bring your elbows forwards, trying to touch them in the front. Allow your upper back to stretch, curl and round.

Now take your elbows out to the sides, as wide as you can. Feel a stretch on the front of your shoulders. Sit tall and lift your chest. Your upper back may arch a little, but do not let your lower back arch too much. Make sure you take your shoulders back and not just your elbows, so as you feel the stretch from the breastbone, across the chest and front of the shoulders.

AS Group of Victoria Report by Annie McPherson

ANKYLOSING SPONDYLITIS GROUP OF VICTORIA

ARTHRITIS VICTORIA UPDATE

In July, I was invited to join other consumer members of the Arthritis Victoria's Research Advisory Panel, to attend the inaugural Consumer Reforming Health conference organised jointly by the Health Issues Centre and the Victorian Government. The conference was conducted over three days with delegates from government, university, hospitals and health/community centres and various not-for-profit agencies, all connected with consumer engagement in the Healthcare sector. Across these organisations, consumers, researchers, health professionals along with university lecturers and government agency representatives attended sessions lead by highly regarded leaders in this field. Over the three days, we attended over 30 presentations including sessions where a panel of leaders, with common specialities in Population Health, fielded questions from the audience.

The concept of consumer engagement is about consumers contributing their "knowledge and experience" into a healthcare project or service in the healthcare system. Terms like advocacy, equality, partnerships, realistic outcomes, experiences, community, literacy, empowerment and participation were used consistently throughout the presentations often invoking interesting discussions.

I found the most exciting sessions were, where a team of healthcare professionals and consumers described projects involving close consumer engagement with the healthcare groups resulting in amazing outcomes for all parties. Some of us (consumers) found the three full days very tiring and we were not accustomed to the early morning starts. All in all it was an astonishingly enlightening experience shared with a great team from Arthritis Victoria.

For our consumer-focused newsletter, AStretch I have provided a selection of the most interesting stories as examples of consumer engagement [having abbreviated them for editing]. There were many more examples of very positive projects (even some experiences that went horribly wrong) and how these initiated changes in the healthcare systems.

- An architect spoke on the building project of the new Children's Hospital in Brisbane. A group of family consumers were consulted and they came up with the idea of a lounge area to be used by the families for an entire day. The families could remain in comfortable surroundings close by, whilst the young patients were undergoing procedures or lengthy treatments.

- A team of NSW health professionals worked with a mental health support group to develop regional consumer groups in NSW. The regional consumer groups were encouraged to participate in focus groups and contribute to projects. Some of the projects, supported by the NSW government were later developed and improved services available for this group of patients.

- A consumer representative from a Melbourne hospital relayed a story about a group of palliative carers who put together a DVD of interviews. The focus of the DVD was the carers' perspective of the patient's journey and steps along the way. The DVD was directed at other carers and health professionals in the palliative care sector. All the feedback they received showed how it helped the carers and patients.

- A researcher at a new Geelong rehabilitation facility developed an electronic survey device to follow through on patient progress. A volunteer consumer, interviews each rehabilitation patient asking five simple questions about their care by the health professionals at the facility. The information was transferred to the researcher's project and the team were able to quickly act upon issues needing attention.

- Our very accomplished Arthritis Victoria, Research Advisory Panel members Esther Lim (Research Co-ordinator) and Melissa Coulson (consumer representative) presented a paper on consumer involvement in the organisation. Melissa, a young mother with arthritis working part-time, commented on the "lived-in experience" consumers could bring to Arthritis Victoria's projects. . This is an aspect researchers do not always have available in a project team.

- The most encouraging outcome of the conference for me, was that on both sides consumer and healthcare providers, there are very strong positive indications that consumer engaged partnerships are successfully improving "patient centred care" in Australia.

Now, "we" need to "act" to enhance this trend.

by Annie McPherson, July 2011.

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AS Group of Victoria Report

At last Spring and Summer have arrived, altogether it seems this year, as we have had a wet spring and warm start to summer. The gardens are over-flowing with flowers and growth and this is a big challenge for those of us who enjoy the outdoor activity, but can manage oh so little with the secateurs and spade.

I embarked on a big project (for me) to have my little courtyard garden tiles re-laid during the winter, as they had become very uneven with tree roots lifting them to all angles. We are very pleased with the result (and so is my Mother) as now it is a much safer environment for me to work in and enjoy, and the landscaper really earned his pennies!!.

We had a good rollup at the **Christmas in July dinner** at the Rosstown Hotel with folks from Gippsland, Berwick, Carrum Downs, Oakleigh and Northcote all well represented. Members of all ages enjoyed the excellent meals and evening together, catching up and welcoming new folk.

Our **annual AS seminar** at the Austin Hospital in Heidelberg, which we run jointly with the Austin Spondylitis Clinic, had good attendance this October with over 40 people. This year we had attendees from as far as Barham NSW and Bairnsdale Vic, and many family groups.

Belinda Martin, our secretary and rheumatology research assistant at the Austin Spondylitis Clinic welcomed the participants, speakers and guests to our 6th AS seminar in Melbourne. In the following notes I have made a brief comment on the speakers and their presentations:

Associate Professor Anthony Hall, Director of Ophthalmology, Alfred Health gave a presentation on management of inflammatory eye disease, including uveitis. Assoc/Prof Hall has a keen interest in research in the medical and surgical management of inflammatory eye disease and has authored over 30 papers. As most of you will know, uveitis is a recurrent inflammation of the iris and anterior segment of the eye and can occur in people with AS. Assoc/Prof Hall previously conducted clinics at the Royal Eye and Ear Hospital in Melbourne where he came into contact with AS patients.

Dr Emma Gollings, Senior Psychologist, Pain Clinic, Austin Hospital gave a presentation on management of pain and the psychological impact on our lives in respect of a chronic illness. During the question and answer session, a number of issues were discussed including impact on work, social, home and study activities.

Dr Michael Gingold, Rheumatologist, Alfred Health gave a presentation summarising recent AS study and research findings. Subjects included advances in early diagnosis of AS, the new family of "spondyloarthritis" conditions (including AS), impact on working life of people with AS, the new ASAS* treatment focus (For example: Aiming to improve or maintain health related quality of life) and non-medication treatments (For example: exercise and physiotherapy). *[*ASAS: Assessment of SpondyloArthritis; International Society]* A section of Dr Gingold's talk included the time he spent at the RNHRD* in Bath, UK and its spondyloarthritis course. The two week intensive course aims to promote self-management, (including exercise) whilst focusing on education and understanding the condition using a multidisciplinary approach. *[*Royal National Hospital for Rheumatic Diseases]*

Dr. Jane Glatz, General Manager Training Information and Programs at Arthritis Victoria, provided a summary of male volunteers and their involvement with exercise activities and programs around the state. Dr. Glatz's theme focused on Men's Health and the emerging trends in health groups' emphasis on this aspect. As you may recall AS affects three times as many men as women *[Source: Population differences in health-care use for arthritis and osteoporosis in Australia, AIHW 2010*. For Example: 18% have a related limitation or restriction; 39% discuss health issues with their GP; *Source: Health of Australian Males, Australian Institute of Health and Welfare, 2011*. Dr. Glatz highlighted the Arthritis Victoria is providing for working age adults held during the evenings, including Your Rights at Work and Self Management programs.

Our **thanks** to the following for making our seminar a successful event this year: Belinda Martin, who contributes considerable time to the event preparations and is our excellent convenor for the evening; Vicky Genius with venue setup, signage and venue preparations; Sophia Koulbanis for our event materials and programs; Maria Makris, Adam Collard and guest Brian Miers [Male Health Victoria group] for registration and venue reception. We would also like to acknowledge Abbott Australasia Pty Ltd, Austin Health, the National Prescribing Service, Arthritis Victoria, for their contributions and resources for the event.

We have our November dinner coming up at the Rose Hotel in Fitzroy as our final activity for the year, and we hope to see you there. In late February 2012 we are planning a joint seminar with Arthritis Victoria in Korumburra, so look for our notice in late January.

On behalf of the committee, we hope you all enjoy your Christmas celebrations with family and friends and summer holidays over January. Please travel safely and enjoy some quite catch-up time when you can.
Best regards to all,
Annie McPherson, October 2011.

AS Group Queensland Report by Ross Wilson

The last few months have really flown by and Christmas is fast approaching. I always find this time of the year very busy, with trying to meet all the deadlines at work before we stop for the holidays, as well as getting the house and yard in order, ready for our relatives and friends. Then there is the Christmas parties, dinners and catching up with friends, so by the time Christmas day arrives I am usually ready to collapse. The AS Group of Qld Christmas dinner is on at Huong's Restaurant at West End, date and details are in the "What's on" guide and the calendar event. They always put on a great feed with excellent and friendly service.

Our last social event was a BBQ at Rocks River side Park at Jindalee. For those who don't know the area, this park was built on the former Qld Cement and Lime Companies old grounds. This is where the barges would unload the dredged coral from Morton Bay to be sent via conveyor belt to their processing plant at nearby Darra. Although most of the old machinery is gone the council has preserved some of the more interesting pieces, including the old Jetty, to remind us of the past. The Council have also done a re markable job fixing this area up after the January floods as the whole area was under several meters of water. Steve put on a Great BBQ as usual which was followed by a walk along the river. This was a very enjoyable day.

Margaret Lewington and her husband Rod have travelled to Izmir in Turkey to attend the ASIF Council Meeting. It is fantastic to be able to have a representative at the Ankylosing Spondylitis International Federation Council Meeting, flying the flag for the Southern Hemisphere. Having input from this side of the world, where things are quite different, like climate and distance, is a great step forward. Margaret should be congratulated for her continued commitment and support to those suffering from AS.

Last month, NASS celebrated World Arthritis Day with the launch of the new "Back to Action" exercise app. which is free to download from the Apple store. The app. features 21 videos of the different mobility, cardiovascular, strength and flexibility exercises as well as all the useful information contained in the printed "Back to Action" Guide. Although the app. is currently only available for iphones, ipads and the ipod touch, the videos are all available to view on the NASS website and on UTube. The printed "Back to Action" guide is also now free to download from the website in PDF Format.

A special thanks must go to Maritza Sullavan, our Newsletter Editor, for all the hours she puts into producing such a quality product each issue. Also a big Thank You to all those who contribute and proof read each article every Newsletter. It really is a big job, and is very much appreciated. It would be great to get some more personal stories from members on your highs and lows of living with AS. If you feel you would like to send in an article please contact any of the committee members.

The AS Qld committee would like to wish everyone a very Merry Christmas and a Happy and Safe New Year.

Ross Wilson

Calendar of Events

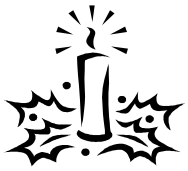
Victoria

- **2011 November**: Social Event : Wednesday 16 at 7:00 pm:
  Dinner at the Rose Hotel, 406 Napier Street, Fitzroy.
  Contact : Belinda Martin PH: 9496 4045

- **2012 February**: Joint seminar with Arthritis Victoria at Korumburra
  Contact: Annie McPherson PH: 0408 343 104

Queensland

- **2011 December 10:** Christmas dinner!!
  Where: Huong's restaurant,83A Vulture St, West End
  When : Saturday, 10th December, 6-30pm
  RSVP : Monday,5th December- 0407118826, qld@asaustralia.org



Merry Christmas and happy new year to everybody

General Information on the web

Spondylitis Association of America

www.spondylitis.org

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

www.nass.co.uk

Ankylosing Spondylitis International Federation (ASIF)

www.spondylitis-international.org

Arthritis Australia

www.arthritisaustralia.com

Optional Information

(this will help us to provide activities suitable for all members of our group)

Are you a member of Arthritis Victoria? Y / N

Are you happy for us to pass on your contact details to other members of the group in your area? Y / N

Gender M / F

Age Group

0 – 20 years
21 – 30 years
31 – 40 years
41 – 50 years
51 – 60 years
61+ years

Preferred Language
…..

Do you suffer from Ankylosing Spondylitis?
Y / N

Do you know someone who suffers from Ankylosing Spondylitis?
Y / N

What other conditions do you suffer from?
……
.....
.....
.....

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

Some of the benefits of belonging to our group:

• Quarterly '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

Ankylosing Spondylitis Group of Victoria
PO Box 3166
Burnley North 3121
Contact Belinda on: (03) 9496 4045
Belinda.Martin@austin.org.au

Ankylosing Spondylitis Group of Victoria

Membership Form
Providing education and support for people with Ankylosing Spondylitis

Who we are and what we do....

The AS Group of 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:
• Support to patients

• Forums for exchange of ideas and experiences

• Distribution of information

• Support to the medical profession and researchers

• Co-ordinate and provide information and speakers for education, information and workshop seminars on Ankylosing Spondylitis

• Co-ordinate with associated Arthritis groups and support groups

• Co-ordinate and participate in Arthritis Victoria activities

• Arrange social functions and activities for people with AS, their families and friends

The Ankylosing Spondylitis Group of Victoria complies with the Privacy Amendment (Private Sector) Act 2000 and will not sell your personal information to another organisation. You will be notified of Ankylosing Spondylitis Group of Victoria events and services and ways of assisting us to maintain these services. If you wish your name to be removed from our database at any time please write to us.

AS Group of Victoria
Under the umbrella of self help groups affiliated with Arthritis/Osteoporosis Victoria

Membership Details

First Name.....
Surname.....
Phone.....
Email.....
Address.....
.....

Membership Type (membership expires June each year)
New Renewal
Mailout # membership ($25.00)
Concession* Mailout# membership ($20.00)
☐ Email member ship ($20.00)
Concession* email membership ($15.00)

Donation $.....
Total $.....

Membership runs to the 30th of June each year and is payable by cheque, money order or direct deposit. Please contact our treasurer for details (asvictreasurer@hotmail.com).

Signed.....
Date.....

Detach this section and send to:
AS Group of Victoria
PO Box 3166
Burnley North 3121

*Concession rate available for pensioners, unemployed with health
benefit card and full time students with student card.
Mailout membership means all correspondence will be sent by Australia Post