

# AStretch

## Ankylosing Spondylitis Australia

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### An exercise program for people with AS Newly Released on DVD

And so it has come to pass..... The DVD entitled An Exercise Program for people with Ankylosing Spondylitis is now produced and will be sent free of charge to all financial members of the AS Group of Queensland with this newsletter. This valuable aid to maintaining mobility was painstakingly produced by the AS Group of Queensland, assisted by an educational grant from Schering-Plough Pty Ltd, Australia. The DVD is wonderful. I know this for many reasons and will relate some of these now. Firstly the actors are like most of you. They are real people of different ages, with all shapes and sized bodies, have varying levels of fitness, some work some don't, but the special quality they share is that they all live with AS. Certainly professional actors may have presented a more streamlined

look and this was considered but this course was decided against in favour of a practical work by actors to whom you can relate. These unpaid actors, some of whom did not appear in the finished product, and especially physiotherapist Margaret Lewington, the AS Committee and Freelance Films deserve much thanks and praise for a job truly well done.

The news gets better! The members of all functioning AS groups in Australia will also get free copies of the DVD. At this stage these will be distributed through your state AS group. Arrangements will also be made so that those who attend the weekly exercise classes in Perth also receive a copy. Check out the review of the DVD on page 1.

John Stafford 

### AS no obstacle to climbing mountains Kilimanjaro - Ascent for Arthritis 2007

Five young Sydneysiders - two of whom have arthritis - will scale Africa's highest peak in July 2007 to fund a new Arthritis Australia research grant.

Having AS has not stopped project leader, lawyer Matthew Leibowitz, from playing first grade AFL for last year's grand finalists Sydney University, swimming open water races or climbing Patagonia. He and his team are keen to get the move it or lose it message out!

Each is paying their own way and is motivated by the shared belief we can all climb mountains regardless of the obstacles.

The aim of the project is to challenge the misconceptions around arthritis, increase awareness of the condition and help people manage their arthritis proactively and positively. At present there is insufficient government funding for arthritis relative to its impact on Australian society. Our project aims to generate

charitable funds for the establishment of a scientific research grant towards a cure and a better future for those with arthritis.

Arthritis Australia has approved the project and is involved in raising awareness and networking as the recipient partner. For more information about our project and to donate to this worthy cause, please visit our website.

The Ascent for Arthritis website is :

[www.ascentforarthritis.com](http://www.ascentforarthritis.com)

or you can follow the links from

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

## Vale Fergus Rogers

by John Ebert



It was with great sadness that I learnt of the death of Fergus Rogers on 17 November 2006. He died peacefully, with his wife Brigitte by his side, at his home in Mayfield, East Sussex from pancreatic cancer.

Fergus had recently resigned from his long held position as Director of the National Ankylosing Spondylitis Society, our sister society in Britain, due to his ill

health. He was the driving force behind the creation of and the first President of the Ankylosing Spondylitis International Federation.

I only met Fergus once in 1993, when he and West Australian physiotherapist Lyn Tinsley visited Brisbane as part of an Australian speaking tour. He impressed me because he was a perfect gentleman and was one of the inspirations that lead to me call the meeting that lead to the formation of the AS Group of Queensland. He was very generous with his time and knowledge to anyone who had any question about AS.

Jane Bruckel, co-founder and former executive director of the Spondylitis Association of America remembers Fergus as "truly a pioneer in the AS community.... With his passion and unique good nature, Fergus did so much for so many worldwide. I know how much he helped us in our infancy starting our AS organization in the 1980s, and his efforts kept going and

going all these years. What an impact; what a wonderful legacy His death is a loss for everyone."

Ken Mulholland, Secretary of ASIF said "Fergus was very highly respected throughout the Spondylitis community both in England and around the world. His dedication, passion and good works have changed the lives of many who have suffered from Spondylitis and related diseases. Fergus was a pioneer and driving force behind the creation and success of ASIF and we will miss his council (sic) greatly."

On behalf of all AS groups in Australia, I send condolences to Fergus' family, his friends and all those whose lives he touched in very many ways.

Rest in peace Fergus.

John Ebert

## AS exercise DVD Review by John Stafford

I had the choice of watching those fake penguins in "Happy Feet" or some real penguins in the AS exercise DVD and always preferring the real thing, I chose the latter. Gosh I felt tired just watching the 50 odd minutes of exercises on the screen but thought that if I, without AS, did the exercises and made the President do them with me too, then I'd be killing two birds with the one stone, getting the President to do more land exercises and making me fitter as well.

So we began watching the DVD together.

I said, "They are going to fast" but John explained that that was done to enable all the exercises to fit on the DVD and when doing them we would slow them down considerably and also repeat each exercise three to five times. Noted! So readers, you note that too. Also John explained that most of them could be done on both sides, even if only one side was shown. However there are so many and I had to commit to doing them all every day, I thought. But no, I have to devise a plan. I could firstly set a time, say thirty minutes a day, or a few times a week and pick out and learn a few exercises at a time. When I know enough for the different parts of

my body that are often stiff on waking (yes, sixty-four year olds, even without AS, sometimes are sore and stiff in the mornings) I can do thirty or more minutes at each session exercising the stiffest parts. I always find that I feel the best results during and after exercising, if I slow down, breathe well and deeply and don't go beyond the point where my body tells me to stop.

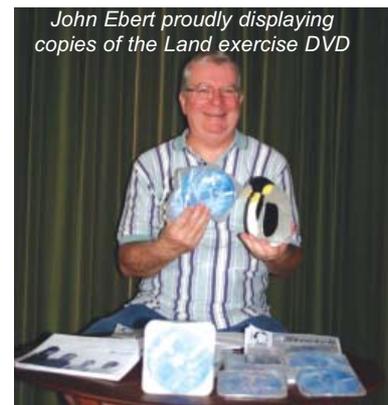
If you have been wise and collected and collated all of Margaret Lewington's AS Stretches published for many years in AStretch, they will be a valuable adjunct to use with the DVD.

The many of you who live in parts of Australia where accessing physical therapies regularly is impossible, now have this special DVD to use in your homes which will be a wonderful benefit to you.

A warning to all of you who may, like me, be technologically challenged. When using the DVD make sure you press the menu, arrow and enter buttons to go to the particular segment you wish to watch. I confess that the President and myself failed to find the last segment

until long after we had declared it to be missing from the DVD. Also regularly use the pause and review buttons until you learn exactly how each exercise is done, so that you can all get maximum benefit from the DVD and end up less stiff.

This great product, which is endorsed by Arthritis Queensland and recommended by the Australian Rheumatology Association, is equal to if not better than any other AS exercise DVD of which your AS Committee is aware. Congratulations AS Group of Queensland.



John Ebert proudly displaying copies of the Land exercise DVD

## **First Australian Recommendations for Diagnosis, Monitoring and Treatment of AS by Dr. Lionel Schachna**



Australia has participated in an international program to develop recommendations for the management of ankylosing spondylitis (AS) in daily clinical practice. This innovative program is called the '3e initiative' after its three phases: (1) the collection of Evidence from the medical literature, (2) a meeting of local rheumatologists who are Experts in treating AS; and (3) an Exchange of information among different countries.

The countries participating in the program included Greece, Spain, Norway, Austria, Italy, Belgium, Turkey, Denmark and Germany. Local 3e scientific committees were responsible for running of the program in the individual countries. The Australian Scientific Committee comprised Prof Matthew Brown (Brisbane), Dr Andrew Taylor (Perth), Dr Jane Zochling (Hobart), A/Prof Nick Manolios (Sydney), A/Prof Malcolm Smith (Adelaide) and myself.

A total of 23 practicing rheumatologists from around the country attended the Australian 3e meeting which was held at the Park Hyatt in Melbourne on 2-3 December 2006. This was the first meeting of its type held in Australia. The international guest speaker was Dr John Reveille who spoke about new discoveries in the genetics of AS.

The goal of the meeting was to address 15 questions related in 1½ days. We first reviewed the medical literature on the 15 questions. These related to the diagnosis, monitoring and treatment of AS. Almost all of the questions were not easily answerable by information from the medical literature, and the experience of participating rheumatologists proved to be very important in tackling these questions. There was much lively and at times heated discussion but at the end of the weekend, we agreed upon a final set of recommendations.

As an example, the Australian group proposed four recommendations related to exercise to maintain spinal mobility in AS.

- (1) An individualised exercise program should be performed regularly to maintain mobility and posture.
- (2) Group therapy may help to maintain long-term compliance.
- (3) Stretching during work activities should be encouraged.
- (4) Manipulative treatments of the spine should be avoided.

In January, representatives from participating countries met in Dublin, Ireland to discuss the similarities and differences among recommendations proposed by the different countries. A set of international recommendations were then agreed upon and will be presented at the European League Against Rheumatism (EULAR) meeting in June in Barcelona.

The Australian recommendations will be presented to rheumatologists and allied health professionals at the Annual Scientific Meeting of the Australian Rheumatology Association in May. Later in the year, we plan to publish the full set of recommendations with the level of agreement for each recommendation. These recommendations will not only be valuable for practicing rheumatologists but also general practitioners, physiotherapists, and individuals with AS.

We gratefully acknowledge the generous support provided by Abbott for the 3e initiative.

## **Anti-TNF biologic treatments no longer dependant on HLA-B27 status**

Australian sufferers of the debilitating arthritic condition, known as ankylosing spondylitis, will no longer have to undergo the blood test diagnosis, human leukocyte antigen B27 (HLA-B27), to access subsidised Anti-TNF treatment, following a government decision.

Until now, the positive results of a test to prove a patient had the tissue type HLA-B27 was a mandatory requirement to access funded treatment. This meant approximately one-in-ten ankylosing spondylitis patients may have missed out.

Arthritis expert, Dr Julien de Jager, Rheumatologist, Southport, QLD, described the change as welcome

news as now all patients who qualify can access what may be life-changing medication.

"This is a welcome decision by the government. It was very difficult having to tell patients who weren't eligible that they did not qualify for a treatment that could effectively turn their life around," Dr de Jager said.

*Thanks to Schering Plough Australia, distributor of the Anti-TNF product - Remicade®, for providing the media release that this article has been based on.*

## Extracts from The NASS 30th Anniversary Symposium

**DR ANDREI CALIN**

(Previously of RNHRD, Bath)

### EPIDEMIOLOGY



Dr Calin started off by reminding us that in the early 1970s and even today, there was a ten year delay of misdiagnosis, this has been reduced in recent years but not by much. During that time patients were receiving inappropriate advice and treatment. It needed an organisation like NASS to educate the patients in their disease and its management. One of the problems is that the GPs had scant knowledge of the condition, therefore very often the patients were referred to the wrong hospital departments. Orthopaedic surgeons did not often recognise the condition in its early stages, and radiologists were not trained to recognise the evidence.

Eventually the association between B27 and the disease was discovered - but what pulls the trigger and when? Is it for instance before birth, or as a teenager, when symptoms are often seen to begin. Epidemiology is about how disease effects populations and people. One of the problems in the past is that studies were done by academics that worked in small units. Their expertise did not represent real life. The next difficulty is that they mostly saw severe cases that did not represent the self-limiting patients who rarely attend hospital.

The other approach would be to take a large chunk of a population. When Dr Calin went to work at Stanford University in California his first job was to investigate 20,000 staff members of Hewlett-Packard. They singled out those people who had early morning stiffness and whose stiffness and pain receded during the day. These people were invited for further investigation. This was an important advance but they were all still working and, therefore, again did not represent real life.

He informed the delegates that he returned to the RNHRD in Bath, encouraged by Dr Dixon. It was a few years after the appointment of Fergus as the full time Director of NASS. During that time the membership leapt

from 300 to several thousand. At the end of the 80s we sent a questionnaire to the entire membership and received a huge response. On the assumption that NASS membership represents the whole spectrum of sufferers, this therefore, was the real world. The sixty question research form compared males with females, the sex ratio, they wanted to know if males, as suspected had more severe disease than females, the age onset and when did people start to retire.

These important studies were helpful as they anticipated the introduction of modern drugs up to today's anti-TNF. We can now demonstrate the experience of the individuals who have the disease for many years and therefore help to pressurise the health authorities. Early retirement had been underestimated, it is not only a huge financial loss to the individual but also to society who loses their lifetime skills.

B27 is now divided into nearly 30 sub-sects and therefore this allowed research workers to start focussing on this gene and its implications; many of these sub-types are not associated with AS and they represent different races and tribes around the globe. It was thought that there was little AS in sub-Saharan Africa. This proved to be wrong as after an epidemic of HIV and AIDS we began to see conditions associated with Ankylosing Spondylitis: why did HIV facilitate the development of this type of arthritis?

The important work has not come from transgenic B27 rats, or peering down microscopes, but by listening to the AS patients through the Epidemiology questionnaires.

One of the problems when we started on the large Epidemiology programme was to define words such as active, mild. This also had to be made clear before the human genome could be explored. These definitions needed refining, if somebody has severe disease, does it mean they have very 'active disease' and what does this mean? Does it mean that they can only drive for short distances at one time, or does it mean that they have a lot of early morning stiffness? The patients are not really interested in whether their ESR is 30 or 70. What interests the patient is whether they can get up in the morning to go to

***The important work has not come from transgenic B27 rats, or peering down microscopes, but by listening to the AS patients through the Epidemiology questionnaires.***

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## Extracts from The NASS 30th Anniversary Symposium

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work, function well and concentrate all day.

There was the question of damage seen on X-rays, or if the person has had related surgery. Gradually we began to answer these questions and in Bath published a series of instruments that were self-administering. These questions could be well understood by patients and filled in at home, for example The Bath AS Functional Index (BASFI), The Bath AS Disease Activity Index (BASDAI) and others.

These indices have been translated around the world. They are an enormously helpful way of assessing disease severity and are widely used today in assessing the criteria in the use of anti-TNF. This raises questions that onset during teenage years carries a greater risk of hip involvement, therefore in order to prevent this surgery, should they been given more aggressive treatment early? Fifteen years ago we published a paper in "The Lancet" on the association of AS and Osteoporosis, we now know that anti-TNF has a beneficial effect on this problem.

### JULIETTE O'HEA

*(NASS advisory physiotherapist)*

#### EXERCISE FOR LIFE



Juliette informed us that her AS started at the age of 11, which was eventually accepted and diagnosed by the age of 19 while a student at Physiotherapy School, and her twin brother was diagnosed a year later.

A few years later while working in New Zealand she drank some unpasturised milk which within days had produced a huge flare up of multiple-joint arthritis, due to a well recognised reaction. With the help of her brother she returned to England and the arthritis took two years to get under control. She recognised that she could no longer carry on with hands-on physiotherapy so took a master's degree to open up wider possibilities. On the retirement of Jane Barefoot from the RNHRD and NASS, the director

invited her to become the NASS physiotherapy adviser. She took over the education role of physiotherapists started by Jane Barefoot which is now known as AStretch. *[Not related to the well known Australian AS publication of the same name - Ed.]* There is now a team of physiotherapists who run these courses. The perception of pain varies between different social and cultural groups. It is often influenced by how much we understand our condition, what sort of coping techniques we adopt, and how much stress and fatigue we are experiencing at the time. Muscle tension, such as often found in the neck, is partly as a response to the inflammatory process. When first attending a NASS branch and you have not carried out much exercise for some time you might find an off-putting increase in pain. This is because ligaments tendons and muscles are being stretched for the first time: therefore the first approach should be more gentle. Many people who participate in a regular exercise programme have found that they can reduce their drug intake or eliminate it altogether.

Exercise maintains and controls posture and delays the stiffening process. It also improves our fitness, contributing to a more enjoyable social and working life, and can assist in improved sleep. Many participants of a NASS branch supervised physiotherapy class have found that it has led to a reduction in anxiety, stress and depression.

There are many reasons why some people cease attending a regular exercise programme. Some make the mistake of thinking that a reduction in pain means that they no longer need to participate in an exercise programme. This is very often not the case, as the disease is often progressing unnoticed. When in flare-up, there is an understandable reluctance to exercise because of increased pain. However avoiding exercise at this time may lead to an increase in long term stiffness, and increased muscle tension. Sometimes the patient does not perceive an improvement and therefore thinks that the effort is pointless. However it should be remembered that exercises increase strength, improve blood circulation, and help to slow down any further loss of posture and stiffness. Posture exercises should concentrate on the back, buttocks and legs. Stretching

exercises put the joints through a full range of available movement. These are especially the neck, the front of the shoulders, around the chest, hips and legs. Stretching these tendons also allows us to maintain a good posture, and the surrounding muscles are able to strengthen to their maximum.

Some resting positions can stretch muscles in the front of the torso which are prone to getting tight. Resting on our back on our beds with the feet touching the floor means that the knees are bent, an effective way of stretching. Being aware of good posture while walking down the road can be a good exercise in itself. Try and stand up against a wall from time to time to check your posture. Examples of good cardiovascular exercises include swimming using a variety of strokes, dancing, cycling, walking with good shoes or supportive in-soles if necessary. During these exercises you will notice your breathing and heart rate increases. This will have the added benefit of maintaining chest movement, which becomes limited as the disease progresses. This has an added benefit of protecting us from heart disease, high blood pressure and diabetes.

Complementary exercises such as yoga, tai-chi, pilates and other alternatives are becoming more popular and are good for improving movement, balance and posture, and muscle tone. Regular ways of exercising can sometimes be built into our commuting to work.

NASS groups are a regular and demanding way of effective exercise in addition to a home programme. You will find empathy, support, friendship and good humour.

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*Morning Stretch with Juliette*

## Extracts from The NASS 30th Anniversary Symposium

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### PROFESSOR PAUL EMERY

(Leeds General Infirmary)

#### ANTI-TNF PATIENT TRIALS



Prof. Emery informed the delegates that it was his job to talk about something called monoclonal antibody. Tumour Necrosis Factor Alpha (TNF) was predicted to have a role in ankylosing spondylitis for many years and in the early 1990s, as soon as they knew that it worked in rheumatoid arthritis, there was a great effort to get the pharmaceutical industry interested in AS. However, incredibly they did not think that AS was important enough (it is now known to be one of the most common forms of arthritis). Many of the original studies were made by individual investigators including a group in Berlin, also Paris and Leeds. A biopsy from an AS joint encouraged the research workers in their suspicion that TNF might have a beneficial effect in AS.

Prof. Emery's Leeds team started in 1997/8 using the TNF agent etanercept by infusion. The group were patients with an average of 15 years of disease duration, and using a visual analogue scale measuring pain of 1-100, the average prior to trial was 70 of 100. At the end of six months the average pain was zero. Prof. Emery had considerable experience in treating RA patients and the response was nowhere as big or as consistent as it is in AS. In many of these RA cases tissue damage has already taken place unless you can treat these cases on the day they present; afterwards because of the damage they do not have the same response. This naturally introduces the big issue as to when patients should be treated.

Proving progress can be difficult when trying to show resolution with therapy. In RA there are lots of affected tissue leading to bone damage, which can be seen by x-ray as there are lots of holes in the bone. In AS it is quite different, because inflammation spreads along the tissue and as a reaction you get new bone. You have to show absence of new bone formation, which is actually very difficult, is even interpreting the

evidence. When looking at the bone after therapy using MRI, 86% are resolved or show improvement. These findings have been completely confirmed by double blind studies.

All three agents which have been licensed so far, show remarkable similarities. However what is remarkable is how other inter-related conditions also show benefit. Colitis shows improvement with the exception of etanercept; it may be true with uveitis. The other remarkable observation is in osteoporosis, a feature in AS, and one of the early observations was demonstrated by Dr Calin several years ago. Anti-TNF switches off the drive to reduce bone formation within the bone, showing dramatic improvement. Slides showing additional bone in the spine and the hips showed that without treatment nothing happens and with treatment there is dramatic improvement. In his trials with etanercept 75% showed improvement. We should remember that this does not mean that 25% do not improve, it only means that their level of improvement does not reach the level of improvement which was being looked at.

The reduction of chest expansion was thought to be largely irreversible. Even patients with fused spines actually show improvement in chest expansion when using Anti-TNF. This is hard to understand, but Prof. Emery thinks it is largely due to the benefit of soft-tissue which allows other movement away from the actual bone itself. Observations of double-blind studies showed some improvement even in some of those patients on placebo. When they are switched to the agents the question arises should they be given a boosting dose to catch up with the group who were on the drug at the start of the trials. This helps to illustrate that there are still so many unanswered questions about dosage and frequency of treatment.

As far as uveitis is concerned, in the trial three of the sixty nine patients had more than one episode of uveitis. Although it is not hard evidence, after treatment only one patient had a new attack. Other observations around the world have shown that there is very little chance of acquiring a first attack while on treatment, and it probably reduces by 80%.

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***The reduction of chest expansion was thought to be largely irreversible. Even patients with fused spines actually show improvement in chest expansion when using Anti-TNF.***

## Extracts from The NASS 30th Anniversary Symposium

*Continued from page 5*

Three-year studies to date show a sustained response. The difference between active and inactive disease when using these drugs is the biggest ever seen in any therapy. This is one of the reasons why placebo studies are very short and in Leeds any patients participating in placebo are afterwards guaranteed therapy.

Nothing comes without a problem, and certain risks have been identified using hundreds of thousands of patients around the world treated for RA and rather fewer (so far) with AS. The exclusions are: TB, patients of latent TB are excluded; Active inflammation (not AS inflammation), this is especially where there is infection in the lungs, an issue with many Patients with AS. Patients with severe heart failure, but recent studies have shown some benefits on the cardiac side. Other conditions are under scrutiny, e.g. in the US where RA and AS patients with MS are excluded.

The use of methotrexate is still being looked at and it is still one of the open questions. There are some patients who do not get a perfect response and, if they can tolerate it, it can be attractive to add that in. There are slightly different responses between patients with only spinal involvement, those with additional joint disease, and those who also have inflammation where the ligament attaches into the heelbone. When looking at the Bath Indices used by the special interest group in Continental Europe, and the similar BSR criteria, about 60% of hospital patients qualify for this new therapy treatment. These Indices are important as they involve the opinion of the patient. A study showed that the physician over-rated mild disease, and under-rated severe disease. Treating early disease has its own built-in problems: one has to make sure that the diagnosis was correct. There is the problem of late diagnosis as it can be difficult to diagnose early. However a team in Berlin are working on a framework where you can move down, including in passing certain markers, leading to a ratio of over 90% certainty of having AS.

Prof. Emery is of the opinion that treatment is long-term, and therefore the question of stopping treatment does not arise. So far the use of other agents

in an attempt to stop treatment has not shown desired effects. There are a lot of new agents coming out which might inhibit the development of AS. This means that, with other forms of effective treatment, less people will meet the BSR criteria and therefore more cases can be treated who are today being excluded. Prof. Emery concluded that, contrary to opinion a few years ago, AS is an important condition. When looking at their Quality of Life studies it is the worst of all the rheumatic conditions. It needs a lot more thought than RA which in itself is very complex.

### DR PETER TAYLOR

*(Head of Clinical Trials,  
Kennedy Institute, London)*

#### ANTI-TNF - HOW DOES IT WORK?



Firstly as the Director of NASS, it gave me great pleasure a few months after the symposium to write to Dr Taylor, on behalf of NASS and those attending the meeting, to congratulate him on being appointed a Professor.

This talk was certainly the most difficult to deliver to a lay audience simply, just because of the complicated science involved. It was also difficult to transcribe without the huge number of helpful slides Dr Taylor used in his talk.

Prof. Taylor started by describing AS as a condition with unmet needs, as the traditional therapy options are not always sufficient to treat the disease in some cases. He decided it might be helpful if he used the image of Batman in Gotham City and all the unpleasant characters involved there, who represented the harmful chemical messengers causing inflammation. It also helped to illustrate how some of the key chemicals help to regulate others, rather in the way the thugs receive orders from those above them who are their henchmen. Acting under instructions, they cause mayhem in the form of inflammation, as in the case of IL6, swelling and joint damage. The Anti-TNF medication can therefore be seen as super crime fighters.

How else do they know that TNF works? Another major TNF action comes from research in rheumatoid arthritis (RA): it affects the way the inflammatory cells in the blood actually enter the joints. There are several ways of following this action. One piece of evidence can be seen when the physician does blood tests before Anti-TNF treatment. It will show blood counts at a certain level, and after TNF the white cells increase. But where are they coming from? In RA they are coming from the joints into the blood, where they can be measured. By blocking with TNF you actually affect the way that cells invade inflamed joints. There are a type of sticky molecule which are always the first to reach the inflamed joint. After TNF these are far fewer and their stickiness has reduced after treatment.

The definitive way to prove that there is a reduced movement of inflammatory cells from the blood into joints is to actually measure this reduction directly. This is by taking blood from volunteer RA patients and adding a harmless radio label onto their white blood cells, and then returning the blood back into the patient. They found that these cells went straight to inflamed joints. The final piece of evidence is by looking at a certain type of enzymes which are destroying joints by eating tough fibrous cartilage, and to some extent bone. These can be measured in the blood, and if you give a dummy drug they do not change. but if you apply TNF their level is reduced, thus joint destruction is also reduced.

Prof. Taylor summed up explaining that the answer to the title of the lecture is not entirely known. However there is a range of known evidence. It is known that TNF regulates a whole range of inflammatory messengers. We know that it reduces migration of cells from the blood in the joints. We know that it reduces the amount of blood flow into the inflamed joints and leakage of fluid into the joints which makes them soggy and swollen. It reduces some of the key players which mediate joint damage.

*Reprinted from the nass newsletter  
ASNEWS Autumn/Winter 2006 issue.*

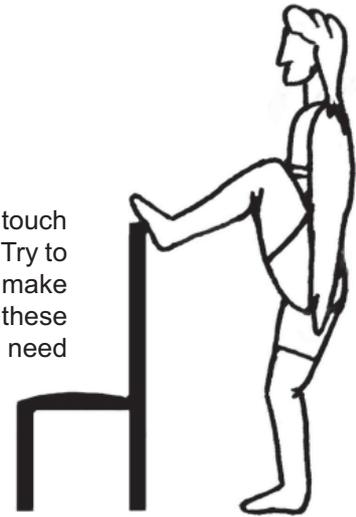
## Physiotherapy - AS Stretches

by Margaret Lewington (B.Phty. Cert Hydro.M.A.P.A)

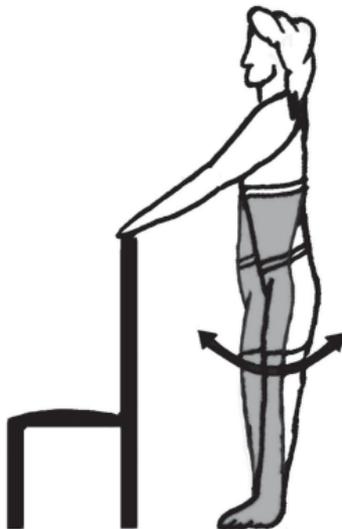
Grab a sturdy chair and get ready to do a few simple exercises. You may be able to fit them in at work, do one each time you get up from your desk.



1. Stand behind the chair, keep tall, lift your chest, drop your chin and lengthen the back of your neck and stretch up through your whole body. Keeping straight, take one leg backwards, working the muscles in your buttocks and stretching the front of the hip. Do 5-10 repetitions and then change to the other leg. Make sure you stand tall on the other leg, don't let the hip drop or poke out to the side, tighten your tummy. Also, do a few slow movements with holds.



2. Stand behind your chair and lift your leg up to touch the back of the chair with your foot. Alternate legs. Try to stand as close to the chair as you can, as this will make you lift your leg higher. You may also do a few of these quickly, to add some fitness to the exercise. If you need to, you may hold the chair to keep your balance.

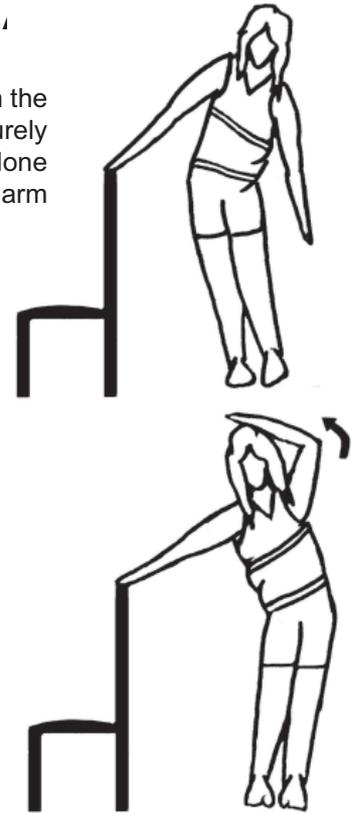


3. Stand behind your chair and keep tall as for Ex 1. Move your hips around in a circle. Think of a clock face and reach each number as you go around. Make the movement as large as you can but keep tall all the time. Do 10 one way and then circle back the other direction.

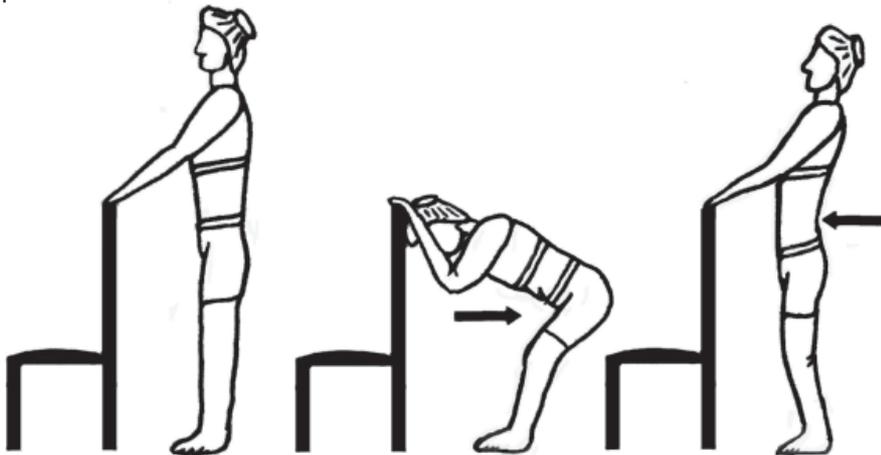
## Physiotherapy - AS Stretches

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

4. Turn side on to your chair. Move your hips out to the side, away from the chair and then in towards the chair. Make sure that the movement is purely sideways ie. don't let your buttocks drop backwards. After you have done a few this way, you can increase the side stretch by also taking your arm over your head and stretch towards the chair. Turn around and repeat facing the other direction.



5. Stand facing the back of the chair and holding the back of the chair for support. Push your buttocks back as far as possible, aiming to straighten your arms. Keep your legs straight or almost so, and drop your chest to the floor and look down. Stand back up straight and then let your hips come forwards towards the chair, arching your back, lifting your chest and looking upwards.



6. Now sit on the chair, but before you relax, stretch down to the floor, reaching your hands through under your chair if you can. Let your head relax, looking at your hands. Pause here and feel the whole of your spine lengthen and stretch. Now sit up tall, arch your back away from the chair, lift your chest, bring your shoulders back and face your palms to the front. Look up a little. Adding deep breathing with this action is very useful.



**AS Australia Calendar 2007**

STATE	EVENT	DATE	TIME	CONTACT
VIC	BBQ at Yarra Bend	Sunday February 4	10.00 am - 2.30 pm	Belinda Martin 9496 4135
TAS	Arthritis Tasmania Ankylosing Spondylitis Seminar	Tuesday February 27	1.30 pm - 4.30 pm	Arthritis TAS 1800 011041
VIC	Seminar & Information Night Keynote Speaker - Lionel Schachna Ivanhoe Reception Centre, Ivanhoe	Thursday March 8	6.00 pm	Belinda Martin 9496 4135
QLD	Annual General Meeting at Arthritis Queensland 1 Cartwright St Windsor	Wednesday March 14	7.00 pm	John 3391 4689
QLD	Annual Bribie Island picnic at Sylvan Beach	Sunday March 18	From 11.00 am	Graham 3263 6196
VIC	Joint Walk & Picnic with Arthritis VIC @ Jells Park Mt. Waverley	Sunday April 1	10.00 am - 2.30 pm	Belinda Martin 9496 4135
QLD	Dinner @ venue to be advised	Saturday April 21	7.00 pm	Graham 3263 6196
QLD	Barefoot Bowls Merthyr Bowling Club Oxlade Drive New Farm	Sunday June 3	11.00 am	Graham 3263 6196
VIC	Seminar & Information Night @ Caulfield	Thursday June 14	6.00 pm	Belinda Martin 9496 4135
QLD	Dinner @ venue to be advised	Saturday July 14	7.00 pm	Graham 3263 6196
VIC	Christmas in July @ Rosstown Hotel Carnegie	Friday July 27	7.00 pm	Belinda Martin 9496 4135
QLD	Ankylosing Spondylitis Symposium Russell Strong Auditorium Princess Alexandra Hospital Woolloongabba	Saturday August 4	9.00 am Register 8.00 am	John 3391 4689
VIC	Seminar & Information Night - Venue to be advised	Tuesday September 4	6.00 pm	Belinda Martin 9496 4135
QLD	Dinner @ venue to be advised	Saturday September 15	7.00 pm	Graham 3263 6196
QLD	Picnic - Venue to be advised	Sunday October 14	11.00 am	Graham 3263 6196
VIC	Dinner @ Rose Hotel, Fitzroy	Friday October 16	7.00 pm	Belinda Martin 9496 4135

SUMMER 2006/2007

## AS Group of Queensland News

Happy New Year to you all. What a fantastic year of activities we have planned for you in 2007.

Our social activities start with our annual Bribie Island picnic on 18 March. There are four dinners planned – the first on 21 April followed by 14 July, 15 September and our Christmas dinner on 1 December. The very popular barefoot bowls day is on 3 June at the Merthyr Bowling Club, New Farm. A picnic is organized for 14 October and our annual barbecue at Jack and Joy's is on 10 November. Further details of some of these activities are on the calendar on page 9.

Our Annual General Meeting will be held at 7.00pm on Wednesday 14 March at Arthritis Queensland, Robertson House, 1 Cartwright Street, Windsor. I look forward to a big attendance. This year some committee members have indicated that they will not be accepting nomination for committee, so if you have ever thought that you would like to assist in the day to day decision making and running of your group, please consider nominating for a position on committee.

As you may have already read, our excellent DVD of land exercises is now available for distribution to our members. I thank Margaret Lewington, our AS models who were in the final cut – Bill, Graham, John A, John E, Melissa, Robert and Sigrid and Liam and Penny who couldn't make it to the final filming. Thanks also to Narelle and Leith from Freelance Films, Francesca and Kira

from Porter Novelli, Dr Julien de Jager, and most importantly Schering-Plough for the grant which made this production possible. I hope that each of you will gain great benefit from these important exercises for people living with AS.

Our annual barbecue at Jack and Joy's in November was greatly enjoyed by those who attended. Though we were only eight in number, we had a most enjoyable afternoon chatting, laughing, enjoying the fine fare supplied by the hosts and attendees (there is no way anyone could starve at an AS function) and relaxing in Jack and Joy's home. Thank you Jack and Joy, I look forward to this year's barbecue. While we were there, Graham, our party penguin, put on his thinking horns to help him come up with some ideas for this year's socials.

I was very pleased to catch up with the wonderful Jane Barefoot whilst on a break at the Sunshine Coast in January. Jane is on her annual summer pilgrimage to Australia and hopefully she will be attending our St. Patrick's Day picnic on Bribie Island. For those of you who don't know Jane, she is the retired consultant physiotherapist to NASS and due to involvement with the Qld group since its inception, was given the title of our Fairy Godmother. If you have never met Jane, the Bribie picnic will be a great chance to do so and if you have met her, I'm sure you would love to catch up with her again.

John Ebert 



Is it a Reindeer?  
A Social Butterfly maybe?  
Got Happy Feet for sure!  
Queensland's original  
Party Penguin Graham  
awaits your response to the  
plethora of social events  
planned for 2007.

Check out the Calendar on page 9.

## AS Group of Tasmania News

G'day from Tassie, we hope everyone had a great Christmas and New Year and are not suffering too many aches and pains.

Our BBQ at Waterworks went well, a couple of new faces came along to help make up numbers as a couple of regulars were missing- hope you had a great time in Sydney Chris and Alicia. We still had an enjoyable evening, weather was fine, wine was nice, food was cooked to perfection, only problem was fighting off the ducks who wanted to eat everything we had.

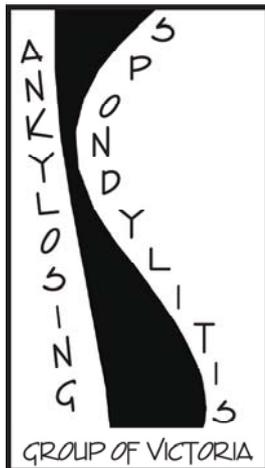
Arthritis Tasmania is running a seminar on Ankylosing Spondylitis on Tuesday 27th February 2007 at the 50 & Better Centre, 108 Bathurst Street, Hobart from 1.30pm to 4.30pm, Gold coin donation. Rheumatologist Dr. Jane Zochling and Physiotherapist Janet Millner will address the seminar. Please ring Arthritis Tasmania on 1800 011041 to register.

Bye for now,  
Murray Limbrick  
Ph 03 6349 4474 or 0400 108874 

**"Remember, AS is easier to tackle as a Group."**

**- AS Group of Tasmania**

## AS Group of Victoria News



Happy New Year to all and Happy Feet all round for the AS Group of Victoria. Late last year the committee put together a submission to the Department of Human Services for a Self Help Group funding grant. With a requirement to detail where that funding would be used within a stringent set of guidelines, the committee tabled a list of general running expenses and project costs for the coming year. We are happy to announce that we are set to receive an \$800 boost to our funds. This is in addition to the \$100 seeding grant provided by Arthritis Victoria and the generous donations provided by members on top of their membership fees. Thank you to all.

It is hoped that in addition to the excellent Land DVD reviewed on the front page of AStretch, the much anticipated Hydrotherapy DVD from the AS group of QLD in conjunction with Margaret Lewingtons Hydrohealth will be made available to our members on a part or fully subsidised cost basis as a

result of the grant. Another great reason to be a fully paid up member.

On the social front, the AS Calendar (page 9.) has been filled up for 2007 with a great mix of Dinners, BBQ's & Picnics together with a number of seminar/information nights. For these, we are aiming to provide a good balance of guest speakers together with ample time for interaction with other people living with AS. This, in my opinion, is one of the best ways of finding out more about AS and how to deal with it.

The Royal Melbourne Hospital, Royal Park Campus Ankylosing Spondylitis Program is on again, with the next evening scheduled for Thursday 15th February. Further on the education front, Jennie O'Reilly is again running the excellent AS course at the Caulfield General Medical Centre. Although it appears to be fully subscribed for the February start, it would be worth contacting Jennie to register your interest in case of cancellations or to get in early for the next course she runs. See the advertisement on this page for details.

I'm sure you would all agree, a very positive start to 2007. On behalf of the AS Group of Victoria, we look forward to catching up with our members at these events and extend a welcome to anyone interested in becoming a member to come along too, I'm sure you'll come away with new information on how to deal with your AS.

Regards,  
Annie McPherson. 

## AS Group of Western Australia News

The WA group holds two sessions of land exercises and hydrotherapy each Monday at the Shenton Park Hospital. While one group of participants starts with hydrotherapy, another commences with land exercises and after an hour they swap. It is an excellent way to achieve a balance between land and water exercises.

### Western Australia Hydrotherapy (Perth)

**Where:** Royal Perth Rehabilitation Hospital  
Shenton park Annexe Selby St Shenton Park.  
**When:** Every Monday evening (Public Holidays excepted)  
**Cost:** \$6.00  
**Times:** Hydrotherapy Pool  
5.30pm - Hydrotherapy exercises  
Gymnasium  
5.45pm - Land exercises

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

### ANKYLOSING SPONDYLITIS COURSE

CONDUCTED BY THE PHYSIOTHERAPY  
DEPARTMENT OF CAULFIELD  
COMMUNITY HEALTH SERVICE

8 Weekly sessions of exercise,  
hydrotherapy & education

COURSE DATES for 2007.  
Wednesday evenings 6pm to 8pm  
14, 21, 28 February, 7, 14, 21,  
28, March and 4 April.

#### COURSE CONTENT

Pre and post course assessment  
Results sent to referring doctors  
Gymnasium & hydrotherapy sessions  
Education on self management  
of the condition  
Presentation on the condition  
by Dr James Harkness  
Home exercise program  
12 monthly reviews

COST  
\$180.00

VENUE  
Hydrotherapy pool CGMC  
Ashley Ricketson Centre, CGMC.

CONTACT  
Jennie O'Reilly  
by Tel. 9276 6804, fax 9276 6126 or  
E-mail: J.O'Reilly@cgmc.org.au

**FEBRUARY COURSE FULLY BOOKED  
PHONE JENNIE FOR FUTURE DATES**

## Hydro News by Margaret Lewington

In November 2006, I was fortunate to have a wonderful overseas trip which included 2 conferences specifically relevant to AS.

I arrived in London, and along with catching up with my brother and his family for a few days, I attended a one day conference specifically for physio's working with people with AS. This was the third annual conference and approx. 30 physio's attended from England and one other international physio ( from Turkey). It was great to catch up with four physio's that I had met on previous visits to the UK as well as to meet and chat with several others. I also met the new director of the UK patient support group, NASS – Jane Skerrett. I am sure she is going to continue the good work of NASS as well as have many innovative ways to make AS understood and recognised in both the medical and the general community.

The theme was 'AS – Motivation for patient and physio'. The day began with an excellent presentation by Juliette O'Hea who is the physio adviser to NASS and who also has AS. Her topic was 'Exercise for Life'. She discussed how experts in the field of AS clearly appreciate the importance of regular exercise in the treatment of the condition. As physio's we play a crucial role in the treatment, and through exercise, patients can experience an increased quality of life and better prognosis. But we tend to see the patients who are already motivated. Some patient groups thrive and some dwindle. While discussing some of the barriers to exercise, including fatigue, time and pain, she discussed and challenged physio's to work with patients to help motivation and empower them to change and take action and control. This presentation was followed by a panel and open discussion of activities in several centres around the UK.

The day also included a presentation from a Disability Employment Adviser, similar to our CRS, on services available to help people who are having difficulties staying in their current employment. The afternoon included a talk by a physio doing some research into Disease and Psychological Status of AS, another physio looking at the working lives of people with AS, especially ergonomic aspects and finally an overview of recent research and developments and current management principles by one of the Rheumatologists from Bath, Dr Millicent Stone.

My next stop was Washington DC. The American patient society SAA holds several patient forums each year, in different centres. They always hold one in November in conjunction with the American College of Rheumatologists and Health Professionals Annual Conference. This was a wonderful day with approx 80 registrations of people with AS and their families. I was made very welcome by Laurie Savage, the Executive Director, and her team. Dr John Reveille gave the first address, discussing the old and the new in research and treatment options. He outlined several research activities that are current and ongoing, including the large one which he is doing with our own Prof. Matthew Brown in Australia. As well as updating on the TNF medication, and giving some reports of excellent results, including one of his very severely affected patients now taking up Skydiving! (not recommended, but his choice), he also stated that 50% of people with AS get adequate disease control with NSAIDS, and emphasised the crucial role of exercise and Physical therapy.

Physiotherapist, Vicki Gall, spoke next on Exercise and Activity. She outlined the need for everyone to do 30 mins of cardio-vascular exercise every day, and that AS specific exercise needs to be AS WELL as this. She suggested that soft tissue stretching and flexibility of problem areas needs to be done daily, a full body stretch needs to be done 2-3 times per week, strength work 2-3 times per week and attention to posture and positions for daily living tasks is an 'always' category. She supported the idea that individualised instruction was important and most effective and that it is important to learn what you can do and adapt to your symptoms. Find out what works for you, be firm, but forgiving. Enjoyment is crucial. She asked the audience for their most important piece of advice that they would give someone with AS. The responses included keep moving; watch your posture; keep at it, be positive and optimistic; exercise daily; take your medication; have a sense of humour.

Another rheumatologist, Dr Michael Ward, spoke on outcomes, functioning and workability issues. He said that in the early stages, the problems that affect functioning are pain and stiffness, muscle spasm and joint swelling, but in the later stages they are spinal fusion, strength and conditioning. Following

this, we broke into three groups to have discussions led by the speakers, who rotated to each group. I had been asked to help lead one of these groups with Vicki and Michael. This was an excellent question and answer time and an opportunity to interact with the people attending. There were very positive responses to the day, and I found it very enjoyable and interesting to attend.

Following this, the main conference started, and I joined the 8,000 delegates for four full days of presentations and posters, with quite a good focus on AS. A lot of this was centred on the new TNF medication and responses in trials that have been going on for a few years now. I also attended some small group sessions which allowed for more interactive discussion and there was one paper on AS presented by a physio from Ireland – Quality of Life and Exercise Compliance in Patients with AS. This paper showed that the current findings indicate that only a minority practice a therapeutically beneficial regular exercise regime. Further research that develops more compliant forms of exercise therapy, which could maximise the benefits gained, is needed.

It was a busy but enjoyable schedule, and many contacts and friends were made. It has reinforced many of my feelings and ideas and entuses me to continue aiming for optimum management and education for both people with AS and Australian physio's.

### HYDROTHERAPY in Brisbane

*Pool Exercise Sessions  
for people with AS*

Supervised by Margaret Lewington  
( B.Phty. Cert Hydro. M.A.P.A.)

WHEN: Tuesday Nights

TIME: 6.30 – 7.30 pm

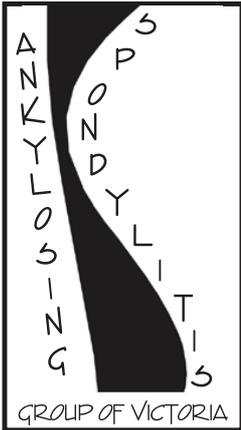
WHERE: Hydrotherapy Pool,  
Level 2, Ned Hanlon Building,  
Royal Brisbane & Women's Hospital,  
Butterfield Street Herston.

COST: \$8 or 10 classes for \$75

ENQUIRIES:

Margaret (07) 3376 6889 or  
John (07) 3391 4689

# AS Group Membership Form



## Ankylosing Spondylitis Group of Victoria Membership Application Form

I wish to become a member of the Ankylosing Spondylitis Group of Victoria and enclose my remittance, contact details and preferred membership type.



### YOUR CONTACT DETAILS:

Name:

Address:

Telephone:

Email:

*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.*



### MEMBERSHIP TYPE:

*Note: Membership runs through to 30th June 2007*

- |                          |   |         |
|--------------------------|---|---------|
| <input type="checkbox"/> | Full: (Includes mail out of Newsletter) | \$25.00 |
| <input type="checkbox"/> | E-mail: (Newsletter by e-mail only)     | \$20.00 |
| <input type="checkbox"/> | Concession: *                           | \$20.00 |
| <input type="checkbox"/> | E-mail Concession: *                    | \$15.00 |
| <input type="checkbox"/> | Donation:                               | \$      |

*Please make  
cheques or money orders  
payable to:*

**Ankylosing Spondylitis  
Group of Victoria**

**TOTAL:**

\$

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



### RETURN COMPLETED FORM TO:

Ankylosing Spondylitis Group of Victoria  
P.O. Box 3166  
Burnley North, VIC, 3121.



### FOR MORE INFORMATION:

Contact Belinda Martin - (Phone) 03 9496 4135 (Email) [belinda.martin@austin.org.au](mailto:belinda.martin@austin.org.au)