



AStretch

Ankylosing Spondylitis Australia

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American College of Rheumatology 2007 Annual Scientific Meeting - Dr. Lionel Schachna

The Annual Scientific Meeting of the American College of Rheumatology (ACR) was held in Boston, MA from November 6-11 2007. There was much excitement about the recent discovery of two genes strongly associated with AS by a research group led by Professor Matthew Brown from the University of Queensland. (See page 1 for Professor Browns report) Using a technique called genome-wide association scanning, the researchers analysed DNA samples from 1000 patients with AS and 1500 people unaffected by the disorder in search of genetic mutations that increase the risk of developing AS. They identified two new genes, ARTS1 and IL23R, which increase the risk of developing AS. Both genes code for molecules that play an important role in the body's immune response to infection. This major discovery may help unravel the complex relationship between a genetic background, reaction to infections and the development of AS. There is also hope that these discoveries may lead to new therapies targeting these genes or molecules.

The other very exciting news from the ACR meeting was the description of two studies of TNF medicines in early AS. In the first, 40 people within 3 years of the start of their AS symptoms who were HLA-B27 positive and had MRI changes of sacroiliitis (inflamed sacroiliac joints) were given either infliximab (Remicade®) or placebo infusions. After 16 weeks, a moderately good response was seen in about 80% of the infliximab group and an excellent response in 60%. In the second study, 46 individuals with two of (1) inflammatory back pain, (2) HLA-B27, and (3) MRI changes were given either adalimumab (Humira®) or placebo injections. After 12 weeks, a moderately good response was seen in about 70% treated with adalimumab, and an excellent response in 55%. Taken together, these studies suggest that TNF medicines when used in early AS can achieve similar or even greater benefit compared with patients with long-standing disease. In future, it is likely that TNF medicines will play a major role in the treatment of early AS before the development of x-ray changes.

A study of golimumab involving 356 patients with AS was presented at the meeting. Golimumab is a new fully humanised TNF medicine that is administered by subcutaneous (under the skin) injection once per month. The results that were shown at the meeting are very similar to those previously reported for the other TNF medicines. In the future, golimumab is likely to provide a further treatment option for Australian patients with AS.



Finally, a study from Drs Peter Cheung, Kathleen Tymms, and Kenneth Khoo in Canberra described the results of infliximab treatment for AS patients with total spinal fusion. Among 11 patients with total spinal fusion, a moderately good or better response was seen in more than 80% of individuals. Remarkably, the rate of full time employment increased from 45% to 82%. This study strongly suggests that TNF medicines may provide major beneficial effects even among those with long-standing AS and severe fusion of the spine.

In summary, I believe that the studies presented at this year's ACR meeting were the most exciting since the results of TNF medicines were first described in 2001.

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NEW GENETIC FINDINGS IN ANKYLOSING SPONDYLITIS - Matthew Brown



We have known for nearly 40 years that the gene HLA-B27 is a major cause of AS. However, only about 5% of people who carry HLA-B27 develop AS. Those B27-carriers that develop AS also carry other genes that cause the disease, but until

recently we haven't known what those genes are.

In the November edition of the major international genetics research journal, *Nature Genetics*, an international group of researchers in which our group plays a leading role (1), reported the identification of two new genes that play a major role in determining the risk of getting AS, contributing about one third of the risk of the condition. These two genes are called IL23R and ARTS1, and their identification is arguably the biggest advance in our understanding of what causes this disease since the discovery of the involvement of HLA-B27 in 1970.

IL23R carries the genetic code for a receptor for a chemical produced by white blood cells called IL23. IL23 promotes inflammation. It had never been considered to be involved in AS before but we now know that it is a major player in what causes inflammation in the disease. You may be aware that AS often occurs in people who also have the skin disease psoriasis, and the bowel diseases Crohn's disease or ulcerative colitis. We now know the reason for this – the genetic variants of IL23R affect the risk of each of these three diseases. Excitingly, there are already treatments which have been trialled in other conditions that target this system, and our findings suggest that they will also be effective in AS. We hope to initiate trials of these treatments within the next couple of years.

Despite the fact that we have known about the importance of HLA-B27 in AS for so long, we still don't know how it causes the disease. The ARTS1 gene goes a long way to answer this question. The main function of HLA-B27 is to take fragments of pathogens

(such as bacteria) and displays them on the outside of immune cells. These fragments then trigger the immune system to fight against the pathogen and clear the pathogen from the body. ARTS1 is involved in breaking up the pathogen into "bite-size chunks" that can be displayed by HLA-B27, and the genetic findings indicate that it is likely that faulty handling of these chunks of the pathogens by HLA-B27 is what causes the disease.

There are likely to be many other genes also involved in AS and our group is the hub of a major international program of research to identify those genes. Sadly, the Australian government through the National Health and Medical Research Council has not funded any of this work (despite five applications from our group alone over the last three years!), which is hampering our ability to make progress. Partly this is due to the poor state of medical research funding in Australia. But it also makes you wonder about why such a low priority is given by the organization to this condition. Let's hope that this changes soon.

MATTHEW BROWN
Professor of Immunogenetics,
University of Queensland.

1. *Wellcome Trust Case-Control Consortium, Australo-Anglo-American Spondyloarthritis Consortium 2007 Association scan of 14,500 nonsynonymous SNPs in four diseases identifies autoimmunity variants. Nat Genet 39(11):1329-1337.*

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EULAR 2007 Congress Summary - Dr Andrei Calin Consultant rheumatologist, MD, FRCP, Bath, U.K.

The European congress of Rheumatology met in Barcelona in June 2007, attended by approximately 1,000 rheumatologists.

A striking 224 presentations on ankylosing spondylitis were made during the four day meeting.

The purpose of this brief review is to summarise areas of interest.

I would be happy to comment by e-mail correspondence should any reader be interested in further data.

1. The first abstract was presented by an Arab group. Many readers of NASS will have remembered taking part in our studies of BASFI, BASDAI, BASMI and BASRI in terms of assessing disease activity, function, metrology, global status and radiology, and it is gratifying to see many groups around the world translating these self administered instruments into local languages and indeed the BAS Indices have been translated into some thirty or forty languages around the world and studied in different communities.

2. A group from Spain from many different cities studied the relationship between iritis - inflammatory eye disease - and outcome in terms of disease activity and severity, in ankylosing spondylitis, and in contrast to the findings from Bath/NASS, found that iritis was not a marker for more severe disease.

3. Some years ago in Bath we developed the Bath Ankylosing Spondylitis Radiology Index as a hoped-for and more simple improvement over the existing study from Stoke-on-Trent of some years earlier. A study from many different centres in Europe carried out an extensive investigation looking at a new core of patients comparing BASRI (the Bath model) and that of the Stoke model (SASS). The authors concluded that both instruments are valid for measuring spinal radiological change in psoriatic arthropathy, but felt that BASRI was quicker and easier to perform than the SASS.

4. A small study from Turkey revealed a hitherto unrecognised side-effect of etanercept (anti-TNF) treatment, in ankylosing spondylitis. Specifically, three patients developed amyloidosis, a potentially serious complication - albeit one that is particularly rare, and no doubt, around the world, we will keep

a careful watch on other patients on this drug to see if there are any further cases.

5. A study from Poland assessed the effect of etidronate, an anti-osteoporotic treatment in the management of ankylosing spondylitis, and showed that treating osteoporosis in ankylosing spondylitis reduced the level of inflammation in this condition - a not unexpected finding, given what we know about the effect of other bisphosphonates.

Indeed, here in Bath, we are carrying out a very large study looking at one of the newer anti-osteoporotic drugs, in order to determine how much benefit we can get in ankylosing spondylitis, both from the inflammatory and pain point of view and in terms of increasing the strength of the underlying bone.

6. There were many studies on the different anti-TNF agents revealing safety and good outcome in ankylosing spondylitis. For example, a study from Leeds showed that the majority of ankylosing spondylitis treated with biologics show good outcome, that is sustained over a long term and only very few patients stop the drug because of side-effects. Further, they revealed that BASDAI and BASFI continued to improve over time in those individuals who stay on biologics - an encouraging finding for physicians and patients alike.

7. A study from Spain showed that smoking in ankylosing spondylitis patients is associated with more severe progressive radiological disease - confirming what we have known long-term: that it is even more important to avoid smoking as a spondylitic patient!

This article is an extract from the Autumn/Winter 2007 issue of the U.K. NASS AS newsletter



A study from Spain showed that smoking in ankylosing spondylitis patients is associated with more severe progressive radiological disease - confirming what we have known long-term: that it is even more important to avoid smoking as a spondylitic patient!

Alternative Solutions: Meeting the need for activity - David Smalley on the benefits of Dance for AS

The following article is an extract from the Autumn/Winter 2007 issue of the U.K. NASS AS newsletter .

Having been an AS sufferer for longer than I want to put in print, I guess that most patients have never had a "strategy". The fact is one just tries to get along with life in the best possible way.

It is apparent that for some, symptoms may be mild. In others, unfortunately, the affect of AS can alter the whole of one's lifestyle and can be drastic. In my case, had I not been in a senior management position where I had wide flexibility, I could easily have been unemployed for long periods of time.

In the post war era, NASS had yet to come into existence. This meant there was less pooling of information and treatments varied. At one point I was given high dose aspirin. This made me ill as I coughed up blood from the effects of what aspirin did. Patients like me were given radiotherapy treatment - nobody knew at the time what effects this would have in later life. Some I understand were put in plaster casts.

It seemed a very hit and miss affair as to what treatment one had if you had the fortune or misfortune to be correctly diagnosed.

After the forming of NASS and what came out of the Royal National Hospital for Rheumatic Diseases in Bath, treatments converged.

The pooling of experiences and work from professionals brought in changes for patients. Treatment would be centred on activity, with the front being threefold. NASS would progress to form local activity groups. Sufferers were urged to join and AS clinics insisted on the following:

- Daily exercise at home on a prescribed programme
- Join a local group for exercise in a hydro pool with a physiotherapist supervising
- Exercise in a local public pool three times a week

With this sort of regime, and what with trying to hold a job down and bring up a family, I simply couldn't take on board the drastic new changes. I hated water and I simply was not going in any public pool.

Then she asked if I was going to the local AS Group. When I said again I wasn't I could see her disapproval growing. Then she asked me if I was doing any sort of exercise. I said, "Well err yes, I dance".

Continued page 4



David Smalley and Serena Elford after their dance demonstration to the physiotherapists at Poole hospital.
L to R: Jane Haynes, Senior physiotherapist, Serena, David and Barbara Harvey, dance teacher.
Back row: Poole hospital physiotherapists.

Alternative Solutions: meeting the need for activity

Continued from page 3

In depression, I decided I would not go on any more clinics so I discharged myself and got on the best way I could. After a time, common sense prevailed and I knew I needed to get back on clinics again, because at some point I would need support. I thought over how I could mitigate the flak I would get when I walked in. One thing I did was to think about how I could substitute going in a pool with some other activity.

I thought, I used to dance in my teens, and that was fun - how about having a go at that. So I went back to classes. I soon found that whilst I did all the ballroom dances, it was Latin and American dances that had better action that would benefit AS sufferers. After a few months, I got in touch with the hospital again and was promptly seen on a clinic.

A lady doctor kept repeating, "Why have you come back now?" I tried to explain but I have to say, she took some convincing. Next came, "Are you doing your home exercises"? Sheepishly I had to say that I wasn't.

Then she asked if I was going to the local AS Group. When I said again I wasn't I could see her disapproval growing. Then she asked me if I was doing any sort of exercise.

I said, "Well err yes, I dance".

I could see that it wasn't the sort of reply she expected and this changed the tone of the consultation. So the doctor then asked what I did.

I explained that if one performed the full ten dance syllabuses of both the ballroom and Latin dances, a good number of exercises would be covered in the standard dance figures, with such dances as samba going into the knees and ankles and rumba into hip action and the like. Not easily conned, she looked me straight in the eye and said "Show me what you do". I knew this was the moment of truth so I gave the doctor a demonstration of both the samba and rumba action.

Satisfied she made a few notes and asked how many times a week I danced and similar questions. She said, "Now you just keep that up". As I left the consulting room, that ice cool practitioner became a charming lady with a broad smile and a twinkle in her eyes. With the smile came, "Good luck with your dancing, Mr Smalley!" This is one consultation I remember as if it were yesterday. Perhaps because dance has had such a positive and meaningful effect on my AS and my life outcome.

I thank that doctor those many years

ago for endorsing dance as an approved exercise for me to undertake instead of swimming.

As most dance schools have social activities, one can make new friends interested in the activity of dance. It becomes an attractive proposition to go to any event. I cannot think of any other activity that can compare with dance for consistent activity and enjoyment. In recent years I note that even Physiotherapy Departments are running music at AS activity sessions - it may be late coming - but we're getting there!

So at workshops, practice nights, socials and the like, time soon slips by with laughter, fun and friends.

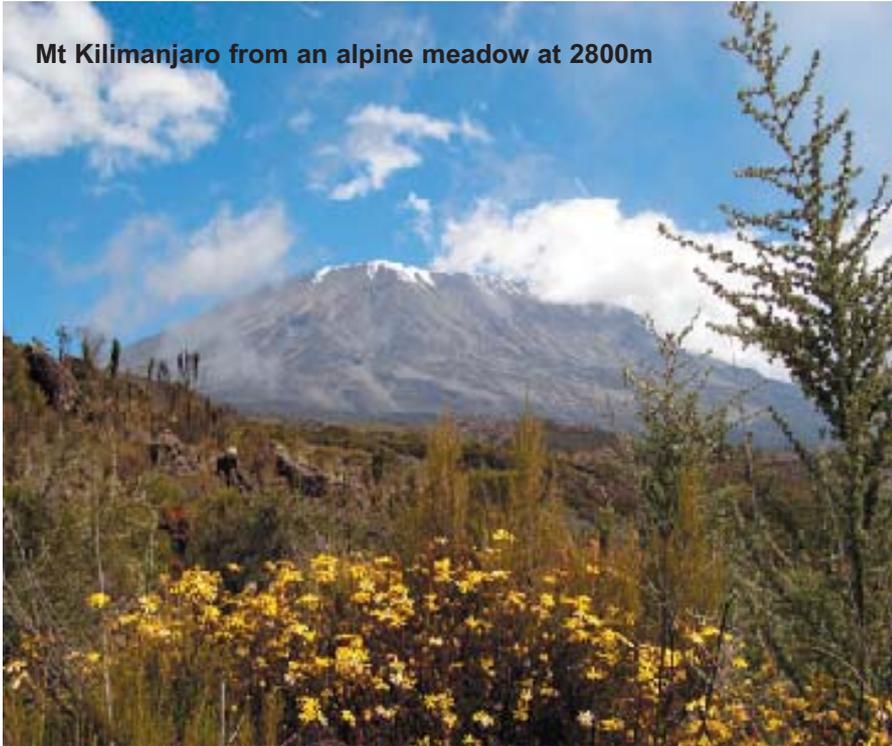
Dance may not be as good as going in a public pool, but where it wins hands down is on the "feel good" factor of fun and activity.

I would like to place on record my thanks and appreciation for all the work undertaken by the Department of Rheumatology together with the Department of Physiotherapy at Poole Hospital NHS Trust. I have now had it confirmed that it was consultant rheumatologist Dr Karen Mounce who made the notes on ballroom and Latin dancing back in the 1980s. To Dr Mounce, many thanks for agreeing dance as an approved activity for me and for your encouragement. I also register my thanks and appreciation to my current rheumatologist from 1990, Dr Paul Thompson and Dr Helen Robertshaw consultant dermatologist.

To my dance coach and all the ladies who have partnered me, sharing their dance experience with me - grateful thanks. I could not have done it without you.

Not easily conned, she looked me straight in the eye and said "Show me what you do". I knew this was the moment of truth so I gave the doctor a demonstration of both the samba and rumba action.

**Ascent for Arthritis
- Jim Bertouch**



Mt Kilimanjaro from an alpine meadow at 2800m

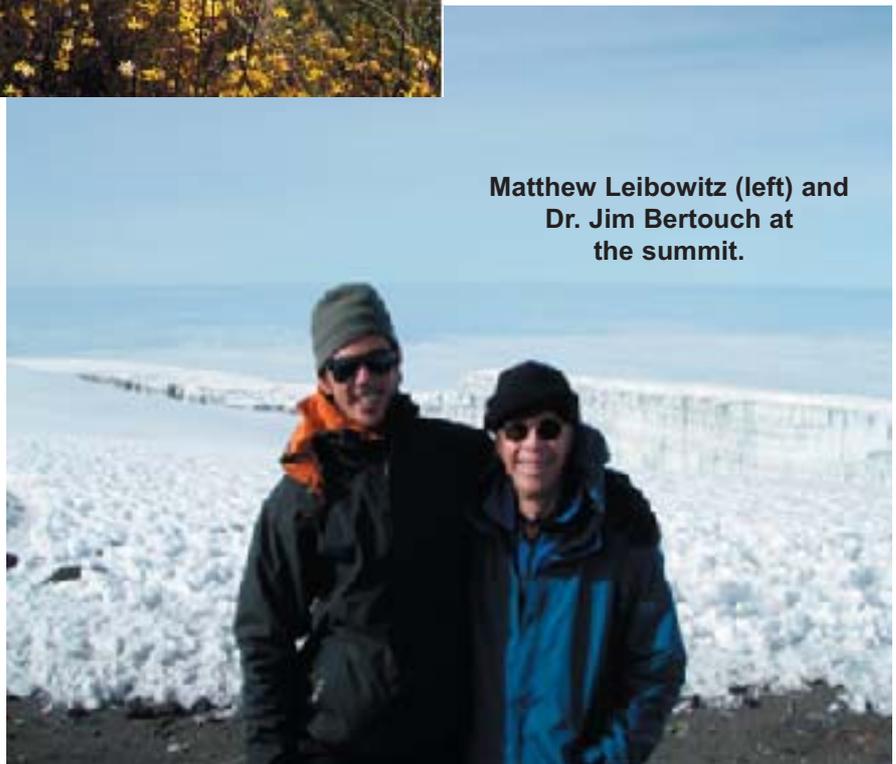
The project was devised by Matthew Leibowitz, a 27 year old lawyer in whom I had diagnosed Ankylosing Spondylitis in 2003. He had decided to try and raise the public profile of A.S. and had wanted to raise money for research.

In June/July this year I joined a group of 20 people for an ascent of Mt Kilimanjaro in Tanzania. The project was devised by Matthew Leibowitz, a 27 year old lawyer in whom I had diagnosed Ankylosing Spondylitis in 2003. He had decided to try and raise the public profile of A.S. and had wanted to raise money for research. He approached Arthritis Australia and Ascent for Arthritis became an official fund raising event. He set up an organizing committee of 4 of his friends consisting of Daniel Been, Peter Collins, Jonathan Shapiro and Jeremy Ungar.

After 6 months of training the group of climbers met at the Marangu Hotel in the town of Moshe at the foot of the mountain. Mt Kilimanjaro, at 5895m (19,300 feet), is the highest in Africa and the tallest free standing mountain in the world. It is a dormant volcano and despite its proximity to the equator has an ice and snow capped peak.

Our group consisted of Matthew and 3 other members of his family as well as 13 other friends. Professor Phil Sambrook, my son Edward and I made up the 20. All climbers set out to raise sponsorship money which was donated to Arthritis Australia.

The climb was planned for the winter as there is little rain at this time. Mt Kilimanjaro has 2 peaks called Mwenze and Kibo which are joined by a saddle. It is surrounded by a national park that is world heritage listed. We had planned



Matthew Leibowitz (left) and Dr. Jim Bertouch at the summit.

to use the northern Rongai route with a schedule that would take a total of 6 days.

We set off through the foothills surrounded by banana palms, cornfields and a pine plantation with occasional glimpses of monkeys in the trees. On the first day we were accompanied by a local guide armed with a rifle in case of attacks by animals. On subsequent days we ascended through

Continued page 6

Ascent for Arthritis - continued

Continued from page 5

alpine meadows covered in wildflowers and then through increasingly rocky terrain which eventually gave way to a desolate, windswept moonscape. After 4 days we reached Kibo hut (4750 m) and set out for the summit at midnight wearing head torches and multiple layers of warm clothing. Using walking poles we slowly zigzagged up a 30° slippery, rocky scree slope surrounded by patches of ice, as the temperature hovered between -10°C and -15°C. Just after dawn we reached Gillman's Point (5681m) on the edge of the rim and 2 hours later arrived at the summit which is called Uhuru peak. We were elated to have made it. The view was fantastic with the cloud layer way below us, and the African plains beneath. The crater is full of ice and snow and we were surrounded by ice walls and glaciers in every direction. At the peak the organizing group unfurled a banner for Arthritis Australia.

Of the group 13 made it to the top (including 4 out of 5 members of the organising committee, my son Edward and all of the over 50s!) and another

4 to Gillman's Point. Almost everyone suffered from the effects of altitude sickness, ranging from shortness of breath and headache through to nausea, vomiting and lethargy. One climber had to be evacuated from 4000m but luckily no-one had any long lasting effects.

In all more than \$80,000 was raised from sponsors and Arthritis Australia will be calling for A.S. research proposals later in the year. Speaking personally it was an unforgettable experience with a great group of people. All credit should go to Matthew Leibowitz for his enthusiasm in conceiving and directing the project and for having the fortitude to reach the summit himself, despite his medical condition.

Jim Bertouch
Chairman, Dept of Rheumatology
Prince of Wales Hospital
Sydney

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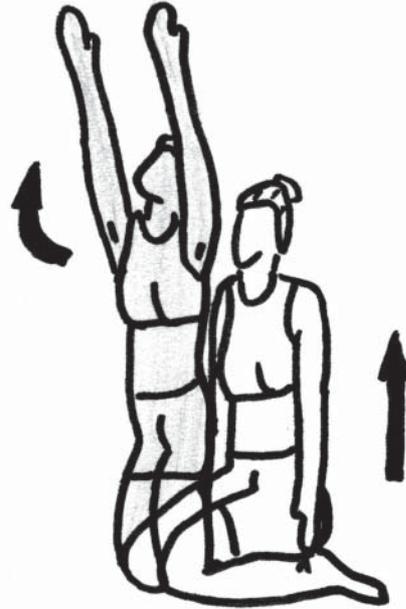
Arthritis Australia on top! (from left) Peter Collins, Johnny Shapiro, Matthew Leibowitz, Daniel Been, Stephen Kimey (chief guide)

Physiotherapy - AS Stretches

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

The exercises for this newsletter are all done in a kneeling position. This is a difficult position for some, and I apologise to those who find that they are unable to do them. You may like to adapt them and try them in a chair for similar effect. Other ways to help, if your knees are painful, try putting some good padding under them. A pillow under your bottom, between the calf and the thigh may also help. It is good to do things in different positions, so I hope some of you enjoy something a bit different and challenging. Some exercises may feel strange and awkward to start with but persist and I am sure you will find new flexibility.

1. Start in the kneeling position sitting down on your heels. Come into upright kneeling by lifting your buttocks and bringing tummy and hips forwards. Sit down again and then up. Come as tall as possible, tummy forwards, chest tall, and look up a little, keeping your head in alignment with your body. You may also like to take a deep breath as you rise up. As an extra, lift your arms up forwards and over your head, looking at your hands.



2. Start in the tall kneeling position and lean to your side, sliding your arm down your leg. Come tall and repeat to the other side. Make sure you keep up as tall as possible, don't let your bottom sag backwards. After a few repetitions, also take your opposite arm over your head to get extra stretch.



3. Start tall on your knees, keep your chest up tall and lean back with both hands towards your heels. You may feel a bit unbalanced at first, but take it carefully, going just as far as you can. You will feel your thighs working hard. Make sure you keep your hips forward to avoid sitting down.

Physiotherapy - AS Stretches

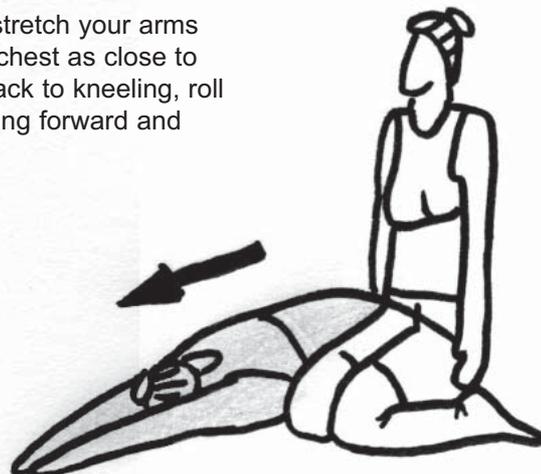
by Margaret Lewington (B.Phty. Cert Hydro.M.A.P.A)

4. This is similar to no 3, but gives you some rotation as well. You often feel more in control with this one. Sit tall and turn to look behind you taking your left hand back towards your heel. This may be your left heel, but if possible try to reach to the opposite heel. Again, make sure you keep as tall as possible. Repeat to the other side. As an extra, take the opposite arm up over your head at the same time.



5. Sit back down on your heels and turn and look behind you to the left. Place your right hand on your left thigh and help to pull yourself further around and reach towards your left heel with your left hand. Keep your chest tall.

6. Sitting back on your heels stretch your arms out in front, trying to get your chest as close to the floor as possible. Come back to kneeling, roll your hands to have palms facing forward and shoulders open.



The British Society of Rheumatologists Conference (BSR) Birmingham, May 2007 - Jane Skerrett, NASS Director

This was the first time I attended a BSR conference and I would like to thank everyone there for their help and for their friendly reception. It is a demanding few days simply because there is so much going on and so much that you want to see, read, sit in on and participate in. NASS has a stand in so called "charities' alley" where all the major charities associated with the work of rheumatologists set up their stalls. It was informative to talk to some of the charities there about the problems and challenges they face and how they seek to solve them. The stall needs to be manned all day ideally so that there is always someone available to answer questions about the work of NASS and to take orders for the patient handbook.

A number of presentations and posters featured AS: it is encouraging to see the level of interest and research that is going on. Wednesday, on which the majority of events on spondyloarthritis took place culminated in a special interest group session which was so packed people were turned away. The session was convened by Dr Millicent Stone and Dr Paul Bowness and included a presentation from Dr Annelies Boonen, University of Maastricht, on the economic analysis of response to anti TNF treatment in AS.

Among other items, I would highlight the study prepared jointly by Northwick Park Hospital, London and Norfolk and Norwich University hospital, on the work status of people with AS receiving biologic therapies. Although a small sample, the conclusions were that these treatments are associated with "improved capacity for work, increased gainful employment and better quality of sleep". Studies such as these are clearly vital in collecting data to provide support for access to anti TNF drugs.

Norfolk and Norwich hospital had also done some work with a small patient group, on anti TNF, looking at their commitment to physical therapy. Their conclusions were that patients do spend a significant amount of time doing exercises away from the hospital setting and that their motivation levels have improved after being treated with anti TNF therapy.

This same hospital had also completed an audit of Norfolk GP's to assess their knowledge of inflammatory back pain (IBP) and AS. The results were that inflammatory back pain is not well recognised by GPs and this shows up a need to educate them about it to improve early diagnosis and referral.

This study certainly reflects anecdotal experience here at NASS. It would appear that a great deal more could be done to try and put AS on a GP's mental map so that it is considered if a patient arrives in their consulting room with the key symptoms, (defined as pain at night, stiff joints in the morning for longer than half an hour, pain helped by exercise but not by rest and alternating buttock pain.) There were some other interesting findings from this study: physiotherapy was easily available with less than a two week wait for only 2% of GPs and only 26% were aware of anti TNF therapy for AS.

Members of the Academic Department of Musculoskeletal Disease, the University of Leeds, presented a number of studies on aspects of anti TNF. One looked at the level of non response to anti TNF in AS patients. The level of non response in rheumatoid arthritis (RA) is high - up to 40% but the conclusion of this study was that non response to biologics in AS is rare and the majority of patients will respond to a second drug, so switching should be considered. Again, this is an area where more data is needed so that the case for switching can be made authoritatively: NICE specifically referred to the need for more information on this topic in their preliminary findings on AS and the biologics.

The work done on exercise in AS by various departments of the University of Central Lancashire was also interesting. The aim of their study was to develop an understanding of patient's beliefs about exercise and how and why they chose to do the exercises they selected. Work in this area will be helpful in understanding the best way to ensure patients do the exercises they need to do: more than one patient has said to me recently "I wish I had done my exercises!" But you only have to observe the general population to see that a commitment to exercise is something which it is difficult to sustain, even when we all know the

benefits. How much more challenging it is when you are also dealing with pain and fatigue as barriers. Next year the BSR conference will be held in Liverpool, 22-25 April.

This article is an extract from the Autumn/Winter 2007 issue of the U.K. NASS AS newsletter

Work in this area will be helpful in understanding the best way to ensure patients do the exercises they need to do: more than one patient has said to me recently "I wish I had done my exercises!"

AS Group of Queensland News

Well folks, nothing stays the same forever and the AS Group of Qld is no different. After being instrumental in the formation of the group and heading it up ever since, John Ebert has resigned due to health reasons. John put his heart and soul into building the group to where it is today and I sincerely thank him for all he has done.

With a number of the Committee members unable to continue on for various reasons, it was decided to call a forum to seek direction for the future of the group. The main decisions made were to re-elect a new committee and re-align the group with Arthritis Queensland.

I would also like to take this opportunity to thank Lynn Adamson, Melissa Stuart and Jack Costello for keeping everything on track in the interim and also Bob Unger from Arthritis Queensland for all his help.

A special general meeting was held on the 24th October and a new Committee was elected. They are as follows:-

President - Ross Wilson
 Secretary - Paula Murphy
 Treasurer - Lynn Adamson
 Committee Members -
 Graham Collins
 Melissa Stuart
 Bill Harvey

I am very pleased with the make up of the new committee. With AS affecting all ages and genders this new committee reflects this fact.

The future is what we make of it. Myself and the other committee members will be working hard to continue the success of the group. I encourage all members to become involved even if it's just by attending one of the social events or coming to Hydro. Meeting others and sharing experiences is a great way to learn more about AS and the different ways other people manage their lives.

I look forward to meeting you all as our paths cross.

Ross Wilson
 President



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: \$10 or 10 classes for \$90

ENQUIRIES:

Margaret 0404 414 501 or 07 3376 6889

John Ebert Farewell & Thankyou.

Farewell to you as President John, and thank you for your dedication and motivation in steering the Ankylosing Spondylitis Group of Queensland over the past 10 years since its inception.

John was a foundation member and as President has been a driving force of the Ankylosing Spondylitis Group of Queensland. His inspiration and hard work has raised the profile of Ankylosing Spondylitis (AS) in the community. This includes developing practical links with the University of Queensland Medical School to assist both AS sufferers and the medical profession.

John has always been there to help people with AS. He has been the first point of contact whether it was by letter, phone or email and always provided continuing support. His devotion to helping other people with AS and their family members has been laudable.

John and the Committees that have supported him during the years have been able to ensure that people, with the debilitating disease of AS, have access to numerous projects and social events. This has enabled them to move forward and enjoy the highest possible quality of life.

Thank you again, John from the Ankylosing Spondylitis Group of Queensland Committee and all its members.



John Ebert addressing an AS Symposium in Queensland.

Editors Note: This picture was not digitally altered and that does appear to be a halo above Johns head - pretty much sums up Johns contribution to AS in QLD and Australia in my opinion.

AS Group of Victoria News

PRESIDENTS' REPORT

The following is a summary of activities over the last couple of months:

ARTHRITIS VICTORIA SEMINARS

CRANBOURNE ARTHRITIS SEMINAR

A small group (8) of AS members and family attended the Cranbourne meeting in October and enjoyed the excellent hospitality and a long chat. The Cranbourne group is a very large, established regional group with regular Tai chi, water exercise and line dancing classes for its members. The seminar included a talk by Dr. Lerma Ung, the new General Manager, Education and Services, Arthritis Victoria, on the role of patient and self help group advocacy in the health industry and how we can contribute.

SELF HELP GROUP NETWORK, COMBINED REPRESENTATIVES MEETING

A number of AS members attended the two meetings arranged by Arthritis Victoria in July and October, a forum to allow group representatives to exchange ideas, events and knowledge. Arthritis Victoria provides updates from its various departments, volunteers and support/self help groups, new staff members and a guest speaker. The various Victorian support/self help groups were represented and gave short talks on their activities for the year. We have picked up a number of suitable projects/events we may trial over the next couple of years.

In July, the primary speaker was Dale Nelson, Welfare Rights Unit, an independent body providing information regarding laws pertaining to all pensions.

In October, the primary speaker was Beth Wilson, Health Services Commissioner of Victoria, who entertained us with a talented rendition of how to deal with bugs (infection) in the hospital system. The idea of the catchy song was to remind staff to wash their hands on a regular basis, a very effective method of communication. Beth further elaborated on the procedure for dealing with and processing, complaints in the health system.

EARLY ARTHRITIS NETWORK SEMINAR

Several of our AS members attended this series of three seminars (Elsternwick and Carlton) over the year. The seminars are tailored to address newly diagnosed people with arthritis. However we find the general rheumatologist' talk on arthritis (including AS) and the complimentary health professionals have well covered most aspects of living with a chronic condition. We provide volunteers to chat with AS people and their families who attend the seminars, and introduce them to our support group and activities.

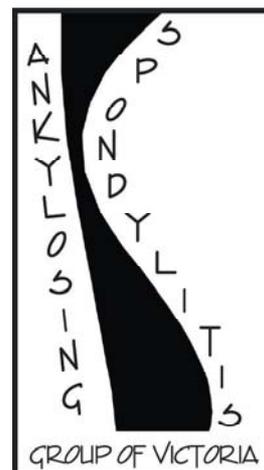
Next year 2008, Arthritis Victoria is planning two regional seminars in country Victoria, Numurkah and Swan Hill. So we will keep you up to date with their schedule and hopefully catch up with you during the year.

AS GROUP OF VICTORIA

In July and August we have provided material (printed, booklets and exercise sheets) to community health clinics (Broadmeadows & Peter James) to support rehabilitation of AS patients.

In September through to October, a group of AS members and newly diagnosed AS patients are attending the exercise and hydrotherapy program conducted by Jennie O'Reilly in the Physiotherapy area, at the Caulfield General Medical Centre, community services centre. This extensive land and water exercise program is enhanced with a visit from our medical advisor from the Austin, Dr. Lionel Schachna, for an informal discussion. A representative from our support group attends for informative talk on our group's activities and other services available in the community.

In October, the Australian Rheumatology Association arranged a selection of volunteers (including an AS member) to evaluate newly drafted patient medication information sheets. The focus group review was arranged by a market research company and held at Arthritis Victoria. The sheets are to be used by general practitioners and rheumatologists to enable people with an arthritis condition who may be prescribed the medication, to have a better understanding. This is an ongoing project, and we will keep you posted of progress.



In August, we provided a volunteer to RMIT Bundoora campus, health education programs for an informative talks on a patient experience and the management of AS, a chronic condition.

In October, a small number of new members attended an informal group discussion on diet and living with a chronic condition at Arthritis Victoria. Unfortunately we were unable to have the RACV speaker due to insufficient numbers so we plan to run this program again in early, 2008.

Our community services work, has really escalated this year with and we are playing a vital where our volunteers contribute to education of AS people. We are always delighted to find AS members, who can assist us with these services, as well as every day administration such as seminar setups or filling envelopes with flyers. If you are able to assist us in any way, we would really appreciate you contacting Belinda Martin, our co-ordinator, who can direct you to our committee for various activities.

We will be issuing an updated schedule for the first half of 2008 in the new year, so look out for it in the mail. We hope everyone has a safe and happy Christmas and holiday period and all stay well.

Annie McPherson.

AS Group of Tasmania News

"G'day from Tassie again, Winter has gone although sometimes you would not know it, Spring is here, the days are getting longer, flowers are out everywhere and the grass (and weeds) are growing too fast. I know about weeds now as after 30 plus years at Somerdale Road we have moved. Still in Claremont but have done the reverse of what most people my age (nearly 60) are doing, we have upsized, bigger house and 3200 square metres of land of which about a quarter is landscaped and lots of weeds on the rest.

Still it can't hurt me to be digging out a workshop under the house and moving wheelbarrows of dirt from one spot to another, sometimes uphill, can it?

Socially we had a very enjoyable breakfast at The Metz back in August. It was nice to welcome Anne and Warren to our group and hope they will continue to grace us with their presence at future functions. Our next function is our Christmas get-together at Noeli's place on the 24th November of which some organisation was done at the breakfast (hope everyone remembers what was said).

Well that's it for this time. My new address is 9 Parkwood Court, Claremont Tas 7011. Phone and Email remain the same.

Bye for now,

Murray Limbrick
Ph. 03 62494474 or 0400 108874

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

AS Group of Western Australia News

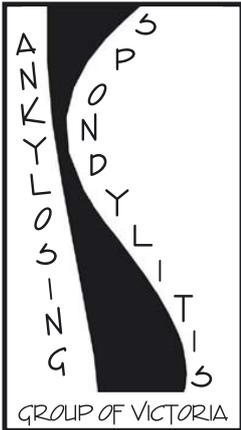
The WA group holds two sessions of land exercises and hydrotherapy each Monday at the Shenton Park Hospital. While one group of participants starts with hydrotherapy, another commences with land exercises and after an hour they swap. It is an excellent way to achieve a balance between land and water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

AS Group Membership Form



Ankylosing Spondylitis Group of Victoria Membership Application Form

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

New Member

Renewal

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 2008

Full: (Includes mail out of Newsletter) \$25.00

E-mail: (Newsletter by e-mail only) \$20.00

Concession: * \$20.00

E-mail Concession: * \$15.00

Donation: \$

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

TOTAL:

\$

● **SIGNATURE:** _____

 **RETURN COMPLETED FORM TO:**

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

*Please make
cheques or money orders
payable to:*

Ankylosing Spondylitis
Group of Victoria

? **FOR MORE INFORMATION:**

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