

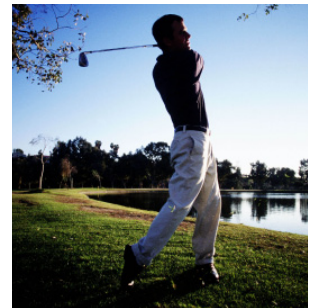
SUMMER 2010
NEWSLETTER



AStretch

ANKYLOSING SPONDYLITIS AUSTRALIA

www.asaustralia.org



Margaret Lewington reports from the 9th Ankylosing Spondylitis International Federation (ASIF) Council Meeting 2009

On the 15th October, I arrived in Salzburg in a small propeller plane to an unseasonably early light fall of snow. Travelling from here by bus along a picturesque valley into the mountains to a small ski village and spa town – Bad Hofgastein – I was surrounded by GREEN mountain slopes, fast flowing rivers, a light fall of snow on the trees and village fountains of naturally warm water.

This was the setting for the 9th ASIF (AS International Federation) Council Meeting. ASIF came into being in 1988 following a meeting when representatives from a number of patient societies met to discuss the foundation of an international body. It now has member societies in 26 countries. ASIF seeks to encourage and assist the formation of societies in other countries. "The main objective of all patient groups is to educate patients and to emphasise the important active role those with the condition must play in the management of their disease."

ASIF also supports and has strong links to medical groups associated with arthritis, rheumatology meetings, PARE – People with Arthritis and Rheumatism in Europe, and supports research.

The council meeting is held each two years, with up to two delegates invited from each country. The executive meet several times between this.

This is the second time that Australia has had a delegate present, as Greg Tate represented us in 1999, and this was warmly remembered. They appreciate the great effort for us to travel the extra distance. I was pleased to be supported as the Australian delegate and thank the Queensland group for assisting me with the cost of registration and some meeting and land costs.

This meeting was hosted by the Austrian Society - *Osterreichische Vereinigung Morbus Bechterew* - and was attended by 27 delegates from 18 countries. The couple of ▶



Delegates at the 9th ASIF Council Meeting
15-18 October 2009 in Bad Hofgastein

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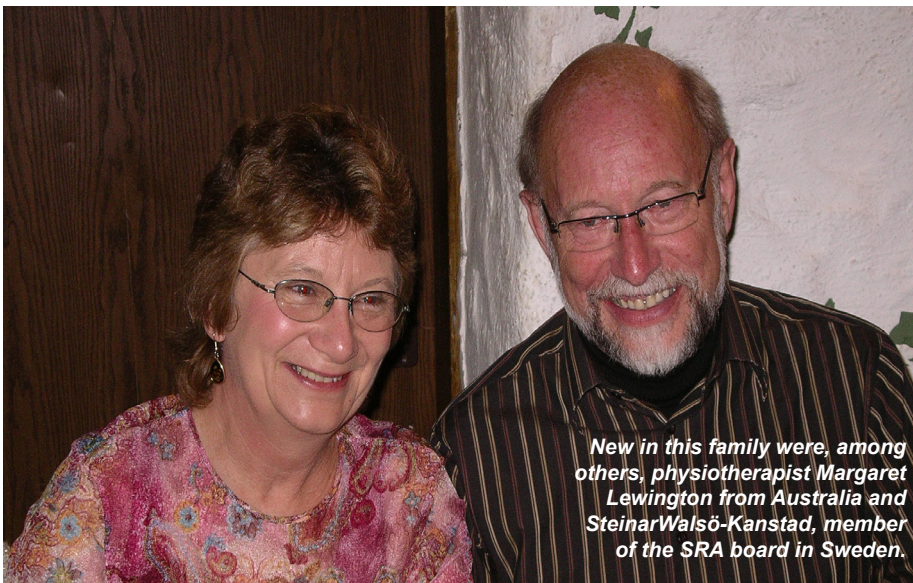
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The information contained in this newsletter should not take the place of advice and guidance from your own health-care providers.

Be sure to check with your doctor about changes in your treatment plan.

Report on the 9th ASIF Council Meeting. continued from page 1



New in this family were, among others, physiotherapist Margaret Lewington from Australia and SteinarWalsö-Kanstad, member of the SRA board in Sweden.

days are very busy with meetings and discussions, as well as local hospitality. The Austrian society had worked very hard to organise an interesting and efficient meeting. It was lovely to meet and chat with several of their members.

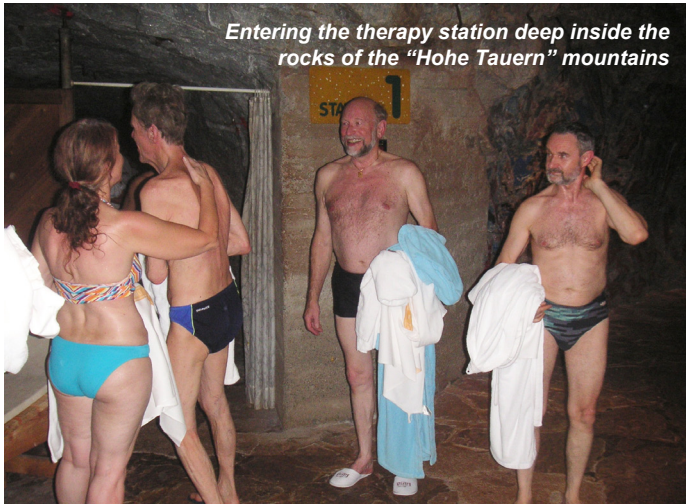
Reports of activities over the last few years were presented by the ASIF executive. Several countries present-

ed on events in their own countries. (see page 11) A talk was given on spinal fractures and AS, a DVD to educate emergency personnel about handling AS patients, (produced by the American society - SAA, and available for viewing on their website), was shown and also multimodal treatment for AS in Germany was outlined

A major component was a workshop session, when we broke into three groups to discuss future activities of ASIF. Many topics were discussed, with recommendations for further action and development to be done by the executive. This was a positive session and included discussions on a World AS Spondylitis Day in May; collaboration with PARE; education for emergency personnel on handling patients with AS; influencing hotels to have comfortable pillows and ways to improve ASIF funding to upgrade communication.

Informal discussions during meal breaks and when travelling to and from venues was a great opportunity to find out how AS groups work in various countries. In most countries, the AS society is a separate entity from their Arthritis Associations. Denmark and Sweden are part of their Rheumatism Associations.

On the whole, most societies are quite large, with many members and many regional groups. A common theme is that most groups exist in conjunction with a physio led exercise class, on a weekly basis, with support and co-ordination from ►



Entering the therapy station deep inside the rocks of the "Hohe Tauern" mountains



the small yellow train which brings the patients two km deep into the Radhaus berg rocks to the therapy stations.

the AS society. It is amazing to think of the numbers of people gathering weekly around the world to exercise together. I continue to dream and plan to have more activity in this area in Australia – and would support and assist in any way possible to make this a reality.

Several groups brought examples of their newsletters and other promotional material. I took copies of our Land ex DVD, Pool ex DVD and the DVD of a person with AS climbing Mount Kilimanjaro (produced by Arthritis Australia). These were all gratefully received, and we have received thankful and complimentary emails since. The pool DVD is currently being translated into German, as there is no similar product available anywhere.

The meeting was sponsored by the "Gasteiner Heilstollen" a treatment facility in the neighbouring village. This is a cave made in the late 1930's when mining for gold. It was reported that the miners with rheumatic conditions improved. It was found that the elevated temperatures (38*), high humidity, and concentrations of radon were the reason. In 1953 it opened as a treatment facility and today is a very modern centre where patients come to ride the train inside the mountains, rest on simple wooden beds, breathe and absorb the air, in silence. We were able to experience this, for an abridged treatment time.

Along with this, patients also attend physio exercise sessions, both land and pool, go Nordic walking in the beautiful valley, attend educational sessions and also have some physio

treatment sessions with manual and electrotherapy techniques as indicated. Visiting this centre was my other motivation to attend this meeting. I was fortunate to spend some time with the physio's and tour their department. It was pleasing to see that they are also finding the use of some manual therapy beneficial, as I have done for many years.

This centre sees the largest number of AS patients in the world, as the Austrian health system subsidises a yearly three week visit for all AS patients to this or one of the other 50 similar resorts in Austria. This one is the most popular due to the radon. Other conditions are also treated.

The new ASIF committee was elected, with the new president Seoirse Smith from Ireland, Vice President –

Hedley Hamilton from UK, Secretary – Ken Mulholland from Canada and Treasurer – Torben Jorgensen from Denmark. Other committee members are from Turkey (rheumatologist), UK (exec Director of NASS) and Netherlands. They are an enthusiastic group and committed to furthering the awareness of AS and supporting the AS population and their patient societies. I am excited about the future of ASIF.

Another special moment for me was swimming in a spa pool – continuous from indoor to outdoor – with the water cooled to 34C – and experience snow falling on my head. I did this while giving Hedley (UK) a hydro treatment. What a place to work!!



Evening view from the access to the fortress Hohensalzburg to the center of Salzburg with the cathedral (at right) and the gothic Franziskanerkirche (centre).



Opening Lecture of the 2009 ACR/ARHP Annual Scientific Meeting (with thanks to the ACR for permission to reproduce)

Report on the American College of Rheumatologists Annual Scientific Meeting

Dr Lionel Schachna

The Annual Scientific Meeting of the American College of Rheumatology (ACR) was held last year in Philadelphia. Once again, ankylosing spondylitis (AS) figured prominently among the abstracts and oral presentations at the meeting.

Patients with AS are fortunate to have a talented group of researchers who make up the Assessment of SpondylArthritis international Society (ASAS). These leading researchers include Professors Desiree van der Heijde (The Netherlands), Jurgen Braun (Germany), Joachim Sieper (Germany) and Maxime Dougados (France). Under the umbrella of ASAS, much of the AS research in recent years has focused on trying to make an earlier diagnosis of AS.

On average, the diagnosis of AS is made only after 5-8 years of symptoms. There are a number of possible reasons for this long delay until diagnosis. Chronic back pain is common and the recognition of early AS requires clinical experience and a high index of suspicion by the health care professional. Of importance, changes on x-ray at the sacroiliac joints are often a late finding and commonly do not appear until more than a decade of AS symptoms.

To address the problem of delayed diagnosis in AS, the ASAS group has proposed the term 'axial spondyloarthritis' to describe an individual with the symptoms but without the usual x-ray changes of AS.

Earlier last year, the ASAS group proposed that axial spondyloarthritis be diagnosed when one of the following is found:

1. Sacroiliitis (inflammation of the sacroiliac joints) as seen on x-ray or MRI scan with at least one feature of AS (e.g. Inflammatory back pain, arthritis of the limb joints, uveitis (iritis), psoriasis, Crohn's disease or elevated C-reactive protein (CRP)), or
2. HLA-B27 together with two or more features of AS

At the ACR meeting, Dr Martin Rudwaleit (Germany) and colleagues presented a study that confirmed the validity of this definition for early AS.

This new definition is a major step forward for several reasons. First, it allows for an earlier diagnosis so that patients can start to focus on appropriate interventions including an exercise program and anti-

inflammatory drugs. With an early diagnosis, inappropriate testing and treatments can also be avoided. Second, in order to perform clinical trials of new therapies, a standard definition for the condition of interest is necessary. Up until now, almost all clinical trials performed in AS have limited their enrolment to patients who satisfy the modified New York criteria for AS. The modified New York criteria require the presence definite x-rays changes of the sacroiliac joints. As x-ray changes can take 10 years or more to appear, clinical trials in AS have generally included only patients with long-standing disease. By identifying early AS as part of the spectrum of axial spondyloarthritis, clinical investigators will be able to use TNF medicines and other new treatments among individuals with early disease.

Early studies suggest that patients with axial spondyloarthritis respond as well if not better to TNF medicines than patients with established AS. If these findings are confirmed in larger randomised controlled studies, it is hoped that recommendations such as the Pharmaceutical Benefits Scheme (PBS) criteria will be modified to allow earlier use of TNF medicines and perhaps greater impact on the natural history of AS.



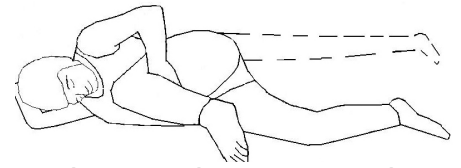
Dr. Lionel Schachna

Physiotherapy - AS Exercises

by Margaret Lewington (B.Phty. Cert Hydro)

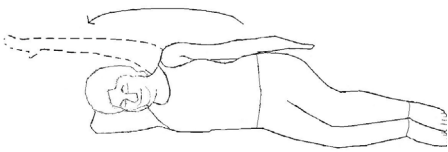
In this issue, I would like us to get down on the floor, in the side lying position, and by moving the arms and legs, we are able to also get movement and stretch in the side of the trunk and in the ribs. This can help with chest expansion and breathing. You may need a small support under your head. If you do, use a small pillow or just put your bottom arm and hand under for support.

4 Knee bend and curl



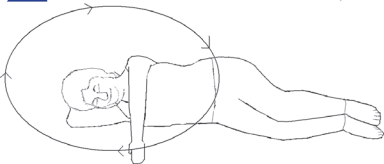
Bend your top leg up to your chest. Bring it forwards and up as far as possible, making your low back curl and round and stretch. Help it up with your hand, tucked under your knee between the thigh and calf. Don't squeeze your knee. Bring your head and upper body down towards your knee also. Pause and stretch here. Then straighten your leg and stretch it down long, allowing your back to straighten. Lengthen the whole body.

1 Side arm lift



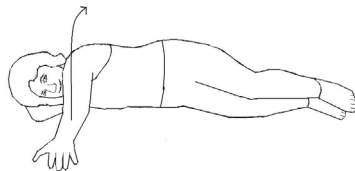
With your top arm resting along the top side of your body, lift your arm up and over your head to reach long and away from your head. Breathe in as you do this, to expand the top lung and move the ribs. Bring your arm down again along your body. You may also like to stretch the top leg down long at the same time - to get a full stretch through the whole side of the body. Do some each way.

2 Arm Circles



To make a large circle with your top arm firstly reach and roll forwards: up and over your head - stretching long
back behind and roll
back down to your side
Look at your hand throughout, if you can. Do several one way and then some in the reverse direction.

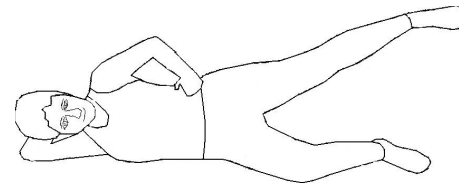
3 Upper body turning



Place your top arm out in front of your chest. Slide your arm forwards, reaching as far as possible. Let your body roll forwards, your chest facing down. Lift your arm up and over your body and back behind you.

Look at your hand the whole way and let your body roll back. Don't let your knees lift too much. Breathe in as you take your arm back and open up your chest. Pause here and allow time for a stretch. Lift your arm and return it to the front, breathing out and rolling forwards.

5 Side leg lift



Keeping your legs on top of each other, in line, lift your top leg off the lower leg. Your top leg can be a little bent, 'soft'. Don't roll your trunk forwards or back. Only lift as far as you can while holding a stable position. This is more for muscle strength than a stretch.

6 Cycling



Move your top leg around in a cycling action. Keep your body still, avoid rolling.

Bring your knee up as far as possible - then out a little in front - and down and back to get a stretch on the front of the hip.

Allow your back to curl when your knee is bent and to arch when your leg is straight.



Jane Barefoot joins Margaret Lewington's Queensland Hydrotherapy Class

The Australian Experience!

From Jane Barefoot

Australia - here is a challenge:

My first visit to Australia was in the very early 1980's, to present a paper at the International Rheumatology Conference held in Sydney. I landed in Perth and spoke to the AS group, newly formed by physiotherapist, Lyn Tinsley. She had come to Bath on a Churchill scholarship prior to this, to observe the work we were doing with AS groups.

She returned, enthusiastic to set up similar programs. This included outpatient self help programs, inpatient programs and weekly evening exercise sessions. The positive results of these programs convinced the local rheumatologists to support them.

They continue to have a thriving evening exercise group of both land and pool sessions, taken by a team of Physiotherapists.

The state Arthritis Foundations funded my early visits following this, to talk to patient groups and physios about AS and other arthritic conditions. I went to Brisbane, Sydney, Melbourne, Hobart, and Canberra.

I was also a guest lecturer, for several years, in the Post Graduate Hydrotherapy course for physios in Melbourne, that began in 1988. This course taught specific exercises for many conditions especially AS. This means that there are quite a few physios interested and with the knowledge to help with groups.

One of these physios, Margaret Lewington returned to Brisbane and set up the Brisbane weekly exercise group. With her hard work, dedica-

tion and passion - it continues, 20 years on.

She has also done several educational and exercise 'Weekend Workouts', both with me and by herself, throughout Queensland.

Margaret is very keen to assist interested physios and patients anywhere to set up groups.

There have been some education and exercise groups in Sydney.

Melbourne continues to have a couple of eight week education programs each year, that include land and pool exercise.

Consistency is the key to successful AS exercise. A weekly group session is what is needed.

Socialising in a group is important, as is information from the newsletters, but group exercises specifically for AS are also needed.

By attending once a week, a person can slow down deterioration, keep fit and able to work, and have physio guidance. The camaraderie of a group is motivating and fun, and it is helpful to share tips and ways of coping.

Groups can be self-supporting, run by people with AS, with physio guidance.

By paying a small fee individuals cover the cost of venue and physio.

DVDs are also available now, with suggestions for both land and pool exercises.

There are so many advantages of regular specific group exercise - I urge people with AS to get groups up, running and active in their area.

The treatment of AS through exercise and physiotherapy - how it all began

by Jane Barefoot

Starting out as a physiotherapist

When I first became a physiotherapist I learnt in my training that treatment of AS consisted mainly in the "sufferer" being put into a plaster jacket to prevent further flexion of posture. This did nothing for mobility as you can imagine. Otherwise breathing exercises were considered

important, and work for the extensor muscles, which get the body back to a better posture, but before fusion has occurred. Deep X-ray treatment was also used, which could relieve pain but was discontinued because of concern about side effects. ►

I was on the spot and wanting to stay in Bath when the AS programme at the Royal National Hospital for Rheumatic Diseases (RNHRD) or the Mineral Water Hospital also known as the Min, needed someone to lead it. But I didn't know an effective way of helping people with AS. So I needed to look through the somewhat sketchy existing research to try out different means of getting improvements, and then find how to assess them in a way that would be credible world-wide.

In those days, people with AS mainly came to the Min when beds were available. In the 3 week period in the hospital as well as seeing their rheumatologist, there was an activity in the morning and another each afternoon but not enough to get anyone much fitter. But patients did leave feeling better, and there was a demand to increase the intake to more groups in a year. That lead fairly soon to having a new group in every 3 weeks, nonstop.

How the programme at Bath developed

Strangely, a porters' strike gave the chance to change what we could offer. Since the strike meant a stop on admissions, I was given permission to do more work with the AS group that were already in, rather than share my time treating those with different diseases. So I added:

- group discussions to help understand the personal effect of having AS - information that had been ignored or never followed up
- talks to each group by one of the rheumatologists, with a chance to ask questions
- more sessions made more demanding, in the pool or the "body shop" to make a measurable difference to fitness
- explaining the reason for what we were doing to the patient, motivating them to continue
- time to quantify the effect of the different components of the treatment

I had a huge programme with emphasis on stretching before trying to

straighten and was keen to devise new exercises both in the pool and on land to achieve this.

Suitable exercise is important

Knowledge of the condition and its effects is needed, both physically and psychologically. The exercises have to be accurate and specific and understood by the recipient. It was a huge vindication for me when a patient answered the question by a specialist "So it doesn't matter what activity you do?" with "Well, Jane has lengthened my stride, (he was a serious runner), I now take less medication, and I feel a whole lot better." Our emphasis on stretching could do something even for the fittest. Just going swimming didn't get the same results.

These results had to be spread (and as a traveller, I thought "round the world"). This needed interested, dedicated physiotherapists willing to learn how to be effective not just getting or keeping someone fit, but applying specific stretching and strengthening exercises, teaching the reasons for these and proving that they were working with accurate measurements. The best motivation for the patient is to know you are improving on the measurements.

Dr Dixon's input

Dr Dixon was the rheumatologist at the Min who started up and encouraged the active treatment. It had been seen during the war that with a really active programme, men could continue to serve in the forces and use their training, rather than be treated as people complaining about back pain that came and went, who surely must be "putting it on". There needed to be concrete evidence of the efficacy of the course so I devised individual measurement cards that listed possible areas of restriction. These were measured at the beginning and end of every course and their purpose explained to the card holder. They monitored progress and we tried to make sure that they were noted by the reviewing rheumatologists.

NASS in the beginning

Dr Dixon encouraged me to write up my findings and present them at international conferences, and get

papers showing the results published. Dr Dixon was instrumental in founding NASS and before long we were explaining AS and the thoughts behind our treatment to a newly appointed director of NASS. Eventually I got the chance to promote our methods by becoming physiotherapist representative on the board of trustees who could be referred to in relevant cases. Juliette a'Hea, who is both physiotherapist and patient, took over from me. She is now concentrating on private practice and has been succeeded by Claire Harris who works with Dr Andrew Keat at the Arthritis Centre in Northwick Park.

Soon I had patients helping to form other branches of NASS mainly to promote activity sessions, with physiotherapists to supervise in the pool and gym.

This development meant there was an urgent need for these dedicated physiotherapists who were prepared to give up evenings to run the group. Training was needed for these willing physiotherapists. So I held courses all round the country. It is wonderful to think that there are now branches all over the UK.

How we chose our equipment and exercises

A registrar from Switzerland working at the Min showed us a DVD of patients exercising with gym balls and that seemed a good way to vary the exercises. We worked out ways to get the most out of them. I have found them a good way to persuade a patient to do more than was thought possible and they were fun to use, good for individuals or a group. Gym balls are now in use in many departments, for many physical conditions.

Hoping to demonstrate what motivated a patient most successfully, Julie Barlow, a lecturer from Coventry who herself has AS, joined me in running weekends for people with AS. They could come with a significant other person: wife, partner or parent. In the 2 days we explained all we could about any aspect of AS, and any treatment that had proved helpful, whether it was reflexology, relaxation, stretching, strengthening, on the floor, on a ▶

ball, or against the wall; getting fitter, heat treatments, or cold therapy, massage, yoga, Pilates, getting clued up about AS and/or TLC.

We monitored results, and the parameter that improved most consistently was the feeling of self efficacy. Because they had learnt so much about their disease, and what could be done and what they could do themselves to lessen its effects, people felt in a better position to cope. Partners also felt they had benefited, and the extra understanding they had gained would be a big help. Information that encourages a patient to stick to a routine of exercise/fitness that is time-consuming is needed all the time. We are all human and have these difficulties.

The importance of physiotherapists' input

In treating people with AS physiotherapy is needed, hand in hand in many cases, with appropriate medication.

Physiotherapists have the knowledge to suggest and direct an appropriate course of action and patient self help. This can vary with each individual, but is often not immediately

comfortable. It needs encouragement, and nearly always involves persistence, and commitment to overcome the effects that AS can induce and to affect the outcome of the disease.

NASS branches can provide a great camaraderie; they are even the means of making compliance fun! My admiration for the people who keep this up is tremendous.

Jane Barefoot is a legendary physiotherapist who has made a substantial contribution to the well being of people with AS both in the UK and abroad. She is remembered with great affection by many NASS members. She started work many years ago and has now retired but is still a member of NASS and still takes an interest in AS.

(reproduced with thanks from a recent edition of AS News, the newsletter for the UK based National Ankylosing Spondylitis Society (NASS))

Hydrotherapy in Brisbane

Supervised by Margaret Lewington

(B.Phty. Cert Hydro)

WHEN: Tuesday Nights

TIME: 6.30 – 7.30 pm

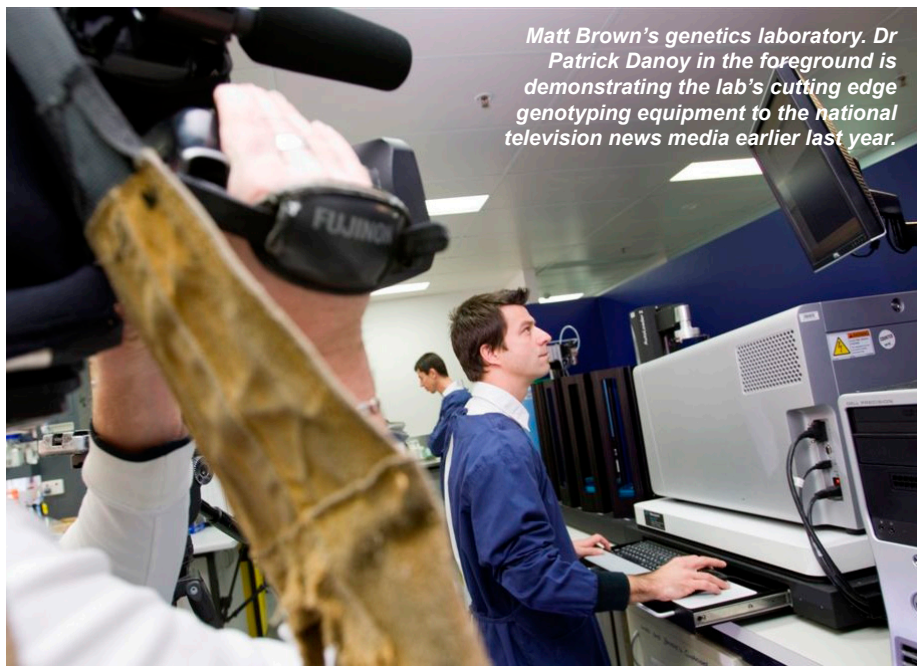
WHERE: Hydrotherapy Pool,
lvl 2, Ned Hanlon Building,
Royal Brisbane & Women's
Hospital, Butterfield St
Herston.

COST: \$10 or 10 classes for \$90

ENQUIRIES:

Margaret 0404 414 501
or 07 3376 6889





Matt Brown's genetics laboratory. Dr Patrick Danoy in the foreground is demonstrating the lab's cutting edge genotyping equipment to the national television news media earlier last year.

Progress in Ankylosing Spondylitis Genetics.

From Matt Brown, Professor of Immunogenetics, University of Queensland.

We've known for decades that AS runs in families, and for nearly four decades that the gene HLA-B27 is the major gene that causes the disease. However only about five per cent of people who carry HLA-B27 develop AS, and so our group has been researching what it is that cause this minority to develop the disease. We know from studies of twins and families with AS that it is an individual's genetic makeup that explains this, and that nearly all of the difference between individuals in their risk of developing AS is genetic. Progress in identifying those genes has to date been very slow.

In the past three years major advances have been made in the ability to identify genes that cause common human diseases, such as arthritis, diabetes, obesity and so on. Studying thousands of individuals for hundreds of thousands of genetic markers each, we can now identify many, but not all, of the genes that influence the risk of developing conditions. These studies are expensive (minimum cost >\$1 million per study), complex, and generally involve multinational consortia to ensure the skills and patient cohorts are available to complete the studies.

Our group in Brisbane is now well

equipped and skilled in performing these sort of studies, and has become an Australasian centre for this type of research. Although we research several different diseases, AS has been a long-standing focus. We are the main genetics centre for an

"It is thought that HLA-B27 may cause AS because it presents particular proteins which induce these lymphocytes to become excessively active, leading to inflammation and arthritis."

international consortium termed the 'Australo-Anglo-American Spondyloarthritis Consortium' (TASC). This group involves more than 20 researchers, and are engaged in studies aimed at identifying genes involved in AS, and also non-genetic factors, such as work, lifestyle and psychological factors which influence the severity of the condition and how it affects patients. We have now completed two major studies which have identified four definite new genes/genetic regions involved in AS, and several others that are very likely to be true AS-genes.

The first big breakthrough came in 2007, when in collaboration with another group (the Wellcome Trust Case Control Consortium), TASC

identified two genes, called IL23R and ERAP1, as being involved in AS. These were really exciting findings because of the known function of the genes, and neither had been suspected as having been involved in AS previously. Both tell us a lot about the processes which lead to AS developing.

IL23R codes for a receptor for a protein called IL-23. IL-23 when bound to IL-23R causes a particular type of immunological cell to develop and become active. These cells are called TH17 lymphocytes, because they produce another protein called IL-17. TH17 lymphocytes are involved in protection against mucosal infections.

Since the discovery of the association of IL23R with AS, several genes involved in determining the activity of TH17 lymphocytes have been demonstrated to be involved in AS or the related conditions, inflammatory bowel disease (IBD) and psoriasis. This tells us that this lymphocyte-type is really important in the process by which AS develops. What we don't know yet is if the genetic variants that lead to AS cause the lymphocytes to be under-active or overactive.

This may sound a simple thing to resolve, but isn't!

Serendipitously though, pharma-

ceutical companies have found that targeting this system is effective at treating IBD and psoriasis. Trials of antibodies which block IL-23 (and IL-12, a related protein) have been shown to be very effective in these two conditions and are in the process of being licenced for use in Europe and America. Disappointingly, the company involved, Centocor, has not yet initiated trials in AS, even though they are very likely to be effective in this condition, and we are obviously in desperate need of new treatments for AS at least as alternatives to TNF blockade. Thankfully, other companies are also targeting the system, and trials of antibodies blocking other parts of the system are underway. ►

The other gene we identified, ERAP1, most likely works to increase the risk of AS by influences on HLA-B27. We don't yet know how HLA-B27 causes AS (despite LOTS of research), but one leading theory suggests that HLA-B27 presents short proteins to cells called T-lymphocytes. These T-lymphocytes normally serve to protect us from infection and cancer, but can cause disease themselves if the control of their activity gets upset. It is thought that HLA-B27 may cause AS because it presents particular proteins which induce these lymphocytes to become excessively active, leading to inflammation and arthritis.

ERAP1 is known to process peptides before they are passed on within cells to HLA-B27. Thus the association of ERAP1 with AS is strongly supportive of the theory that HLA-B27 causes AS by a mechanism involving peptide presentation.

Of course the story is not quite as simple as that, as there are other possible mechanisms by which ERAP1 causes AS, but this is the most likely. If proven to be true, this would represent a major advance in working out how the biggest AS gene, HLA-B27, causes the disease.

The other two genetic regions we have shown to be involved in AS are what we call 'gene deserts', which are regions of the genome where the DNA contains no genes. These regions used to be called 'junk DNA', but are now known to contain areas which control the expression of other genes. We don't yet know what the other genes are that these gene deserts control, but we are working at it, and hope that by working this out, we can use the information to develop new therapies for AS.

One other area you can use genes is to help with diagnosing AS. At the moment, it takes on average around eight years between onset of AS symptoms and a diagnosis being made. This is way too long, and no doubt many readers will have experienced even longer delays.

As a clinician I often see people who have had inappropriate surgery and other treatments because their AS has not yet been diagnosed. Our genetic tests are now very good at diagnosing the condition (at least as good as an MRI scan), and we are testing them out to see if we can use them to screen the general community to identify people at high risk of developing AS, so that they can get treatment early on if and when they develop signs of the condition.

We have also shown that using a test for which genes are being expressed in blood, that we can accurately distinguish between patients

with AS and healthy people. This test is now being developed to help in early AS-diagnosis. Using these tests we hope to be able to pick up AS early on, help avoid inappropriate treatment, and instead allow treatment to prevent the damage that joint inflammation in AS leads to.

Many more genes have yet to be identified which cause AS, and there are other large studies underway in Europe, Canada and China that will report findings in the next 12-18 months which will increase this list further. In particular, the International Genetics of AS consortium (IGAS), will be performing a study with about 13000 samples from all over the world, which we will be genotyping in our lab in Brisbane. So the next two years will be a very exciting time for discovering genes in AS.

To complete these studies we are in great need of samples from patients with AS to help us.

If you have been diagnosed with AS, and would like to help our research, we would love to hear from you.

Please contact us either by mail:

Diamantina Institute for Cancer,
Immunology and Metabolic Medicine,
Level 4, R Wing, Princess Alexandra Hospital, Ipswich Road,
Woolloongabba, Qld, 4102.

or by emailing my research nurse,
Linda Bradbury (lbradbury@uq.edu.au) ph (07) 07 3176 5999

Awareness campaign in France
 "A fond contre la spondylarthrite"



Ankylosing Spondylitis Activities From Around the World

Compiled by Margaret Lewington.

IRELAND held a country-wide campaign titled – Get Your Back UP. It received media attention, was launched by a sporting personality, had targeted mail-outs and supported by new booklets distributed to patients and GP's. Evaluation of the campaign showed it to be successful in being remembered and in the contacts that were received.



Rugby legend John Hayes and model Jude Nabney at the launch of "Get Your Back Up", a public awareness campaign developed for the Ankylosing Spondylitis society of Ireland.

FRANCE has united two groups into one. It now has 2,000 members in 14 regional groups. They produce three magazines each year, held two awareness campaigns- FactS and ActionS, have a national phone enquiry line and have produced a series of six educational booklets. Their next project is to get words from patients describing their pain –

and target GP's and health professionals – to get them to listen and understand more.

SWITZERLAND has been active for 30 years, and to celebrate had a "Tour 08" – 120 people with AS rode electro bikes a combined total of 12,000km – approximately 320 km each. This was over five days, with car support, each stop was in a new region and targeted new media. They set up a tent in several places and had free diagnostic

testing, lectures, discussions and advice. They also launched two new books. Each of their local groups were encouraged to do something special for their members – and 40 events were held. Switzerland has 100 exercise groups, conducted by physio's, held every week. The classes are organised by the society, the physio's are paid by the society and people pay the same fee at all classes – similar to our Brisbane class - about \$10. They also hold two educational events each year for their physio's- one in French and one in German.

AUSTRIA has been active for 25 years. They have 1,300 members in nine regions and have 50 weekly physio groups supervised by physio's. The treatment program for most AS patients in Austria consists of seeing their GP, referral to a rheumatologist, medical tests, encouragement to exercise regularly at home, to visit a health resort, such as the Gasteiner Heilstollen each year, if they are working or every two or three years if they are not. A very positive approach.

UNITED KINGDOM has approximately local 100 groups throughout England, Scotland and Wales, supported by a strong national office NASS. The groups are also based on a weekly exercise session conducted by a physio. They also have a small committee of physio's who support and provide training for the other physio's.

Sponsorship was obtained for many of these special events and activities.



Awareness campaign in Switzerland by travelling with tents from town to town and offering interesting activities

Rare But No Less Serious - The Challenge to Cope with a Rare Rheumatic Disease.

This essay by **Angela Graham** was a runner up in the 2009 Edgar Stene Essay Prize - a prize organised by People against Arthritis/Rheumatism in Europe (PARE), and the patient arm of the European League Against Rheumatism (EULAR)

(reproduced with thanks from the Autumn 2009 edition of AS News, the newsletter for the UK based National Ankylosing Spondylitis Society (NASS))

I have ankylosing spondylitis, the disease from which Edgar Stene himself suffered. This is an inflammatory rheumatic disease which affects 0.05 to 0.23% of the British population - up to 139,000 people out of 60.5 million. It can cause fusion of the vertebrae, making the spine inflexible and may affect any joint, the eyes and other organs. To paraphrase Donald Rumsfeld in the rheumatological field, we have Rare Knowns and Rare Unknowns! There is a significant difference, from a patient's viewpoint, between a seldom occurring condition which is familiar to doctors and the public, and one which is both rare and unfamiliar. Difficulty of diagnosis worsens the effects of a disease and makes it much harder to bear, not least psychologically, and it is this psychological aspect on which I'd like to focus.

Where ankylosing spondylitis is concerned the average gap between symptom onset and diagnosis in Britain, where I live, is 6 to 9 years - in my case 19 years. During this gap how are individual sufferers to understand what is happening to them? Any suffering is worse if it feels meaningless or causeless or if the meaning offered by experts does not tally with the sufferer's experience of it. My body is mine, is it not? And my body, mind and my sense of self are so inter-related that a delay in diagnosis or an erroneous one, sets up a conflict between me and my presence in the world. I begin to doubt my very self.

Following a food poisoning episode when I was 24 I was told I had ulcerative colitis, a reasonable pronouncement given my symptoms and drastic weight loss. From that point of diagnosis - in this case by a young gastro-enterologist - I was boxed in. No matter what other symptoms I reported to my GP over the years there was only one

response: a repetition of the diagnosis and an insistence on treating it. While crippling symptoms took hold and the "eye infections" and gastric problems worsened, with appalling fatigue and headaches, no new investigations were deemed necessary. Once an authoritative diagnosis is made, a patient who does not get better under the treatment regime risks being told, as I was, that the "failure to respond" is deliberate. I was subverting my own health. Who does such a thing but the wicked or the mad? There's not much a state health care system can do about wickedness but it can refer one to psychiatrists so various professionals were given the task of plumbing my depths to uncover the roots of my alleged desire to be ill. We didn't get far.

After fourteen years a new colleague at work persuaded me to push for a review with her former boss, the local professor of gastroenterology. He established that the original diagnosis had been wrong due to his colleague's inexperience at the time (the biopsies taken then did not support the diagnosis) and told me that I was also in a minority of patients who could not tolerate the carrier of the sulphasalazine I'd been prescribed. A load lifted from my shoulders! I had not invented nor imagined the horrible reactions. I was not mad!

Or at least not completely. He assured me that I did have some - unidentified - physical problem so he referred me for "physiotherapy" which turned out to be more psychotherapy! A rheumatologist I saw privately told me he was puzzled too and I had better order a wheelchair because soon I would be unable to walk. I was a mother of three, in my thirties.

It is difficult to maintain belief in oneself in these circumstances. If one can't be trusted with one's own

health how can one be trusted in the family or society? In addition there is either no therapeutic support, or the wrong kind, on offer. Then begins the search for amelioration: the visits to alternative therapists; the expense; the humiliation when these things don't produce improvement; the family's puzzlement and despair and the subsequent apparent confirmation that one's basic stubborn lack of co-operation is unchanged. Does a person like this deserve to be well? Guilt and shame add to the burden of physical symptoms.

Eventually a chiropractor, in manipulating my spine, caused me such unspeakable pain that I passed out. I had become so self-blaming that I didn't challenge him but then his self-serving "looking the other way" pushed me to beg my GP for a referral to a specialist. He opted, hesitantly, for rheumatology. Five minutes with a rheumatologist to whom AS was a 'Rare Known' and I had a diagnosis. Though shocking in its implications, the diagnosis meant I could begin a journey towards comprehension and symptom management. In this I have found membership of the National Ankylosing Spondylitis Society (NASS) invaluable, particularly the weekly exercise sessions and access to information, treatment and self-management techniques. More than anything, it has been a huge support to meet others like myself, whose experiences confirm for me that I was never mad or bad. Through NASS, I have also used my hard-earned knowledge, in a firm partnership with medical professionals, to develop resources for newly diagnosed patients and to influence health policy.

But not everyone is lucky. One evening a few years ago a member of our NASS group noticed someone who had the very stooped posture characteristic of advanced AS. Considerately, he approached this stranger who as a result joined our group and re-commenced his therapeutic journey. He too had been told by a rheumatologist that nothing could be done. Brian (not his real name) was the most deformed of us all though only in his forties. He was socially isolated. He had had to stop working. He was mocked in the street for his crooked appearance. He had become poor. He struggled against depression and mental illness. Yet his dry humour ►

and his determination to help himself earned him the respect and affection of everyone in the group.

Brian died after a night of agony in a police cell. His depression had caused a crisis. The police were called. To restrain him one of them allegedly knelt on his spine. It broke. Paramedics arrived and, unaware, mishandled him. Officers reported that he had howled all night in the cell "like a wolf".

I think of Brian as I work to promote understanding of AS for professionals

Congratulations to Angela for being named as a UK runner up for the Stene prize. This is now an annual competition. The object of the prize is to stimulate the interest of the many people with rheumatic disease in the work of EULAR and their national organisation. There is a small cash prize for the winner and the prize is given at the annual EULAR congress which in 2010 is in Rome. EULAR also provides travel and accommodation for 4 nights at the congress for the winner. Entries normally have to be in by the end of February. For further information have a look at the EULAR website, www.eular.org.

Angela has written a very powerful piece on the problems that can be experienced for people in 2 circumstances: when their AS is still undiagnosed and when they come into contact with the police and emergency services.

We would all like to think that

the problems of diagnosis are not such an issue now but they still remain a challenge: there are good reasons why the diagnosis of AS is difficult. Here at NASS we are looking at what we can do to see how this can be improved.

Do have a listen to the podcast of Dr Andrew Keat, a clinician who is very experienced in the treatment and management of AS, talking about the problems of diagnosis - now on the NASS website. It sits with the podcast of a patient talking about their own delays in diagnosis. These podcasts are proving very popular: if you know of anyone who is concerned that they may have AS, do suggest they listen as both Andrew and Hannah flag up some of the issues and what can be done to address them.

NASS has also made contact with the police and we are beginning to work with them to raise the awareness of AS among their

staff. This work is very much at the beginning but I have been pleased by their openness to us as an organisation and I will keep you informed through AS News and the website how this is going and where there is an opportunity for members to be involved.

We are also looking at ways of using the medical alert system for people with ongoing medical conditions such as AS and will give feedback on this in the next few months: keep an eye on the website.

Jane Skerrett

Director and the public as research progresses. The role of disease-specific groups like NASS, national umbrella bodies like the Arthritis and Musculoskeletal Alliance (ARMA) and European networks such as EULAR is essential in linking all who want to help us flourish despite our disease.



Arthritis Victoria Report

From Annie McPherson

These last few months Annie has been involved in a number of activities run by Arthritis Victoria and here she summarises some of those we believe are of benefit to Ankylosing Spondylitis Australia members.

Northern Region Self Help Support Group Seminar

Lauren Baker from Arthritis Victoria lead a small group of Self Help group representatives through a session on grant applications, similar to the May representatives meeting

The Broadmeadows Arthritis Self Help Group hosted the seminar at the Dianella Community Health Centre in Johnstone Street Broadmeadows.

Surprisingly two of their committee members, Jessie and Mary - both older ladies - have AS and had not

heard of our group. Consequently we had an interesting time prior to the meeting chatting about treatments and exercises specifically for AS.

Early Arthritis Network Seminar

The Arthritis Victoria Network seminar series concluded for the year at the Elsternwick offices with Rheumatologist Dr Alberta Hoi's presentation on Inflammatory Arthritis focusing on Rheumatoid Arthritis (RA).

As with the other seminars in the series, Mary from Carer's Australia presented on strategies to help dealing with the impact of a new diagnosis. Elizabeth McCrea outlined her journey on living with RA. Arthritis Victoria's Health Educator and Exercise Physiologist, Vanessa Rankin spoke on exercise and management of Inflammatory Arthritis and the services Arthritis Victoria provides.

Arthritis Victoria Consumer Advisory Committee

The Arthritis Victoria Advisory Committee (CAC) invited representatives from the Strategy group lead by Geraldine MacDonald (General Manger) to the September meeting. The topics discussed were:

International Study Tour of the USA and Canada by Geraldine MacDonald, Strategy Group, incorporating the US Bone and Joint Decade Patient Advocacy Seminar and US Bone and Joint Global Network in Washington, USA in October 2009. The objective of this study tour is to examine international best practice in musculoskeletal health policy, advocacy and research and identify opportunities for Arthritis Victoria.

An update on this tour's findings and subsequent activities will follow in the next edition of AStretch

AS Victoria Report

From Annie McPherson

On a wintry Thursday afternoon Ellen Makridis, her mother in Law Lorrie and I ventured down to Korumburra for a lovely lazy lunch with some new and old friends. Adam Collard had kindly booked us a table at the Astral Hotel in town. Adam, his mother, and grandfather joined us with Ellen's sister and husband (also AS people) and nephew. Ellen's sister and husband had met in a water exercise class over twenty years ago and were both involved with the original Victorian As group run by John Hulskamp in the early 1980s. We had some amazing conversations about past water exercise leaders.

We concluded that the hotel was an excellent venue for a social function for the Gippsland members and families, with good parking, plenty of options for seating arrangements and the possibility of a private area. Korumburra is approximately one and a half hours from the Melbourne CBD and quite central for our Gippsland members. We thought a lunch towards the end of the summer on a Sunday would be appropriate timing.

We have a new event planned for May to join in with World Spondylitis Day. We have a family activity day planned, so we are hopeful many will join in. See you then.



Queensland Report

From Ross Wilson



Since the last newsletter, we have had another bike ride/walk/BBQ. This time it was held at Nudgee Beach. It was a great spot and very popular with bike riders as the bike paths head off in every direction. The riders on the day opted for the Boondall Wetlands track, which was a good flat ride, then continued on the boardwalk at the visitor's centre, which took us to Cabbage Tree creek, looking across to Shorncliffe. One again, Steve cooked up a great BBQ which everyone enjoyed.

It was great to welcome Annie McPherson, the Victorian Groups President, to Hydro and an after class chat which was held in July. Annie's very passionate about the future of the AS Support Groups and we look forward to working with her and her Victorian Committee, to increase the awareness and support for those with AS.

The new AS Australia website is nearing completion and I would like to take this opportunity to thank Bill Harvey and his son Marc for all of the work they have put in.

We were very fortunate to have Margaret Lewington, the Groups consultant Physio, attend the ASIF Conference in Austria in October as our representative. The Conference is held every two years and is attended by support groups from all parts of the world. Last year 18 countries were represented and Margaret should be commended for taking the time and effort to attend on our behalf. On the issue of Margaret and her dedication to her profession and the group, this should never be doubted. After a slight mishap on the plane ride to Austria, she hobbled her way through the conference and home again only to find that she had broken a bone in her leg.

You would think that this would slow her down, but not Marg, she was straight back to the Hydro pool with a special plastic support strapped to her leg.

Our last event for the year was our Christmas dinner at Huong's Restaurant at West End. A good turn out, the food and service was excellent and the company great.



Calendar of Events

Victoria

Arthritis Awareness Week 21- 28 March 2010

Arthritis Awareness Week aims to support and inspire those with arthritis to positively manage their condition and to raise awareness of arthritis in the wider community.

Joint Walk - Jells Park Sun 28 March 11am

Where: Jells Park, Mt. Waverley

Arthritis Victoria AGM 28 April 2010

Arthritis Victoria's AGM will be held at 3pm on Wednesday 28 April 2010 at the offices of Arthritis Victoria, 263-265 Kooyong Road, Elsternwick.

World Spondylitis Day - BBQ 02 May 2010

The first Saturday after the 1st of May each year has been designated World Ankylosing Spondylitis Day by the Ankylosing Spondylitis International Federation (ASIF). This provides the international AS community the opportunity to stand up and be heard. Stay tuned for events in your area.

Arthritis Vic Patient Forum Sat 22 May 2010 1pm - 4pm

Queensland

BBQ Sun 16 May 2010

New Farm Park

General Information on the web

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

<http://www.nass.co.uk/>

Contains an excellent questions and Answers section and downloadable guidebook - *A Positive Response to Ankylosing Spondylitis - Answers and practical advice*

Spondylitis Association of America

<http://www.spondylitis.org>

Contains message boards, online chat forums, and a members only section for resources

European League Against Rheumatism

<http://www.eular.org/>

Contains (among other things) a history of the Edgar Stene Essay prize and a downloadable book of the last 15 prize winners (under the section for Awards)

BASDAI Bath Ankylosing Spondylitis Disease Activity Index

<http://basdai.com/>

The BASDAI is the result of the work of a research team consisting of rheumatologists, physiotherapists, and research associates with a special interest in AS who developed the index in Bath, England. Take the free test online

Arthritis Australia

<http://www.arthritisaustralia.com.au/>

Information, news and events relevant to Australians.