

A Stretch

European Congress of Rheumatology Vienna 2005 Report by Dr Lionel Schachna

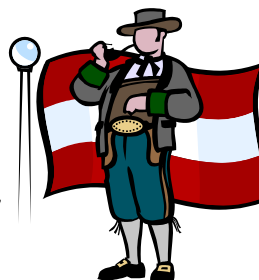


I was fortunate to attend the recent European Congress of Rheumatology which was held in Vienna from 8-11

June 2005. Once again, ankylosing spondylitis figured prominently among the sessions and poster presentations.

The Congress highlighted a major effort currently underway to define the early stages of AS. Commonly, the diagnosis of AS is made 5-7 years after symptoms begin, sometimes longer. International AS experts hope to develop strategies to identify patients with the earliest stages of AS. These individuals can then be targeted for biologic therapies when the benefits of treatment

are probably much greater.



We need to develop a collective experience of what happens when early AS is treated with biologics. Within a decade, it is likely that patients with early AS (< 5 years) will routinely receive biologics such as TNF-blockers. In the June issue of *Arthritis and Rheumatism*, a leading rheumatology journal, it was reported that anti-inflammatory medications (NSAIDs) may be more beneficial for patients with AS when taken continuously rather than as needed. The two-year study included 215 patients. Half received daily treatment with NSAIDs irrespective of symptoms while the remainder used medications only when they experienced symptoms such as pain and stiffness. More patients in the on-demand group developed x-ray progression compared with patients in the continuous treatment group (45% compared with 22%).

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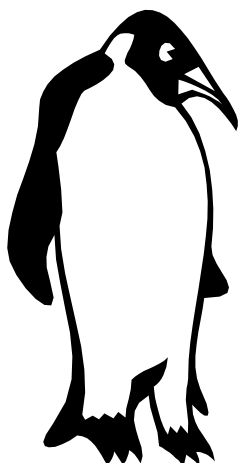
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The Ankylosing Spondylitis Group of Victoria officially formed on the

17th day of May 2005
See page 11 for full report



PLEASE NOTE

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.

European Congress of Rheumatology Vienna 2005 - continued

(Continued from page 1)

These findings are the first to demonstrate slowing of x-ray progression in patients with AS with anti-inflammatory medications, and need to be confirmed by other studies. While there were fewer x-ray changes in patients using continuous NSAIDs, the actual difference in x-ray changes between the two groups was small. But at the end of the day, NSAIDs are cheap and readily available. Unless one cannot take these medications because of side effects, I would strongly consider putting all patients with AS on daily anti-inflammatory medications, whether they are symptomatic or not.

P.S. Austin Spondylitis Centre Update

In this edition, I had hoped to report how patients at our centre have fared with TNF-blockers. We are currently reviewing our results which I hope to summarise in the Spring edition of AStretch.

Lionel.

When nothing works - is continued pain the only option?

By Laurie M. Savage

Pain is our body's "smoke alarm." It fires signals to the brain, alerting us to physical harm. It is letting us know that something is wrong and that we need to take action. Most of us have experi-



enced acute pain-pain that has a beginning and an end. A pinched finger or a sunburned nose are good examples of this. Chronic pain is different. Chronic pain is pain that persists beyond the expected time of recovery. Ankylosing

spondylitis can cause severe, chronic pain. If not treated adequately it can lead to anxiety, depression, anger, and fatigue, sapping energy and making any physical activity seem impossible.

Mary Shanley knows all about pain. She knows that when it is managed inadequately, it can lead to greatly diminished quality of life for the whole family. Mary has severe spondylitis, aggravated by multiple degenerative discs in her spine. In the mid-'90s, Mary's pain specialists, at a loss to help her, suggested that, with very careful monitoring, she try one of the newer time-released opioid or opiate medications then coming to market. For Ms. Shanley, starting these drugs was the beginning of a new life. With careful monitoring, finally, she was able to get adequate relief, which allowed her to start exercising again - gradually regaining muscle tone, and strength and increased stamina. In addition and importantly, Mary's husband, Dave, got his wife back.

What does research tell us?

In September 1998, *Arthritis and Rheumatism*, the journal of the American College of Rheumatology, reported on a study that provided the first data on the efficacy, toxicity, tolerance and additive behaviours associated with prolonged use of the narcotics

codeine and oxycodone on a large group of patients with well-defined rheumatological diagnoses. According to the journal, this study challenged the textbook dogma that opioids are inappropriate in the treatment of pain of non-malignant origin. The journal went on to point out that the study could help to provide support and protection for physicians, who historically had been reluctant to prescribe these medications because of potential sanctions from state medical boards and federal regulatory agencies, thus allowing patients access to effective treatments. That said, the choice to take this course should never be lightly undertaken.

According to Michael Weisman, MD, Director Division, Cedars Sinai, Los Angeles, "The use of opioids in patients with chronic illness such as AS is always fraught with hazard. Now that we have the new class of medication, biologics, approved for moderate to severe AS, there may be more emphasis on disease control and less on a need for pain control. Dr. Weisman concluded that, "There are still going to be patients for whom these medications will not work, and they will need pain control. If one uses drugs like Oxycotin®, it must be considered very likely that the patient may never get off the drug, and that there will be side effects (constipation mostly), and tolerance (the need for higher dosages to achieve the same effect). It should be understood ahead of time by both the doctor and the patient that these issues will be present."

(Continued on page 5)

Exercise plays a key role, as can techniques such as mindful meditation, in the successful management of chronic pain.

When nothing works - is continued pain the only option?

(Continued from page 4)

It isn't without some concern that Mary continues to use the opioids. Over time, the dose has needed to be slightly increased, there are unpleasant but manageable side effects and the long-term side effects of continued usage are as yet unknown. What is known is that drugs cannot do it alone. They don't work in a vacuum. Patients and their care-givers must recognise that the medicines can only go halfway toward satisfactory pain management. In fact, the experts tell us that when patients utilised a multi-disciplinary approach rather than relying solely on medication to do the job, the success rate is much higher. Drugs are important, but as Mary and her physicians recognise, they are just one weapon in the arsenal. Exercise plays a key role, as can techniques such as mindful meditation, in the successful management of chronic pain. With respect to the issues surrounding the use of opiate medication, gradually it is becoming recognised in the medical community that when these drugs are employed to combat pain, that is just what they do. In recent years, these drugs have frequently showed up in the main stream press because of illegal activities associated with their use and distribution. However, we need to be diligent in taking measures to prevent these medications from being used illegally and improperly so that patients can continue to have access to them when needed. As stated by the American Pain Foundation, we must be careful not to turn the 'War on Drugs' into a "War on the Patient."



Mary and David Shanley

Glossary

Opiate: narcotic analgesic (pain relief) derived from a natural source (opium poppy)

Opioid: narcotic analgesic that is either semi or fully synthetic; also refers to the entire family of both opioids and opiates

Codeine: natural opiate, most synthesized from morphine

Morphine: a naturally occurring substance in the opium poppy

Oxycodone: synthesized from codeine and only found as compound product combined with aspirin or acetaminophen (Tylenol)

Pain Resources

American Pain Foundation

201 N. Charles Street, Suite 710, Baltimore, Maryland
21201-41 11
www.painfoundation.org

Myths about opioid medication from the National Pain Foundation

http://www.painconnection.org/MyEducation/MyEducation_Addiction_and_Chronic_Pain.asp
www.painconnection.org

American Chronic Pain Association

PO Box 850, Rocklin, CA 95677
<http://www.theacpa.org/>

Further reading.-

Arthritis and Rheumatism
Vol. 41, September, 1998, No.9
Ytterberg S, Mahowald M, Woods S
Codeine and Oxycodone Use in Patients with Chronic Rheumatic Disease Pain

This article has been reprinted from the Spondylitis Association of America (SAA) 'Spondylitis Plus' Newsletter March/April 2005 edition.

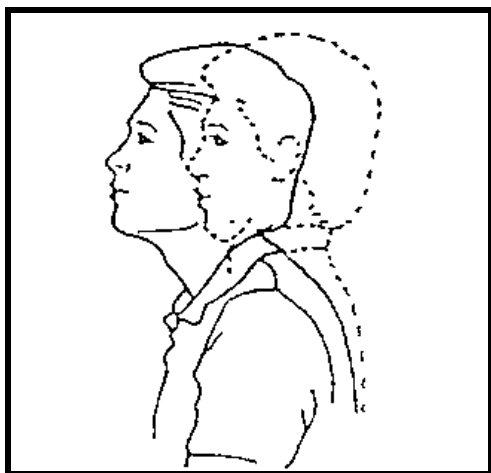
“Move Well - Stay Well” - by Margaret Lewington B.Phty. Cert Hydro.M.A.P.A.

Neck posture and movement is important for all aspects of our daily activities. It is important to keep a good range of motion to be able to turn, look, back the car and move about with ease. Also, a stiff neck is often painful, and stretching the neck muscles often relieves tension, tightness and soreness in the muscles in and around the neck.

Daily stretching of the neck is a must for almost everyone with AS. The neck is almost always involved to some extent. Stretching can be done in the shower, sitting at traffic lights, at a computer rest break, or in standing or lying. The following description is in the sitting position to assist in good body posture, but as long as you maintain good posture, other positions are fine. Stretch in both directions. You may do each side alternately, or you may do all stretches first on one side and then on the other.

The same principles of stretching as we have detailed before are relevant. Stretch slowly, be relaxed, don't hold your breath, contract/relax and then perform a gentle but firm stretch. If you experience any tingling, dizziness or other strange feelings, stop and talk to your physio or doctor before trying again.

You can do all the stretches at once, or you may find it better to do 2 or 3 in the morning in the shower, a couple of others during the day and in the evening you finish them off. Do the ones that you find most helpful to you on several occasions throughout the day.



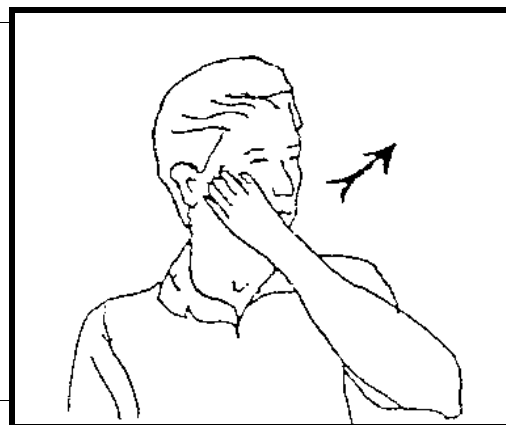
1. Posture correction

Sit well back in a chair with your low back fully supported and keep your hips, knees and ankles at 90° and feet flat on the floor. Don't allow your pelvis to slide forwards. Grow tall, feeling the back of your neck lengthen. Pull your head back, tucking your chin in. Don't lift your chin up or drop it down. Keep your eyes level. Hold this position, but relax the muscle tension and breathe!

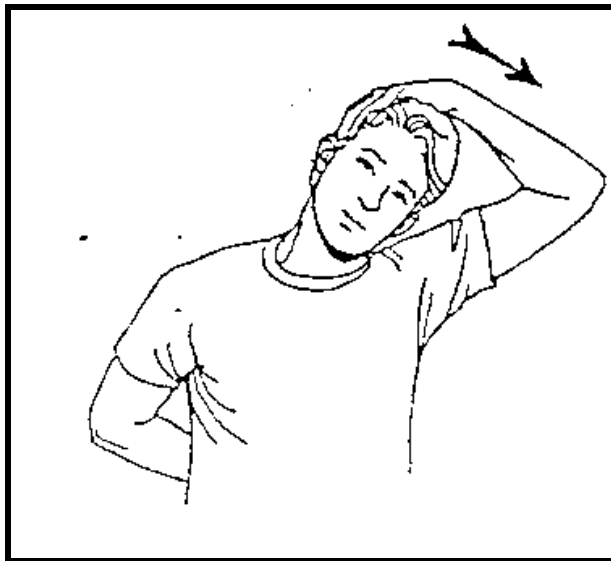
Note: Return to this position before commencing each of the following neck exercises.

2. Neck rotation/turning

Sit tall, relax your shoulders. Turn to look over your left shoulder. Place your left hand on your right/front cheek. Keep your right arm either beside you, behind you, under your bottom or holding the chair. Use your left hand to help ease your head around further to the left until a stretch is felt. With no movement, push gently with your cheek into your hand, relax and then try to turn a little further - look, turn and gently pull around with your hand. Hold the stretch for at least 5 sec. Repeat - for 3 stretches.



“Move Well - Stay Well” - continued



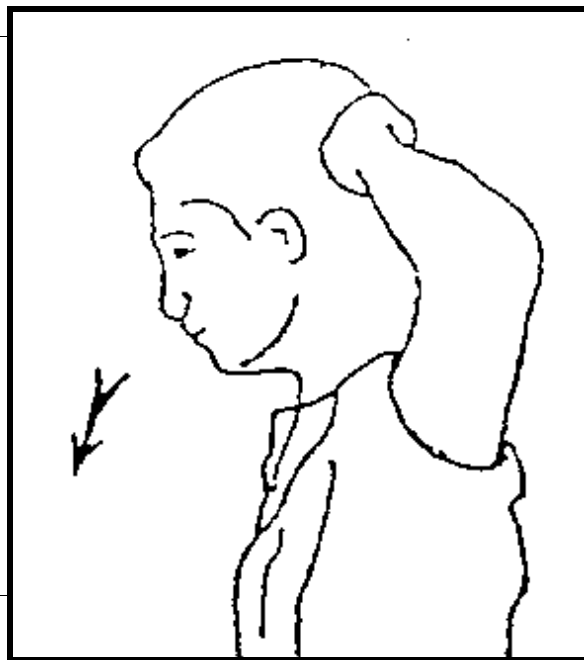
3. Neck side bending

Sit tall, let your left ear drop sideways towards your left shoulder. Place your left hand over the top of your head (hold the side of your head or your ear to get a firm hold). Fix your right hand on the side of the chair to stop you lifting your shoulder. Take your head to the side until a stretch is felt in the side of the neck. Hold for 5 sec. Push up into your hand a little to make the muscle work but not letting any movement occur, relax and then take the head over a little further. Repeat twice more. When finished, push into your hand to slowly come back to the upright position.

If you are familiar with this stretch and want a small variation, before you tilt to the side, look slightly to the right and then side bend, so that you end up looking slightly upwards and also look slightly to the left and then side bend, so that you end up looking slightly downwards. This changes the angle of stretch to target some of the neck muscles more specifically. Only do this if you are familiar with your stretching routine.

4. Neck flexion/forward bending

- a. Place your hands behind your head, keep your chin tucked in and ease your chin towards your chest and feel a stretch in the back of the neck, especially high up at the base of the skull. Try to curl and round the neck, not just pull down on it. Push back into your hands, relax and stretch.
- b. With the same position for your hands, this time relax the neck first and let your chin drop more towards your chest than tucking it in. Allow the whole of the back of the neck and the upper back between the shoulder blades feel the stretch. Still sit tall, don't slouch your posture.



“Move Well - Stay Well” - continued

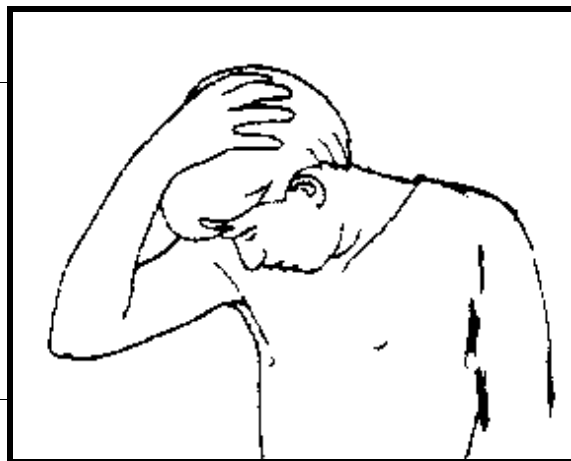


5. Neck extension/looking up.

Look up to the ceiling. It is very important to be sitting up tall. Also, don't just tip your head back, moving the top of your neck only, but lift your chin up and try to get a smooth arch back of the head. Some find it helpful to put a hand behind the head to support and guide the head, especially if you are not very stiff. Place the other hand on your chin and ease the head back until a stretch is felt in the front of the neck. Push forwards, relax and then help it back. Do 3 stretches. It is very important with this stretch to push forwards to come to the upright position at the end and not to just let go and try to lift your head forwards unsupported.

6. Neck diagonal/Levator Scapula stretch

Turn your head to the left and a little forwards to look under your left armpit. Place your left arm up and over your head to hold the back. Gently stretch forwards and down, feeling the stretch in the muscle that goes to your shoulder blade. Push back into your hand gently, relax and stretch forward down and across.



Acute Anterior Uveitis (AAU) Study

By Laurie M. Savage

"Researchers uncover genetic region involved with a cause of potential loss of vision in people with AS"

A locus on chromosome 9p predisposes to a specific disease manifestation, acute anterior uveitis (AAU) in ankylosing spondylitis a genetically complex multisystem, inflammatory disease.

Ankylosing spondylitis (AS) is a rheumatic disease of largely genetic origin, which means that it runs in families. It affects not only the joints and bones; other parts of the body can also be impacted. These include the heart, the lungs and the eyes.

In this study, Dr. Martin and her colleagues sought to uncover whether a specific gene or multiple genes are involved in susceptibility to a serious inflammation of the eye called iritis or acute anterior uveitis (AAU), in people with AS. AAU may occur in the absence of other inflammatory disease or in the presence of AS and related diseases. Since 40% of patients with AS also have AAU, the study enrolled a large proportion of participants with AS as well as AAU. AAU is potentially a serious disorder that can lead to blindness if not properly identified and treated.

Conclusion of the study

The study was able to identify the 9p chromosomal region as being implicated in AAU. In addition, several chromosomal regions associated with AS also were linked with AAU. Of note, the researchers indicate that the 9p region identified here is relatively large and contains at least 100 genes. Fine mapping studies (refined) are under way to further narrow the boundaries of this region on the chromosome.

The future

The results of the study are highly encouraging and suggest that some genes may influence particular complications of AS, such as eye involvement. However, the authors note that this relatively small genetic study will require follow-up with much larger cohorts (numbers of study participants) to confirm its findings.

This is important work on behalf of Dr. Martin and her colleagues. It represents a potentially important contribution to better understanding of the causes of AAU, which, as stated previously, is a very common problem in AS and which can lead to blindness.



AS has a strong familial component and is associated with HLA-B27- particularly in people with European heritage. In regard to AAU it is generally estimated

that among people of Caucasian origin, up to 50% of those with AAU are positive for the HLA-B27 gene. Interestingly, even though candidate genes - those located in a chromosomal region suspected of being involved in susceptibility - have been identified for AS, none as yet, in any of these genomic regions has been specifically implicated in extra-skeletal (parts of the body unassociated with the bones) manifestations of the disease.

The study employed a genome-wide scan (a "look" at all the chromosomes) to identify regions with linkage. This in itself was unique in that it was the first study to identify a genetic region for AAU using this method.

This article has been reprinted from the Spondylitis Association of America (SAA) 'Spondylitis Plus' Newsletter March/April 2005 edition.

RESPOND-NSW NEWS BY DENISE MCKEON

The NSW Group is looking for new committee members! Come along to the next bbq or call me on 9328 1384 (ah) or email denisemckeon@bigpond.com to let me know that you're interested. Debra and I have not had the time we'd like to properly keep things moving, so any assistance would be greatly appreciated.

Please see attached flyer for details of the next bbq.



The AS Group of NSW thanks the Arthritis Foundation of NSW for their valued support.



AS Group of NSW

OBJECTIVES

- To provide a way to meet others with AS
- To provide information about AS
- To raise awareness of AS amongst the Community & all Medical groups
- To assist in the research of AS

CONTACTS

Debra Ward Phone: - (02) 9398 6762
after 7pm

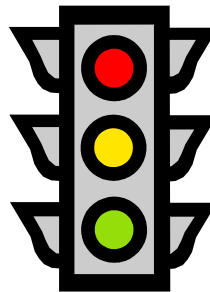
Denise McKeon Phone: - (02) 9328
1384 after 7pm

Postal Address : PO Box R1050
Royal Exchange, NSW, 1225.
E-mail : denisemckeon@bigpond.com
OR

Contact can be made through the
Arthritis Foundation of NSW

Tasmanian 'Anky Sponds' News - by Alicia Groves

Hello from Tassie. We've had a few really cold nights of late with our car windscreens iced up in the mornings so the weather has been keeping us on our toes. As I started to write this report I realised that I have been slaving away at the computer nearly all day and as a consequence my back is a little worse for wear. I only have to look at the notice board in front of me to see the list of "Office Exercises" for those of us who are desk bound. I really have to look up more often! On my drive home I must remember to use the 'red dot method' i.e. every time you stop at an intersection or are held up in a traffic jam (yes we do have traffic jams in Hobart) do a few neck stretches



and back arches (you might look a little silly to those around you but what the heck it's your back!).

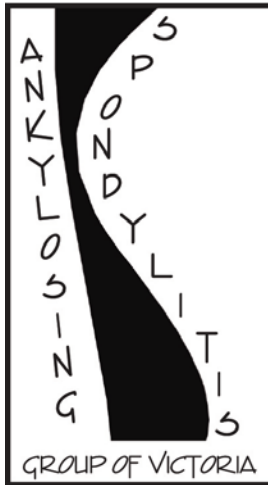
I have heard that Murray and Judy are up around the Tennant Creek area so keep a look out for them.

Our little group is continuing on in their absence but we hope to all catch up in the next month or so.

If anyone would like to attend our (irregular) functions please let us know so we can advise you when they are on.

Remember "A.S. is much easier to tackle as a group"

AS Group of Victoria News - by Greg Tate



In response to the Ankylosing Spondylitis in Victoria Questionnaire collected from recent AS Seminars held at Arthritis Victoria, the Ankylosing Spondylitis Group of Victoria has been officially formed at a meeting held on the 17th of May 2005.

People who responded with an interest in helping to start an AS Group in Victoria were invited to attend. The agenda covered the goals and objectives for the AS group, prospective group activities for the coming year and appointment of Committee members.

Nominations for committee positions were made and elected as follows.

President: Annie McPherson
Treasurer: Rosemary Stephens
Secretary: James McCracken
Assistant Secretary: Danielle Wood
Newsletter Editor: Greg Tate

Guidelines and procedures for the group were set with input from Arthritis Victoria representative, Gillian van der Drift, as the group is to be recognised as a Self Help group under the auspices of the Arthritis Foundation of Victoria.

The newly formed Ankylosing Spondylitis Group of Victoria Committee would appreciate your Membership contribution for the upcoming year this will enable us to provide you with a quarterly copy of the 'ASstretch' the national AS newsletter, develop regular interaction with other members through social gatherings, provide introductions to available therapies and keep you up to date on the latest medical information on AS.

Our aim is to organise some of the following activities for members in 2005 and 2006.

Social - Fun run/walk or bushwalk, Barbeque, Family Fun Day.

Therapy - Intro to Self management & Exercise Program sessions e.g. gym, tai chi, hydrotherapy and massage.

Information evenings - In conjunction with Arthritis Victoria, the AS Group will participate in the evening sessions already scheduled for 2005 and schedule more seminars in 2006, with participation from Rheumatologists, Gastroenterologists, Dermatologists and other health professionals.

Victorian based readers of this newsletter will find an Ankylosing Spondylitis Group of Victoria membership application form attached.

We look forward to hearing from you.

Greg Tate (National Newsletter Editor) and a member of the Ankylosing Spondylitis Group of Victoria Committee.

The Paper Place



www.paperplace.com.au

Thanks to The Paper Place - Paper Supplier to the Ankylosing Spondylitis Group of Victoria

AS Group of Queensland News - by John Ebert

Our first restaurant night this year was at La Kasbah Moroccan Restaurant. The ten who attended enjoyed a delicious banquet of traditional North African dishes, as we celebrated Graham and Denise's wedding anniversary and John's birthday. The birthday boy and Peter both enjoyed a shimmy with the resident belly dancer.

Our first foray into fundraising with the Entertainment Book has been a resounding success. The group sold 65 books and several people made a donation to the group in lieu of purchasing the book. I thank our secretary, Brent Watts, for suggesting this form of fundraising and for all his hard work in promoting the book. My thanks also to all of you who purchased the book and promoted it to your friends and workmates.

We recently celebrated our first anniversary at Royal Brisbane & Women's Hospital's hydrotherapy pool. Our thanks to all in the Physiotherapy Department there for making us feel so welcome and providing us with our new hydrotherapy home. A group of ten members enjoyed extra hydrotherapy sessions, when we took part in two exercise demonstrations at the pool, on the hospital's successful open day.

I recently read the following quote in a book called *The Suspect* and was struck by its truth. "**Most people don't know how to handle someone else's disease.** Unfortunately, there's no book of etiquette or list of dos and don'ts about it. You either get the watery-eyed, I-can't-bear-it-I'm-going-to-cry look or forced jokiness and buck-up speeches. The other option is complete denial." From my experience, often as the first point of contact for our group, I hear of the frustrations that many people endure upon diagnosis, because of these exact attitudes. These come from their family, friends and even health professionals and can, of course, be coping mechanisms. When people newly diagnosed with AS

eventually come to group activities, I regularly hear how good it feels to be with a group of people who don't react to them like those in the quote. If you haven't been to hydrotherapy or to one of our social activities, come along and enjoy the company and support from people who care, understand and were probably once in a similar situation themselves.

Our dedicated physiotherapist, Margaret Lewington, has recently suffered a debilitating, recurring flu. Despite this, Margaret still attended our weekly hydrotherapy class. This is not only an example of Margaret's dedication to our group but also an example of how she inspires all of us with AS to reclaim our own power and to take responsibility for our own health, including our mobility, at times when we feel least able to do so. Thanks Marg.

Congratulations to our California based former secretary Larissa Fitzsimmons and her husband Simon Hoyle on the birth of their second child, a daughter named Anna, who was born on 16 June at Scripps Memorial Hospital in La Jolla. She weighed 5 pounds 14oz (2.66kg) and was 19 inches (48cm) long. Her proud father Simon says that she is "Small but perfectly formed". Larissa and Anna are both doing very well. Her big sister Elise is delighted with her little sister. I know that Anna will be much loved and look forward to meeting her when the family returns to Brisbane.



AS Group of Queensland News - continued

Photos from La Kasbah Moroccan Restaurant.



HYDROTHERAPY Pool Exercise Sessions for people with AS

- Supervised by Margaret Lewington (B.Phty. Cert Hydro.M.A.P.A.)
- WHEN: Tuesday Nights 6.30 – 7.30 pm
- WHERE: Hydrotherapy Pool, Level 2, Ned Hanlon Building, Royal Brisbane & Women's Hospital, Butterfield Street Herston.
- COST: \$8 or 10 classes for \$75
- ENQUIRIES: Margaret (07) 3376 6889 or John (07) 3391 4689

Note: There will be no Hydro class on Tuesday 16th August 2005

WHAT'S ON IN QUEENSLAND

Dinner at Amphora, St Lucia For bookings, phone Graham Collins on 3263 6196	Saturday 23 rd July 2005 at 7.00 p.m.
Barefoot bowls at Merthyr Bowls Club, New Farm For bookings, phone Graham Collins on 3263 6196	Sunday 28 th August 2005 between 3.00 & 5.00 p.m.
Dinner at a venue to be advised For further information or bookings, phone Graham Collins on 3263 6196	Saturday 1 st October 2005 at 7.00 p.m.

AS Group Contacts & Recommended Websites

Recommended AS Web sites

**Ankylosing Spondylitis International
Federation (ASIF)**

<http://www.asif.rheumanet.org/>

NASS

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

Spondylitis Association of America

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

KickAS

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

AS Group of Queensland

<http://www.asaustralia.org>

Arthritis Foundation of Victoria

<http://www.arthritisvic.org.au/arthritis/as.htm>

Ankylosing Spondylitis in Australia

AS Group of Queensland
P.O. Box 7366
East Brisbane
QLD 4169

Phone: (07) 3391 4689
Email: queensland@asaustralia.org

AS Group of Victoria
C/- Arthritis Foundation of Victoria
P.O. Box 3166
Burnley North
VIC 3121

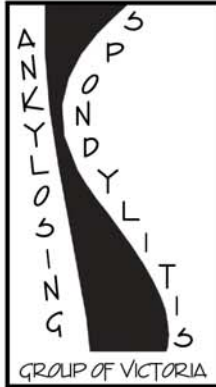
Phone: (03) 9530 0255
Email: gillian@arthritisvic.org.au

AS Group of New South Wales
P.O. Box R1050
Royal Exchange
NSW 1225

Phone: Debra Ward
(02) 9398 6762 after 7pm
Email: denisemckeon@bigpond.com

AS Group of Tasmania
c/- 16 Somerdale Road
Claremont
TAS 7011

Phone: Alicia Groves (03) 6227 8987
Email: mlimbric@tassie.net.au



Ankylosing Spondylitis Group of Victoria Membership Application Form

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



YOUR CONTACT DETAILS:



Name:

Address:

Telephone:

Email:

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



MEMBERSHIP TYPE:

Note: Membership runs through to 30th June 2006



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:

\$

TOTAL:

\$

*Please make
cheques or money orders
payable to:

Ankylosing Spondylitis
Group of Victoria*

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



RETURN COMPLETED FORM TO:



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