

AUTUMN 2012
NEWSLETTER

AStretch

ANKYLOSING SPONDYLITIS AUSTRALIA

www.asaustralia.org



Ankylosing Spondylitis International Federation

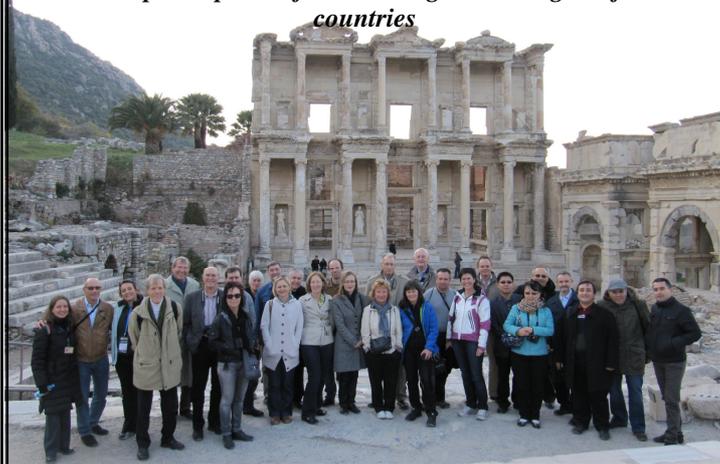
World-wide network of societies of patients suffering from ankylosing spondylitis or related diseases

10th Council Meeting

held on 17th to the 20th of November 2011 in Izmir (Turkey)

By Margaret Lewington

*ASIF Group Among the roman ruins.
The 30 participants of the meeting were delegates from 13
countries*



Every two years, ASIF holds a council meeting, open to two delegates from each member country to attend. The recent meeting was held in Turkey, over three days, consisting of meetings, presentations, social events and visiting some therapeutic and tourist sites. The 30 participants of the meeting were delegates from the following 13 countries: Australia, Austria, Canada, China, Czech Republic, Denmark, Germany, Ireland, the Netherlands, Norway as well as Switzerland, Turkey and the United Kingdom.

Prof. Tuncay Duruöz, the president of the Turkish Spondylitis Association (ASHAD) empha-

Contents

ASIF– 10th Council Meeting by Margaret Lewington	1
ASIF Photos at the Congress in Turkey by Margaret Lewington	4
My twentieth year... by Ken	5
People's Experiences with Hydro Classes and Exercises!!	6
AS Exercises by Margaret Lewington Physiotherapist	7
AS Group of Victoria Report by Annie McPherson	8
Queensland Report by Ross Wilson	9
Calendar of Events	10

*The information contained in this newsletter should not take the place of advice and guidance from your own health-care providers.
Be sure to check with your doctor about changes in your treatment plan.*

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sized during the opening ceremony that ASIF now represents approximately 5 million persons with AS.

New society memberships were approved from China, Cyprus and South Korea. ASIF president Seoirse Smith and vice president Hedley Hamilton talked about proposed changes and upgrade of the ASIF website. This included ideas for new ASIF logos, one of which will replace the current one. Seoirse Smith presented the ASleep project. This campaign seeks the cooperation with hotels who are willing to present a choice of pillows and mattresses for their clients with AS.

Seoirse Smith displayed an overview of the ASIF activities in the past and its challenges for the future too. This includes a better positioning within the patient organization "People with Arthritis/Rheumatism in Europe" (PARE) and eventually in the UN-World Health Organization (WHO). The question was also raised on whether ASIF should hire professional staff, as there are limitations on what can be achieved if all are volunteers.

Various lectures were held during the meeting. Debbie Cook, the new director of NASS, presented their successful media relations in the UK and stressed the importance of networking with politicians and other patient organizations. Prof. Paul Wordsworth, Rheumatologist from UK, spoke on influencing patient management. He also did an excellent presentation on the AS genetic research development. He mentioned that developments in this area could play an important role in finding new medical therapies for AS patients. Wordsworth managed to make this rather scientific theme comprehensible for nonprofessionals as well.

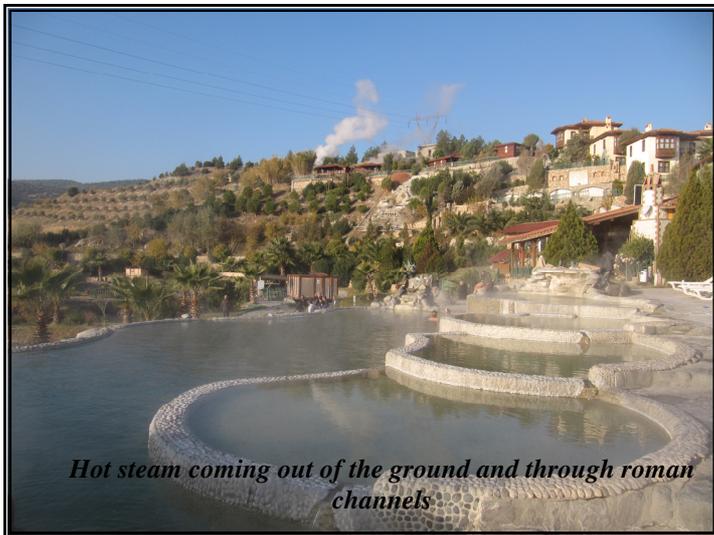
Prof. Tuncay Duruöz, Rheumatologist, from Turkey presented approved new medical therapies in Ankylosing Spondylitis. Claire Harris, NASS physiotherapist from the UK, gave an overview of the pros and cons of exercise groups, highlighting the challenge to motivate young people with AS to participate. Reto Baliarda from Switzerland showed the results of a study on cardiovascular training in patients with AS. The ASAS project "information on appropriate patient behavior" was presented by Prof. Ernst Feldtkeller, Germany, who also distributed to all delegates a survey on doctor instructions to AS patients.

New ASIF secretary and treasurer

The elections of the [ASIF executive committee](#) were an important issue, as there were quite a few replacements. Secretary Ken Mulholland (Canada) as well as Torben Jørgensen (Denmark), the treasurer, decided to step down. The delegates voted for Michael Mallinson (Canada) as the new ASIF secretary. Likewise, René Bräm from Switzerland was elected as the new treasurer. Furthermore, Debbie Cook from the UK was elected as a new member of the board. She replaced her com-

patriot Jane Skerrett.

The 10th ASIF meeting in Izmir was excellently organized by the Turkish AS Society ASHAD, and particularly by its president Tuncay Duruöz. The three day-event included a Turkish Night with typical national music and dancing as well as a journey to the ancient city of Ephesus and the world famous UMUT thermal resort and the Travertine Hot Springs at Pamukkale. UMUT has hot springs and mud baths, that are used for treatment of many conditions including AS and Psoriatic Arthritis. We were able to sample a mud bath treatment. We also had a guided tour of the medical facility at Balcova Thermal where the meeting was held. The



head physiotherapist took us through the facility, showing the medical assessment areas, gym areas for exercise, hydrotherapy and balneotherapy areas including small and larger pools, and treatment areas for individual physiotherapy.

Balcova Thermal is a medical centre with an adjoining hotel and unit accommodation. It is based around European medical spa therapy. They see people with many conditions, but rheumatology is a large percentage. They have treatment programs that may be 2 to 4 weeks long. Turkish people are able to attend the centre, however, this has decreased recently as the government is not funding the treatment as much as they used to. Hence, the people need to attend privately and consequently those who can still attend are coming for shorter periods.

The Norwegian government sends approx 1,000 AS patients to Balcova each year, for a 4 week stay. The Norwegian government pays for AS patients to attend this centre, one in Montenegro or a local one in Norway, every second year, for a 4 week period of medical assessment, exercise, physiotherapy and education. It is cheaper for Norway to purchase this health care in Turkey, even with the cost of travel. This includes individual and group sessions of water and land based activities.

Exercising, stretching and fitness are included. This is similar to programs in some other European countries and in Bath in the UK. Studies have been published showing the beneficial effects on range of movement, fitness and quality of life following this program and also similar programs. A study was done comparing the improvements of those attending the one in the Mediterranean to the one in Norway. All showed very good improvement but the Mediterranean group showed better results than the ones in Norway, presumably due to the warmer climate.

The study concluded that the findings supported the ASAS/EULAR recommendations of non-pharmacological therapy (including education, exercise and physiotherapy) as an important part of the management of AS.



ASIF Photos at the Congress in Turkey

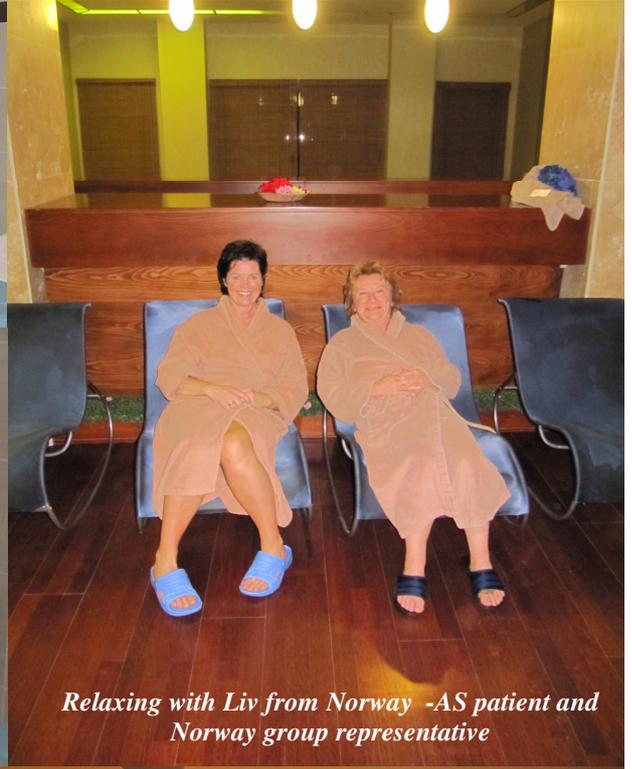
by Margaret Lewington



Being wrapped up – covered in mud, then plastic then a blanket



Health resort treatment facility in UMUT – having the mud treatments



Relaxing with Liv from Norway -AS patient and Norway group representative



Hot steam coming out of the ground and through roman canals



Talk by the local physio as she took the group on a tour of the medical facility.



Liv and Margaret standing in the calcium water



Calcium rich mineral water



My twentieth year...

by Ken



Taking a dip on Ken's 20th birthday

In 1992 I was diagnosed with AS. This was after 28 years of pain – in my chest, lower back and hips.

This 2012 year when I returned to Margaret Lewington's hydrotherapy classes following two bypass operations I thought: mm.... 20 years. 20 years!.

I was referred to hydrotherapy and Margaret by my rheumatologist as a recommendation and I joined the class at the Wesley Hospital at Auchenflower in 1992.

In the following year we moved to the Holy Spirit Hospital at Spring Hill, and we moved again in 2004 to the Royal Brisbane Women's Hospital at Herston. I attended every Tuesday night for 20 years except for annual closedowns, illness and travel. And what an important part of my life it has been.

My hydrotherapy sessions have been central to

management of my AS: both when the disease was active and now that it is dormant. Although now I do not have inflammation, the damage has been done and the stretching exercises are invaluable in keeping me mobile. This has been all the more important to me over the last four years when, prior to my operation, I found walking very painful.

Margaret has been an inspiration to me and to all of the AS Hydrotherapy Group over the years: an inspiration and a beacon of guidance. For over 20 years she has always been there for us, and for me. Her dedication to the cause and her enthusiasm for hydrotherapy exercises is central to why, for 20 years, I have attended hydrotherapy and received so much benefit from it.

To Margaret and all the AS Group members who have given me so much friendship, happy times, and concerned support over the years, I thank you so much. You have been so much an important part of my life.



Ken and Margaret sharing good times!!

Hydrotherapy in Brisbane

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

WHEN: Tuesday Nights

TIME: 6.30 – 7.30 pm

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

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

ENQUIRIES:

Margaret 0404 414 501
or 07 3376 6889



People's Experiences with Hydro Classes and Exercises!!

"Hydro with Margaret has changed my life completely. Before I started taking these classes I was having restless nights and taking medication that was not helping.

Thanks to hydro I am getting the best sleep ever. I am playing sport again, and my activity and well being is nothing short of fantastic.

Hydrotherapy has completely changed my life for the better.

Margaret's hydrotherapy classes are super dooper grouse house!!!"

Jason



"In the midst of the distress of chronic pain with unpredictable pain flare ups, Hydrotherapy is a soothing ritual we can always count on to be there and get us through.
Thank you Margaret!"

Penny

"whilst I would prefer not to HAVE to attend hydro each week because of my health, my AS is what it is so I might as well make the best of it.

The beauty of Tuesday night hydro is that most attendees feel the same way and tend to enjoy it for what it is. It is a happy place that you miss when you aren't there. There is a great camaraderie between us all which motivates us to keep going which in turn is good for each of us health wise."

Michael

" I am so happy that around 15 months ago I chose to commence Margaret Lewington's Hydrotherapy sessions. I find them incredibly rewarding from both physical and mental points of view. Even though I generally keep on the outer, I enjoy the occasional banter between fellow participants and have benefited from sharing experiences such as details of medication, symptom severity and pain management in the occasional one on one chat.

My fitness, posture, range of movement and even attitude have improved. The weightless environment of the warm water takes away the impact of exercise and allows me to tailor the intensity of the workout to suit how well I feel on the day. Although I found it a little challenging in the beginning, I am now totally addicted to this feel good drug called Hydrotherapy! I take my hat off to Margaret for her dedication to deliver affordable, thoughtfully balanced and varied programs in a casual and relaxed atmosphere."

John

" Since I started doing hydro with Margaret and yoga classes at the GYM at least once a week, and having a good diet, my body is more flexible and healthier than ever!!
I encourage you to do it more often!!

Thanks to Margaret and Yoga!!!"

Maritza



AS Exercises

By Margaret Lewington
Physiotherapist

Maintaining 'good' upright posture is a key to management of your AS. To help with this, you need to do the following:

Be aware of your posture or body position and aim to improve it.

Stretch the muscles and tissues that tend to tighten and pull forwards.

Strengthen anti-gravity (back) muscles to help you stay straight with less effort.

The following exercises will help achieve the third aim. It is important to have strong muscles to assist you to maintain your fight against gravity and remain upright. As they are postural muscles, we want them to work at a low load for a long time. Hence, endurance is the key, and this is the way we need to exercise them. Keep the movement small and controlled with at least a 5-10 sec holds.

If you lift too high, you will just arch your back and not strengthen the muscles you need to.

Recent research (done in Canberra) has shown that if you do these exercises with too high a load - eg with your arms out in front of your head - the extra load and effort means your tummy muscles work harder and are counterproductive - actually causing an increase in the kyphotic (bending) curve of your spine. (Bow-string effect) Therefore, low load/effort with longer holds - gives best results for strengthening the upper back muscles to assist with improving and maintaining upright good posture.

Lie flat on tummy, preferable resting on your forehead to keep symmetrical.

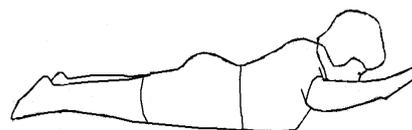
1. Place your arms by your sides.
 - a) Lift your shoulders ONLY off the floor - working the upper back and bringing the shoulder blades together. HOLD
 - b) Lift your shoulders as above, and then also lift your hands off the floor - but only a little - level with your hips. HOLD (if you lift higher- your shoulders will roll forwards - the opposite of what you want)
 - c) Do (a), then (b), then lift your head and chest - again - just a small amount. HOLD.



2. Place your arms at shoulder height - in a 'stop sign' position

- a) Lift your shoulders and arms - small - HOLD
- b) Lift shoulders, arms and then your head and upper body - small and HOLD

(If you feel your tummy muscles working more than your back muscles, you are lifting too much)

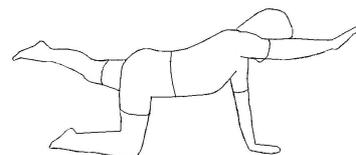


3. Now extend your arms above your head. Lift one arm and the opposite leg. Again - small and HOLD. Lower and repeat with the other arm and leg. As you lift, stretch long through your body - finger tip to toe.

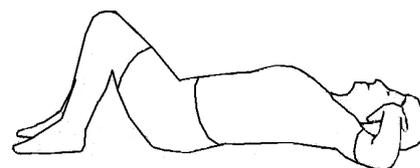
(as only one arm is lifted, there is only low/moderate effort and the tummy muscles do not work to oppose the straightening. Do not be tempted to lift both arms, as mentioned at the beginning)



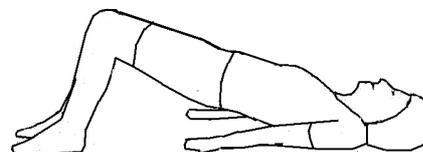
4. Come up onto your hands and knees, and turn your tummy muscles on gently to keep your body steady and balanced. Straighten one arm out in front and the opposite leg behind. Hold this position for good stability and also for strength of the back and buttock muscles. Stretch long through your body, from finger tip to toe. Change to the other limbs. You may also like to try with the same arm and leg or just singly as legs or arms.



5. Now roll over onto your back, bend your knees up with feet flat to keep your low back flat and steady. Place your fingers beside your ears. Push back into the floor with your elbows and try to raise your upper back off the floor, arching between your shoulder blades. HOLD



6. Lie with your arms by your sides, palms up. Now lift your bottom off the floor. Bridging. Tighten your buttock muscles and your low tummy muscles. HOLD





ANKYLOSING SPONDYLITIS GROUP OF VICTORIA

Our AS Group of Victoria committee joins me in welcoming all to the New Year and its new challenges. We hope you are able to join us at one of our events this year, alternatively you may have some suggestions for a new activity for the year.

During November 2011 we held our Rose Hotel dinner in North Fitzroy, with over 12 members and guests including a number of new people. Many experiences were shared with the new folks, who appreciated the friendly informal night. The excellent food and man-sized portions kept everyone busy in between exchanges of tips and ideas about living with AS. It was great to catch up with some past members who were able to make it to the inner city location.

Our next event will be an information seminar, on a Saturday afternoon in early March at the Austral Hotel in Korumburra. This is our first regional event and is being run jointly with Arthritis Victoria. It is open to the public and members of Arthritis Groups from the district, a number of excellent speakers have been selected for this event. We have held a number of successful lunches at this venue over

the last couple of years and have a strong representation of members in the region. Keep a look out for the mailings for Arthritis Victoria's notice and please register directly with them or contact us for further information, we hope to see you there in March.

I have been in contact with a couple of members of the past couple of months who have indicated they were really improving in their health management program through various changes to the exercise activities. Commonly this was as a result of a re-evaluation of their treatments and health programs. It is very encouraging to find even older members of our community can greatly benefit from even a small change in their programs.

ARTHRITIS VICTORIA

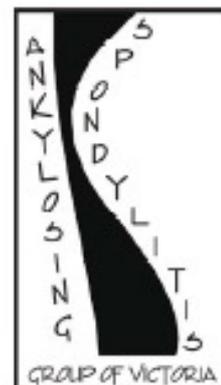
The final Consumer Advisory Committee meeting for 2011, was held in November at Arthritis Victoria (Arth. Vic) with a good attendance of consumers. Some of the issues discussed were the strategic directions indicated by the board during their planning sessions in September including some in-line with our own AS Group's objectives of being "A strong consumer-driven organisation".

Senior management attending the meeting indicated Arth. Vic would continue to be a consumer focused organisation with strong consumer engagement. At the final Research Advisory Panel meeting for 2011 in November, the panel assessed the PHD applications for grants. The recommendations were sent to the board for consideration

and will be released during this year.

During the Arthritis Victoria Board meeting in December 2011, a decision was made to disperse the Consumer Advisory Committee and the Research Advisory Panel and seek a broader representation of consumer interests directly through the staff and Chief Executive Officer, Linda Martin. The board currently has five consumer members representing different groups. Linda has spoken with each of the consumers from the CAC and RAP committees assuring us our support groups' issues will be addressed.

As previously mentioned one of the key strategic directions of the organisation is to be "consumer focused" and their Consumer Engagement Strategy and Volunteer Strategy are being reviewed and re-developed. We will continue to contribute to consumer advocacy issues and consumer services and further information will be issued as they develop. As a peer support group we will continue to raise issues from our AS groups' members with the State Arthritis organisations so we may continue to support you in the community.





Let me start by wishing everyone a Happy New Year.

Hopefully everyone is well over the indulgences of the Christmas period and back on track with your exercising and those other New Years resolutions that we all make each year.

So far I have been pretty good; I've cut down on my chocolate intake, I'm getting along to Hydro classes each week and riding my mountain bike more often rather than taking the easy option of my motor bike.

On the subject of Hydro classes, it is easy sometimes to forget just how long Margaret has been running the weekly classes.

This fact came to light the other week when we celebrated Ken Rich's milestone of 20 years of attending Hydro. (There will be a more detailed article from Ken in the Newsletter).

20 years is a long-term commitment. We all just turn up each week or when it suits us and Margaret is there, with all that enthusiasm and support we all rely on.

We have had a lot of enquiries from people outside the Brisbane area asking if there is a support group in their area. Unfortunately the answer is No. The only way groups can start is by participation and support.

We can offer the support side of things but it is up to the people in these areas to participate. Even if it's just meeting at a coffee shop every now and then. Just talking to others with AS can be helpful and rewarding.

Getting back to Christmas, a great night was had at our Christmas Dinner at Houg's Chinese Restaurant at West End. There was a big roll up with quite a few new faces and everyone enjoyed plenty of good food and conversation. Steve, our social

coordinator is busy putting together the events for this year and is always open to suggestions.

So if there is anything you would like to suggest, good restaurants, a good bushwalking spot or some other activity you think everyone might enjoy, please let us know.

Keep moving.

Ross Wilson.



Calendar of Events

Victoria



Sunday 01 April: Annual Consumer Conference: Arthritis
Victoria Pain Management Seminar, Melbourne Convention Centre



Early May : Lunch event for World Spondylitis Day Details to be advised.

Queensland



Tuesday 10th April: AGM , 8 pm at Earth & Sea Pizza & Pasta
BYO Restaurant, corner of Kedron Brook Road & MacGregor Street,
Wilston (Late dinner after Hydrotherapy)



Sunday 22nd April: BBQ or "Fish & Chips" 10:30 Lunch and walk
at Sandgate Foreshore (meet at shed to right of swimming pool-look for
out banner).

General Information on the web

**Spondylitis Association of
America**

www.spondylitis.org

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

www.nass.co.uk

**Ankylosing Spondylitis Inter-
national Federation (ASIF)**

www.spondylitis-international.org

Arthritis Australia

www.arthritisaustralia.com

Hydrotherapy in Western Australia (Perth)

WHERE: Royal Perth Rehabilitation Hospital
Shenton Park Annex Selby St Shenton Park

WHEN Every Monday evening
(Public Holidays excepted)

COST \$ 7.00

PHONE 08 9382 7307 Lindsay

TIMES:

Hydrotherapy Pool
5.30pm Hydrotherapy exercises

Gymnasium
5.45pm - Land Exercises

*Note: All sessions are conducted by experienced Physiotherapists. Total
Session time is two hours with groups changing over at the end of the
first hour.*

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

Optional Information

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

Are you a member of Arthritis Victoria? Y / N

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

Gender M / F

Age Group

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

Preferred Language

.....

Do you suffer from Ankylosing Spondylitis?
Y / N

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

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

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

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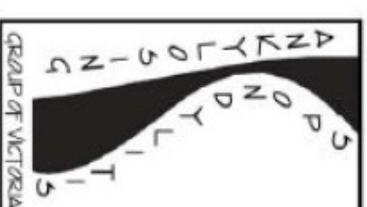
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.....
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.....
.....

Ankylosing Spondylitis Group of Victoria



Membership Form
Providing education and support
for people
with Ankylosing Spondylitis

