

A Stretch

Volume 6, Issue 3

Spring 2005

A Brief History of Ankylosing Spondylitis Support Groups in Australia - by John Stafford

*They drew a circle that shut me out
Heretic, rebel, a thing to flout
But love and I had the wit to win
We drew a circle that took them in
the poem "Outwitted" by Edwin
Markham*

I discovered this poem when I was mulling over how I could best write about the remarkable people, who through their generosity, make the AS support groups in Australia function. Then I realized how the poem seemed to describe the total AS scene - patients, families, society and support groups.

Most AS volunteers say that they live with AS rather than suffer from it. However they, like you, know how often they are shut out, even flouted by those who see them outside the circle because of their perceived differences. Some live with constant pain, immobility, severe drug routines, surgery, relationship difficulties, depression and even loss of employment. I could go on. They know that how living with AS can prevent them from enjoying many

everyday things others take for granted and they are doing something about it, for themselves and for you. Why?

This is the love. That gentle, powerful, life force enjoyed by all AS volunteers, shared within their own families and extended to their wider AS families through their AS support groups. These generous people know that they will win, you will win and because of the insidious nature of AS, it will take wit to win.

I will now set out, not in any order of importance or chronology, events, organizations and most importantly people, who have pioneered the formation of support groups in Australia. The AS Group of Queensland (Qld) has motivated and led this drive towards self help for the last nine years.

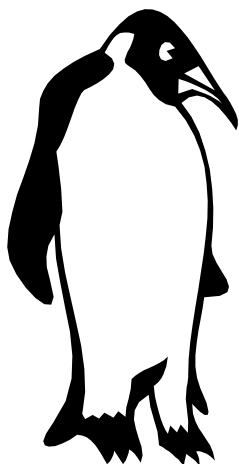
The discovery of the HLA-B27 gene in 1974 and its connection with AS was a huge breakthrough in diagnosing the disease. Research in the USA and

(Continued on page 2)

Inside this issue:

Brief History of AS support groups in Australia	1 - 5
Move Well - Stay Well - by Margaret Lewington	6 - 7
On being a patient Dr. Muhammed Asim Khan	8 - 10
AS Group of VIC News	11
AS Group of QLD News	12
AS Group of NSW News	14
AS Group of TAS News	14
AS Group Contacts	15

*A big thank you to
John Stafford of the
AS group of Queensland
for writing the
History of AS support
groups in Australia
and for his role as chief
proof reader, maintaining
the spelling and grammar
integrity for AStretch over
the last 9 years.*



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.

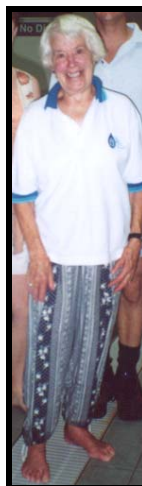
A Brief History of AS Support Groups in Australia - continued

(Continued from page 1)

the UK continues to unveil different types of this gene. Consequently, people were diagnosed with AS at an earlier stage of their disease. This resulted in creating a more urgent need for establishing support groups for everyone affected by AS in Australia. The vastness of our great country, with many people with AS living in remote places and in places not close to available management resources, certainly accelerated the need for support groups which could at least provide some basic contact and outreach to them.

The Arthritis Foundations in some states played early roles in establishing support for people with AS. Even today these foundations are involved to varying degrees in providing this support.

Physiotherapists with a special interest in AS, often gained after post-graduate studies at the world renowned Royal National Hospital for Rheumatic Diseases at Bath in the UK and in Australia, singularly put their newly acquired skills and therapies into practice when they returned to work in their communities.



Jane Barefoot, the amazing and vivacious physiotherapist, from Bath, UK, who is world respected and famous for developing many of the exercise routines that keep people with AS mobile, is part of the Australian AS scene. Jane not only brought these exercises to Australia on her yearly trips to visit family in Brisbane, Qld, but as well as teaching them to other health professionals in Australia, also supervised their implementation with the AS Group of Qld to ensure the purity of their transmission. Jane still visits the Queensland group each year and is affectionately considered the group's "Fairy Godmother".

Sometime in the 1980s, a national AS Group was established in Melbourne, Victoria.

I have been able to find out little about it, other than its funds helped sponsor Fergus Rogers' trip to Australia in 1993, although it had ceased to operate well before that date.

(Continued on page 3)

A Brief History of AS Support Groups in Australia - continued

(Continued from page 2)

In the late 1980s, Lyn Tinsley, a physiotherapist from Perth in Western Australia, set up the first intense AS therapeutic course in Australia there. Lyn practiced many of the AS specialist skills learnt in Bath at these courses.



In 1989, physiotherapist Margaret Lewington completed a hydrotherapy course in Melbourne. In February that year, physiotherapist Liz Lingard established fortnightly hydrotherapy classes at the Wesley Hospital in Brisbane. After six months, Liz moved overseas. Marg saw an opportunity to move into the field she was passionate

about and continued these classes but now on a weekly basis. In February 1997, Marg organized a two day AS management workshop, which she co-conducted with Jane Barefoot. In April 1997, they conducted a one day follow up workshop.



The inspiration, dedication and drive of Fergus Rogers, a pioneer of the British AS support group, National Ankylosing Spondylitis Society (NASS) which was founded in 1976 by Dr A. St. J. Dixon, and

his connection with Australian health professionals who visited the UK and his subsequent visit to Australia in 1993, inspired formation of AS support groups here.

The AS Group of Tasmania has a deserving place in Australian AS history. This small group survives mainly because of the drive and dedication of Murray Limbrick (circled above right) in Hobart.

The group has no access to a hydrotherapy pool but has weekly self-supervised exercise sessions. Its regular social activities and inspirational motto, "AS is much easier to tackle as a group", are an obvious drawcard.



In 1993, when John Ebert was diagnosed with AS and started to attend weekly hydrotherapy classes, he soon realized the huge effort Marg alone was putting into assisting people with AS and decided that the people who benefited most from Marg's efforts could assist Marg and thereby help themselves and others.

In March 1996, he organized a meeting of people attending Marg's AS classes and from that meeting a working committee was established. In September 1996, the AS Group of Qld was formalized as a support group, under the auspices of the Arthritis Foundation of Qld.

The greatest single resource that impacts most on people affected by AS in Australia is the quarterly newsletter *ASstretch*. One of the first things the AS Group of Qld did in its formative months was to decide to call the newsletter *ASstretch*. This name reflected the great benefits obtained from exercise and stretching, that people who regularly attended hydrotherapy classes experienced. The

(Continued on page 4)

A Brief History of AS Support Groups in Australia - continued

(Continued from page 3)

first edition was totally produced by Marg Lewington in May 1996. Marg did this to advertise the impending visit to Brisbane of Dr Muhammad Asim Khan.



From edition two in Winter (July) 1996 to the Summer (December) 1999 edition, AS stretch was the organ of the AS Group of Qld under the editorship of Greg Tate. When Greg relocated to his home city of Melbourne, he assessed the support available to people with AS there and suggested to the Qld group that if the newsletter was to become national, its outreach could be greater. From the Autumn (March) 2000 edition the newsletter became national and Greg remains the editor.



The renowned American rheumatologist Dr Muhammad Asim Khan, who also lives with AS, was attending the International Rheumatology Conference in Melbourne in 1996. After the conference, he came to Brisbane and delivered an inspirational lecture at Queen Elizabeth II Hospital to health professionals and members of the AS Group of Qld. Dr Khan wrote the first mass market book on AS, called Ankylosing Spondylitis the facts, which was published in 2002. Three copies of this book are in the library of the AS Group of Qld and are regularly borrowed by members. In 2001 AS stretch did a cover story by Dr Khan entitled "On Being A Patient".

How did the penguin get into the picture? One evening in 1997, while John Ebert was watching a TV show on Antarctica, he noticed that the profile of the emperor penguins on the screen matched the stance of people with AS. He mentioned this at

hydrotherapy that week and after much merriment the attendees spontaneously agreed to adopt the penguin as the group's mascot. Soon after, Greg Tate was walking to the AS weekend workout at Holy Spirit Hospital in Brisbane, when he stopped to browse in a shop where he saw a life size blow up emperor penguin on display. Greg purchased it, brought it to the hydrotherapy pool and nestled it poolside, where it remained until the pool's demise. A name the penguin competition in August 1997, with a gold coin entry, resulted in him being named Percy Verance. The prize was five CDs donated by member Peter Mitchell from Warner Music. Peter continued these donations for years and the CDs were used in various ways to encourage membership of the group.



The full day symposia on AS, organized by the AS group of Qld, on 24 October 1998 and 20 July 2002 helped expand the public awareness of AS and attracted more members to the group.

The twenty-five rheumatologists in Queensland each receive up to five copies of each edition of AS stretch. They leave them in their waiting rooms as well as giving a copy to newly diagnosed patients. Rheumatologists Clare Barrett, David Bossingham, Martin Devereux and Joe O'Callaghan have given extraordinary support to the AS Group of Qld over the years and deserve worthy places in the history of AS in Australia. Some AS patients have reported back to the Qld group that their rheumatologists have told them that they need to exercise, as they were developing "penguin neck".

Since 1998, the AS Group of Qld has been involved in the Building Partnerships Program which is part of the University of Queensland's School of Population

(Continued on page 5)

A Brief History of AS Support Groups in Australia - continued

(Continued from page 4)

Health's training of medical students. Third year medical students are attached to the group for eight weeks. This program is giving trainee doctors a much better understanding of the total needs of people living with AS.

The Sisters of the Missionary Congregation of the Servants of the Holy Spirit supported the AS Group of Qld by allowing the group free use of its first class meeting and conference facilities at the Holy Spirit Hospital for many years. Two years after the Sisters sold the hospital the new owners suddenly closed the hydrotherapy pool. Marg Lewington and John Ebert had to find an alternative pool and quickly. Thanks to the co-operation of the physiotherapy department at Royal Brisbane and Women's Hospital, the AS Group of Qld were the first outside group allowed to use this up to date facility.

The AS Group of Qld was nominated for a National Volunteer Award in July 2003. Although it failed to win an award, the nomination certainly advanced the profile of AS in Australia. It emphasized the generosity of the Qld group's committee and supporters, all of whom are volunteers.

Through the untiring efforts of various committees of the AS Group of Qld the group went from strength to strength. It became obvious from the number of telephone calls, e-mails and requests for membership that the group was receiving from people in all Australian states and territories and from overseas that there was little support available elsewhere in Australia. When former committee members of the AS Group of Qld went to live in other states, they soon became involved in establishing local support groups. Greg Tate in Melbourne and Denise McKeon in Sydney, New South Wales are outstanding examples of unselfish volunteers who have esteemed places in the history of AS in Australia.

Since 2003, the AS Group of Qld has been co-ordinating giving all known AS support groups in Australia a national presence. A website, <http://www.asaustralia.org>, has already been established and this important work is continuing under the leadership of its secretary, Brent Watts.



The involvement of the very experienced and highly credentialled Dr Lionel Schachna, Deputy Director of Rheumatology at the Austin Hospital in Melbourne, with the AS group of Victoria since

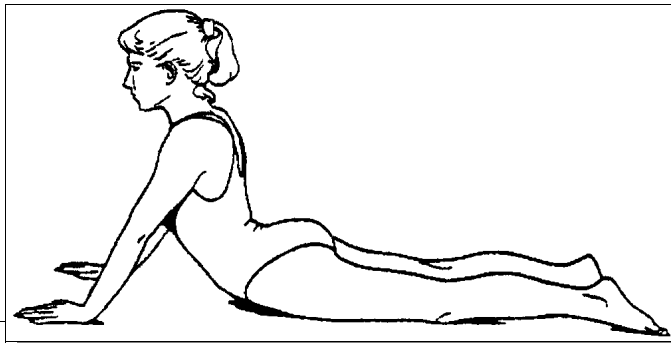
2004 and his contributions to AStretch have given that group a great boost. Watch this group as it regenerates, led by the new and enthusiastic President Annie McPherson and her committee.

The international AS support groups, especially NASS in the United Kingdom and SAA in the United States of America, have generously allowed AStretch to reprint important and enlightening articles from their newsletters. This has given people with AS in Australia a global perspective of the disease. As more overseas places establish AS support groups and exchange their newsletters with the AS Group of Qld, a worldwide bond that advances the support for people with AS is being created.

Over the years many supporters of the AS Group of Qld have made generous financial donations to the group. Thank you to these people and thanks to all of you present and former committee members and supporters, who although not mentioned by name in this article, have made immeasurable, unselfish contributions to the establishment and function of your local AS support groups. All of you have earned a place in the history of AS in Australia.

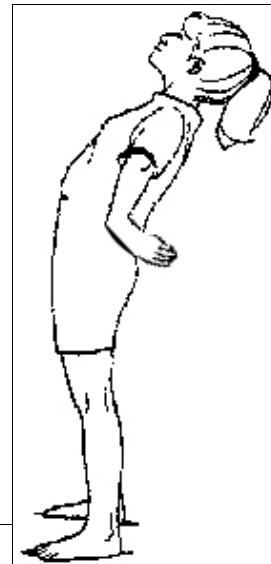
“Move Well - Stay Well” - by Margaret Lewington B.Phty. Cert Hydro.M.A.P.A.

People tend to spend more time on the first leg, arm, or area they stretch, and they usually will stretch their "easy" or more flexible side first. Because of this natural tendency more time is spent on the "good" side and less on the "bad" side. To even out the difference in flexibility in your body, stretch your tight side first. This will help you limber up considerably.



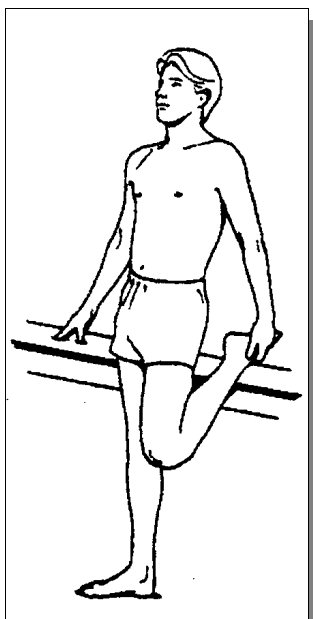
Press Ups:

Do your press up slowly and hold at the end of range. Sag in the middle to get good movement of the lower back. If you are too stiff, only straighten arms as far as you can while tummy is close to the floor.



Back Stretch when Standing:

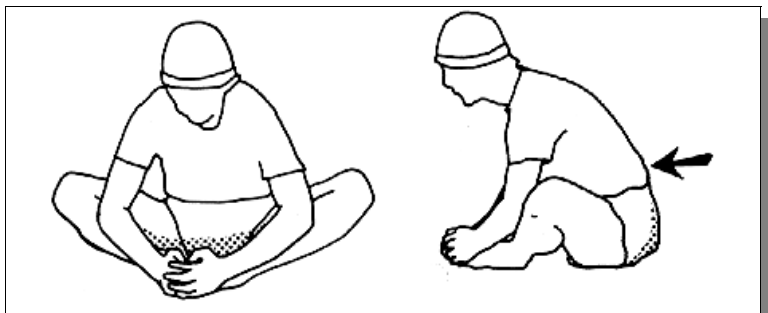
You can use the position of your hands on your back to give you a point to lever back against. Remember, where it is difficult is where you need the most stretching.



Quadriceps - Front of thigh:

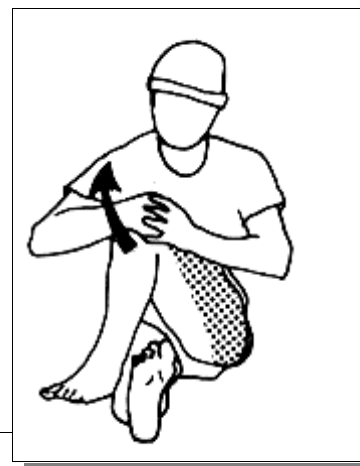
The well known way to stretch this muscle is to stand, with the knee bent and bringing your foot towards your bottom. Ensure that you are well balanced or holding onto something. To assist your balance you can focus on a spot in the distance. If you are unable to reach your foot, you can use a towel or strap. Ensure that you keep your knees close together, lift your head and chest tall, and tuck your tummy in. Extra stretch is made by bringing the foot closer to the bottom and/or moving the knee backwards so as to be under or behind the hip. Do not let your back arch. Sometimes it is easier to use the opposite hand to hold the foot as it helps you keep your knees together.

“Move Well - Stay Well” - continued



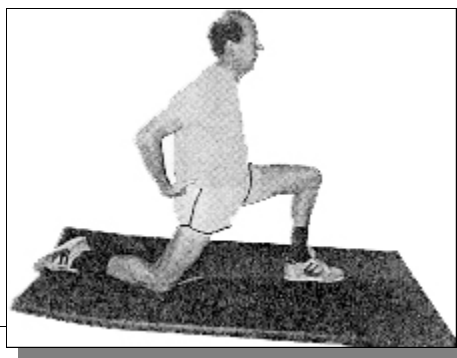
Groin Stretch:

Put the soles of your feet together and hold on to your toes. Gently pull yourself forward, bending from the hips, until you feel a good stretch in your groin. You may also feel a stretch in the back.



Side of Hip:

Sit with your right leg straight. Bend your left leg, cross your left foot over and rest it to the outside of your right knee. Pull your knee across your body toward your opposite shoulder until an easy stretch is felt on the side of the hip.



Hip Flex:

Kneel on one knee, place other foot out in front so that the foot is a little in front of the knee. Keep both hips pointing to the front. You may put the hand on the same side as your back leg onto your bottom to keep the hips forward on this side. Keep your body vertical (helped by placing other hand on your front knee) tighten tummy and bottom to prevent arching of the back.

Move a small amount forwards and allow your hips to sink towards the floor. The stretch should be felt deep in the front of the hip joint of the back leg. hold for ten seconds, gently release and repeat at least 3 times.

If you are quite stiff or sore in other joints and unable to get into this position, you can sit side on in a chair and take your leg backwards. You may also use the testing positions described above as a stretch position. Lying flat on your tummy may also give some stretch to this area.



ON BEING A PATIENT - by Dr. Muhammad Asim Khan

Editors Note: Upon reading John Stafford's Brief History of AS support groups in Australia article, I felt compelled to revisit the personal story of Dr. Muhammad Asim Khan which appeared in the Summer 2001 edition of AStretch newsletter.



On a recent visit to New York City, as I was taking a 15 block walk in midtown Manhattan, I was thinking about how fortunate I have been. In 1998 I underwent a transluminal coronary angioplasty with stent placement and subsequently I received anticoagulant therapy, which resulted in painless hematuria. This led to the discovery of renal-cell carcinoma, for which I had a radical nephrectomy. This experience has prompted me to share with you my perspective as a patient for 44 years, now facing the added uncertainty that a cancer patient has to live with.

You see, I have had arthritis since age 12, and my physician at the time, the chief of orthopaedic surgery at the local university hospital, treated me with frequent bed rests and hospitalisations. There were no rheumatologists in Pakistan in those days. He at one point prescribed one full year of antituberculous treatment (streptomycin injections, isoniazid, and para-aminosalicylic acid), without any resultant clinical benefit. Later on, he treated me intravenously with honey imported from West Germany. By then I was 16 years old and had just become a medical student.

Two years later, during my first clinical rotation in medical school, I spoke to my teacher, a professor in the department of medicine, about my symptoms. He examined me and diagnosed my disease as ankylosing spondylitis. It primarily involved my back, hip joints, and to a lesser extent, my neck and shoulders. He prescribed phenylbutazone, a non-steroidal anti-inflammatory drug, to relieve my pain and stiffness, and it worked effectively.

Soon after I graduated from medical school in 1965, when I was 21, Pakistan was attacked by its neighbour, and I decided to enlist in the Pakistan Army Medical Corps. In my zeal to serve the nation in its hour of need - a nation that had accepted me as a 3-year old refugee and had provided me with almost free medical education - I did not reveal my illness. My service in the Pakistani Armed Forces was a great experience.

In 1967, when I had just left the army, I received a call for assistance from the very professor from medical school who had diagnosed my ankylosing spondylitis. This professor wanted me to treat his best friend, a prominent local businessman, who had just experienced an acute myocardial infarction. I provided the necessary care, including, later that day, successfully resuscitating the patient when he experienced cardiac arrest. (He would go on to live for another 28 years and help build a hospital for the needy, but that is another story entirely).

I arrived in London in the summer of 1967 to begin my postgraduate medical studies - despite my arthritis, which never ceased to plague me - in an effort to pursue my goal of an academic career in medicine. Cardiology was my initial choice for a medical subspecialty, but I felt that the anticipated progressive decrease of my spinal mobility, as well as having limited chest expansion due to my ankylosing spondylitis, might one day impair my ability to resuscitate patients. During the required one year of residency training, I chose orthopaedics as my surgical elective. While assisting the surgeons in various orthopaedic procedures, including total hip arthroplasty, I was keenly aware that the tables would someday be turned and I would be the one at the receiving end of the operation.

I came to the United States in the summer of 1969 and have successfully pursued an academic career in

(Continued on page 9)

ON BEING A PATIENT - continued

(Continued from page 8)

rheumatology. Knowing what it feels like to an arthritis sufferer, and therefore having a special empathy for patients with this condition, my choice of subspecialty was an easy one to make. Not surprisingly, my primary research interests have included ankylosing spondylitis and related spondyloarthropathies, along with the associated genetic marker HLA-B27.

Inevitably, the tables did turn, and I experienced the following: bilateral total hip joint replacement; revision hip arthroplasty; fracture of the cervical spine; non-union of the fracture, despite 5 months of wearing a halo with vest immobilisation; surgical fusion of the fracture and another 3 months of immobilisation; recurrent episodes of acute anterior uveitis; hypertension and coronary artery disease; coronary transluminal balloon angioplasties on three separate occasions; and, most recently, right radical nephrectomy. Perhaps you will agree that my many encounters as a patient serve as sufficient "qualifications", if we can call them that, to assert my own viewpoint. I am very grateful to modern medicine for keeping me going. In some ways, I consider myself a "bionic man". My ankylosing spondylitis, however, has resulted in a complete fusion of my whole spine, including the neck. I cannot turn or even nod my head, and I have to bend at my hip joints to give an impression of a nod. I need to grab onto something to pull myself up from a squatting position. I have virtually no chest expansion. One can imagine what might happen to me if I were to have the misfortune of being in an accident or needing cardiac resuscitation; the probability would be high that, inadvertently, my death would be hastened because of a possible neck fracture or broken ribs.

Although I have always sought the best care possible for myself, I have been unlucky on many occasions in not receiving optimum medical care. However, being a perpetual optimist, I am thankful that I am still alive. I sometimes like to give the analogy of the old Timex watch commercial, because I keep on ticking. But if

my personal experiences as a patient were extrapolated to the population at large, they would unfortunately highlight many deficiencies in the current practices of medicine, even here in the United States: the unreceptive receptionist, the allied health professionals who lack empathy for their "clients", and the physicians for whom time is such a precious commodity that they start looking at their wrist watches just minutes into the history taking to signal their impatience.

We physicians frequently do not acquire the skills of a good communicator, and we often neglect patient education. The word "doctor", as I understand it, means an educator or communicator. Yet some physicians apparently lack the traits required to be a good communicator and some claim that they simply have no time for it, anyway. In such situations, an allied health professional, such as a nurse practitioner, could better handle communications with the patients. Better physician-patient communication is certainly needed.

I underwent bilateral hip arthroplasty as a single surgical procedure at a hospital that specialises in such surgeries. A few years later, I had to undergo a revision hip arthroplasty. Before I left the hospital, I noticed that one leg was now shorter than the other by about a half inch, but my surgeon would not acknowledge this. I still, to this day, wear a shoe lift to minimise my limp.

My first transluminal coronary angioplasty resulted in an extensive internal tear. When I subsequently had restenosis of the involved artery, I was advised by an independent consultant to have a stent inserted at the time of the revision angioplasty. I had my second angioplasty performed at a highly rated medical centre and, although I had requested a stent placement, none was given, and my angina symptoms recurred shortly thereafter.

(Continued on page 10)

ON BEING A PATIENT - continued

(Continued from page 9)

When I fractured my neck, I was treated with the placement of a halo and a vest to immobilise the fracture. I pointed out to my surgeon on numerous occasions that the fracture was not fully immobilised, as was most noticeable when I leaned back or tried to lie on my back. I voiced my concern that the back plate of the vest was not properly conforming to my thoracic kyphosis, but the surgeon repeatedly reassured me that everything was fine. I had to sleep sitting upright. After 3 months, a radiograph revealed non-union of the fracture. Subsequently, the vest was changed, but precious time had already been wasted; because months of further immobilisation did not heal the fracture, I ultimately needed a surgical fusion.

I have never sued anyone. My forgiving and non-litigious nature tells me that as patients we should always give our physicians the benefit of the doubt, just as we physicians, likewise, should always show respect for our patients and give them some degree of latitude. But in our current health care system, there is an obvious need for a more open dialogue between physicians and their patients.

During the 7 month period in which I wore a halo that was screwed into my skull and attached to a vest that surrounded my chest (just imagine trying to sleep at night wearing all that hardware!), I continued to care for my patients. I found myself in ever greater awe at the power we, as physicians, hold as healers. On one occasion, a new patient came to see me, and after our initial handshake, I noticed that his face was turning pale. I immediately had him lie down on the examination table just before he fainted. When he felt better the patient started to laugh, and said, "Doc, I had been hurting and waiting to see you for 2 weeks, but with one look at you all my pains are gone!"

One morning, a few days later, I was walking by the emergency room on my way to the office and had

not yet donned my white coat. A young child noticed my halo and asked, "What happened?" "I had an accident," I replied.

Having surmised that I was en route to the emergency room for acute medical attention, the child inquired, "Is that the steering wheel of your car that is stuck around your head?"

I have enjoyed every bit of my life, with all its humour, hardships, hurdles and dramatics that could even appeal to the Hollywood movie moguls. And I continue to enjoy my walks. After all, my doctor has instructed me to get daily exercise.

Muhammad Asim Khan, MD, FRCP Case Western Reserve University School of Medicine Cleveland, OH 44109

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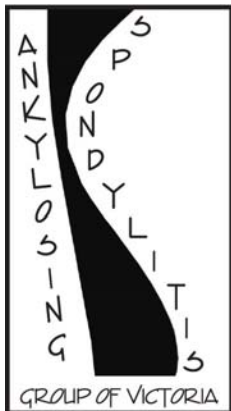
In 2002 Dr. Muhammed Asim Khan released a book called Ankylosing spondylitis the facts. Following is an extract from John Ebert's review of this book which appeared in the Spring 2002 edition of AStretch.

This is a totally unbiased, comprehensive and lived treatise on AS and a must for everyone affected by it, be they patients, families, carers or health professionals. Imagine the possibilities of earlier diagnoses if General Practitioners read this book. Who of you and the general population know that AS is far more common than the better known diseases of leukemia, muscular dystrophy and cystic fibrosis?

Do yourself or someone else you love a favour and give them this book as a present. They will be delighted, not only by its content but also to read that Professor Khan has dedicated it to them.

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AS Group of Victoria News - by Annie McPherson



Presidents Report

Arthritis Victoria had a number of presentations over the August period for Healthy Bones Week. I attended two seminars on osteoporosis and one on osteoarthritis of the knee.

The medical professionals and allied health professionals all gave excellent presentations and

focused on both the medical side as well as the patient side of these conditions.

I found the presentations by the following speakers very relevant to our AS group and would definitely consider them for our future seminars.

Cate Lombard, Dietician, Consultant to the Jean Hailes foundation. (*The Jean Hailes Foundation is a not-for-profit organisation providing important services for women from adolescence to mid-life and beyond. Established in Victoria in 1992, it is now regarded throughout Australia as a leader in women's healthcare.*)

Tanya Conway, Physiotherapist, Arthritis Victoria / Osteoporosis Victoria.

Liz Bongetti, Principal health professional, Arthritis Victoria / Osteoporosis Victoria..

I will be making contact with these organisations to arrange discussions for potential seminars next year.

I have recently made contact with Denise Langford who represents Australian Barbell company. She was very happy to give our group a reduced rate for their weights and other gym products. I will be in contact to determine detail, over the next month.

Psoriasis Australia in conjunction with Arthritis Victoria held a seminar in late August on Psoriatic Arthritis with Dr Lionel Schachna presenting the medical professional segment. I found it extraordinary how some symptoms of this disease are so similar to ankylosing spondylitis.

I met with the secretary of Psoriasis Australia Inc., Mrs Helen McNair, who was most enthusiastic to meet with members of our committee to discuss management and funding issues for self help groups. I shall arrange to meet with her again as soon as possible.

On Thursday 15th September I was a guest speaker representing the AS Group of Victoria at an afternoon/evening Ankylosing Spondylitis seminar program at the Royal Melbourne hospital.

The program began at 3.30 pm and continued through till 8.00 pm with a variety of guest speakers including Physiotherapists, a Rheumatologist, Pharmacist, Clinical Psychologist, Occupational therapist and an Exercise Physiologist. Many topics were covered, including specialist management of AS, pharmacological management, pathophysiology of AS, pain management techniques, posture and back care and of course exercise and activity for AS. My role was to present details on the AS Group of Victoria activities and the benefits of being a member of a support group. If you reside in the Royal Melbourne Hospital Community Rehabilitation centre Northern suburbs catchment area, you may qualify to attend the next one of these excellent programs.

Contact the centre on 03 8387 2237 for more details.

Also, don't forget that the last of the Arthritis Foundation of Victoria's four part Ankylosing Spondylitis seminar series is being held on the 6th of December. Call 03 8531 8000 for more details.

The next edition of AStretch is due out in January, therefore I take this opportunity on behalf of the AS Group of Victoria to thank everybody who joined up in 2005 for their wonderful support. and I wish everybody a very merry Christmas.



AS Group of Queensland News - by John Ebert

It was bound to happen eventually and it did. An AS dinner that was a disaster - not because the food was bad or the staff were rude but we underbooked and the restaurant was unable to add any more seats to our table. For those who were able to get a seat, our July dinner at Amphora was its usual success with seventeen people enjoying the delicious traditional Greek banquet that the restaurant does so well. My thanks to the Watts and Arnold clans who generously cancelled their meal with us and went on to have a great night at another restaurant. Another first- two AS dinners on one night.

A bleak windy afternoon greeted us as we gathered at the Merthyr Bowls Club for our first foray into barefoot bowls. There was lots of laughter as we tried to master the fine art of lawn bowling. A couple of us even got the bend of the bias at the end of two hours playing. We almost froze from the cold river breeze as we waited for our after game barbecue. It was worth the discomfort as we enjoyed tender steaks and sumptuous salads before heading off to the warm comforts of home.

Our October dinner was held at Caravanserai Turkish restaurant and once again the fourteen people who attended enjoyed a delicious banquet, great company and fine wines.

Our Annual General Meeting will be held at 7.00 pm Wednesday 9 November 2005 at unit 11, 34 Park Avenue, East Brisbane. It will be followed by a committee meeting. Please phone me on 3391 4689 for further information about the AGM.

It was with great sadness that we learnt of the deaths of a member, a mother of a committee member and the father-in-law of another. John Hulin died on 27 August 2005 after a long battle with mesothelioma. His widow Kristine attends hydrotherapy with her son-in-law Ross Smith. On 3 September 2005 Kevin Sullivan, a long time group member from Toowoomba died after a long struggle with cancer. On 8 September 2005 Margaret Ella Costelloe, the mother of long time member and committee member Jack Costelloe, died in her home in Tasmania. I extend the condolences of the group to all members of the families of these people. May they rest in peace.

As this is the last edition of AStretch for this year, I wish all of you and your loved ones a joyous, peaceful Christmas and a bright, prosperous and healthy 2006.



Our October dinner was held at Caravanserai Turkish restaurant and once again the fourteen people who attended enjoyed a delicious banquet, great company and fine wines.

AS Group of Queensland News - continued



A bleak windy afternoon greeted us as we gathered at the Merthyr Bowls Club for our first foray into barefoot bowls.



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 27th December 2005

WHAT'S ON IN QUEENSLAND

Barbecue at Jack and Joy's in Bundamba, from 3.00 pm with the barbie at 6.00 pm. Don't forget your togs and towels. BYO meat, drinks and a salad or dessert to share. Phone Graham on 32636196 for more details.	Saturday 5 th November 2005.
AGM at 11/34 Park Avenue, East Brisbane. Phone John on 33914689 for more information.	Wednesday 9 th November 2005 7.00pm
Annual Christmas Dinner at The Vietnamese Restaurant 194 Wickham Street, Fortitude Valley. Book Early! Phone Graham on 32636196 for more details and bookings.	Saturday 3 rd December 2005.

RESPOND-NSW NEWS BY DENISE MCKEON

AS BBQ ... Saturday 29 October - 12.30pm at Paul & Margaret's "Abbotsford House"

2 Abbotsford Cove Drive, Abbotsford

The street is a small private road off Walton Crescent and the house is the only old house in a street of home units. Enter via the green pedestrian gate labelled "Private" and follow the drive round the house to the fishpond. BYO food and drink

Please RSVP to Denise:

9328 1384 (ah)

0408 409 042

denisemckeon@bigpond.com

All are welcome: spouses, friends ...



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

Postal Address : PO Box R1050

Royal Exchange, NSW, 1225.

E-mail : ASGroupofNSW@hotmail

OR

Contact can be made through the Arthritis Foundation of NSW

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



Tasmanian 'Anky Sponds' News - by Alicia Groves

Hello from Tassie. On behalf of the Tassie Group I would like to extend our best wishes for the festive season and also wish all the readers of this newsletter a happy and healthy 2006.

We also pass on our congratulations to Lee & Greg for their upcoming marriage.

If anyone would like to attend our Christmas Get Together please contact us for details.

Noeline has contributed the following to provide us all with a good laugh at her misfortune.

Bye for now, Alicia .

Noelis Bit (of bad luck)

Well I don't know if it's the changeable weather lately that's made me feel a lot worse or I haven't been exercising or I've just taken a turn for the worse. Anyway I have had an eventful couple of weeks - first of all I backed into my gate, the half that I didn't open, (I looked out my side window

instead of my rear vision), put a couple of wee marks on my rear end (the car not me), cracked my head on two consecutive days, fell down a drain and put a hole in my neighbours new rendered wall. I was carrying bricks he was kindly giving me to do some paving and I dropped one, consequently I haven't been back for more bricks! My cat bit me on the hand when I was trying to rescue her from a cat fight (that's all the thanks I got from that). I got a terrible infection hence a course of antibiotics. Then I had a good friend (who shall remain nameless) do the same thing to my gate except a lot worse, totally mangled my gate and did quite a bit of damage to her car. To finish things off I broke my favourite wheetbix bowl, with the wheetbix in it. In between all that I had 3 migraines. I wonder why??? I think I need some help! Who said things happen in three? Not from my side of the fence. Wish I could hibernate for the winter. Oh well it's over now, isn't it?

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

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

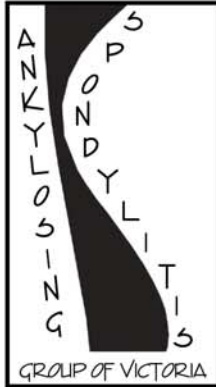
Phone: (03) 9530 0255
Email: gillian@arthritisvic.org.au

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

Email: ASGroupofNSW@hotmail.com

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

Phone: Alicia Groves (03) 6227 8987
Email: mimbric@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.