



## WINTER 2009 ISSUE

### Editor's Letter

Welcome to our Winter 2009 edition of AS News.

We hope that this edition finds you all safe and healthy.

Well, we have had another busy year with the following highlights in particular;

- The planning and execution of what was our second successful awareness campaign, Get your Back Up 2009, and the on-going impact it has had on patients, health professionals and our organisation.
  - Jointly hosting, with Arthritis Ireland, Dr. Joachim Siepers lecture in City West
  - Starting a new physiotherapy group in Ennis, Co. Clare
- Participation in another Ankylosing Spondylitis International Federation (ASIF) council meeting
  - Participation in a number of the Mater Hospital's M.A.S.T.E.R. programme during the year.

Sadly and in contrast to the highlights mentioned above, we have had a disappointing year when it comes to membership renewals and patient involvement.

Our strength is in our numbers and if we fail to maintain a sufficient core membership we will struggle even more to have our voices heard. Also, if we leave all of the work to a number of individuals our efforts will be diluted by too few people trying to do too many things.

All that remains is for Hugh and I to wish you all a Merry Christmas and a Happy & Healthy New Year.

*Seerise*




eular

### What is EULAR?

The European League Against Rheumatism (EULAR) is the organisation which represents the patient, health professional and

scientific societies of rheumatology of all the European nations.

- EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases.
- EULAR fosters excellence in education and research in the field of rheumatology. It does this by supporting research projects in rheumatology by funding collaborative research between European rheumatology groups and, more recently, across the Atlantic.
- EULAR represents the interests of the entire rheumatic disease community and is the natural partner of European policy makers when policies and regulatory frameworks are developed.

ASAI's connection to EULAR is mainly through the representation of ASIF.

To find out more visit: [www.eular.org](http://www.eular.org)

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## EULAR 2009

The European League Against Rheumatism (EULAR) held its annual conference in June this year. Over 4 days, hundreds of studies were eventually gathered into an academic journal on rheumatic diseases. Here are just a few interesting research papers which we've picked out. One of them focuses on exercise, 2 on sleep and sleep apnoea, and one on vitamin D.

In one of the studies, researchers examined the effects of walking, swimming and exercise on quality of life, lungs and depression in patients with Ankylosing Spondylitis (AS).

The treatment of AS aims to reduce morning stiffness, to correct posture and to increase mobility and well-being. Despite huge progress in AS medication, physical therapy and exercise continue to be essential parts of the treatment.

All patients performed exercise but were divided into 3 groups: swimming group 1, walking group 2 or 'exercise only' group 3. Exercise sessions happened 3 times a week for 6 weeks.

Patients were assessed before and after the programme, over many tests examining lungs, oxygen, walking, the 3 Bath AS Indices and for depression.

After treatment in groups 1 and 2, oxygen intake and walking were much better. A big improvement was also seen in energy, lungs, emotional reaction and mobility in all groups after the programme.

Swimming, walking and exercise had beneficial effects on patients' lungs and quality of life. And aerobic exercises like swimming and walking plus regular exercise increased the functioning abilities of patients.

**Annals of Rheumatic Diseases 2009; v68(Suppl3):635**

Another study asked patients with inflammatory rheumatic diseases which health issues should be given priority for improvement.

More than 2000 patients responded; some of them had rheumatoid arthritis, some had psoriatic arthritis, others had juvenile inflammatory arthritis and almost 230 had AS. All were shown a list of 7 frequent health problems linked to rheumatic diseases and were asked to pick the 3 they considered the most urgent to improve, in order of priority.

Pain was the top priority among all disease groups. Interestingly, sleep problems were more important for AS patients than for those with other inflammatory arthropathies.

**Annals of Rheumatic Diseases 2009; 68 (Suppl3):649**

In the other sleep study, AS patients were tested for sleep apnoea. This is a common sleep disorder characterised by short interruptions in breathing during sleep. The airway gets obstructed and this prevents air from entering the lungs, forcing the person to wake briefly to restart breathing before falling back to sleep again; the person is unaware of this. These breathing interruptions can happen hundreds of times a night, resulting in patchy sleep.

## AS News

All patients had their sleep patterns recorded during one night.

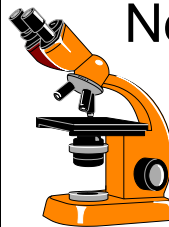
Sleep apnoea was found in nearly a quarter of AS patients. This number increased to over a third for those who have had AS for more than 5 years. Sleep apnoea was therefore seen more often in AS patients than in the general population.

**Annals of Rheumatic Diseases 2009; v68(Suppl3):645**

In the last study we selected, vitamin D deficiency was checked in patients with Spondyloarthropathies (SpA). Vitamin D deficiency is common but has a harmful effect on bone and muscle function.

Researchers analysed vitamin D tests taken in hospital over 3 years on out-patients diagnosed with SpA. Nearly 200 patients with vitamin D deficiency were compared with patients not lacking vitamin D. There were more males and more patients older than 43 with vitamin D deficiency. This suggests that vitamin D deficiency is frequent in out-patients consulting for SpA.

**Annals of Rheumatic Diseases 2009; v68(Suppl3):648**



## News in the field of Spondyloarthritides

### Report on the 6th International Congress of Spondyloarthropathies 2008 in Gent

by Dr. med. Uta Kiltz, Herne, Dr. med. Martin Rudwaleit, Berlin, Prof. Dr. med. Joachim Sieper, Berlin, and Prof. Dr. med. Jürgen Braun, Herne, all in Germany reproduced from ASIF News No. 10 The International Spondyloarthritis Congress takes place biannually in Gent (Belgium).

The 6th International Congress of Spondyloarthropathies (2 – 4 October 2008) was chaired by Prof. Dr. Jürgen BRAUN from Herne (Germany) and Prof. Dr. Matthew BROWN from Woolloongabba (Queensland, Australia). Again the newest developments in the field of spondyloarthritides and especially of ankylosing spondylitis were presented.

### Genetics

With HLA-B27 an important predisposition factor for ankylosing spondylitis is now known since 30 years. This factor explains, however, only 20–30% of the inheritable predisposition. Matthew BROWN now presented two additional genes which contribute to this predisposition: ARTS1 and IL23R. ARTS1 is a protein which takes care for the optimal length of *peptides* (protein fragments) of *MHC class I* molecules (of the immune system) and induces a separation of *receptors* (receivers of chemical signals) of proinflammatory *cytokines* (signalcarrying molecules) from the cell surface. IL23R encodes a *cytokine receptor* on the surface of Th17 helper cells. How these genes contribute to ankylosing spondylitis, is unknown.

Hypotheses assume both a misdirected activation of HLA peptides and an effect in connection with *cytokine* signals.

### Disease mechanisms

In contrast to rheumatoid arthritis, new bone formation is prominent in AS, the interconnections being unresolved.

Joachim SIEPER from Berlin presented a hypothesis which assumes that new bone formation can only start in an interval without inflammation.



Figure 1: Hypothesis for the interaction of inflammation and new bone formation in ankylosing spondylitis according to Sieper, Appel, Braun and Rudwaleit 2008

Rik LORIES et al. from Leuven (Belgium) however assume, based on results of mouse experiments, that bone erosion (by inflammation processes) are not necessary for new bone formation. This question is of interest because only if bone formation and inflammation are coupled, one can hope to prevent also the new bone formation by means of anti-inflammatory substances like TNF-alpha blockers.

### Clinical manifestations of ankylosing spondylitis

The assessment of functional limitations caused by ankylosing spondylitis was an essential subject of this congress.

The term function nowadays implies not only physical abilities but also for instance the possibility to take part in social life. This view is part of the *International Classification of Functioning, Disability and Health (ICF)* of the *World Health Organisation (WHO)*. An "ICF Core Set for AS" presented by Annelies BOONEN from Maastricht (Netherlands) is based on this general definition.

Désirée VAN DER HEIJDE (Leiden, Netherlands) presented a new method to assess the disease activity in ankylosing spondylitis. In contrast to the *Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)*, the *Ankylosing Spondylitis Disease Activity Score (ASDAS)* developed in the frame of the *Assessment of SpondyloArthritis International Society*

(ASAS) contains, besides the judgement by the patient, also acute phase reactants (erythrocyte sedimentation rate or C-reactive protein) and thus helps more reliably to distinguish between high and low disease activity.

### Diagnostics

The diagnosis and classification criteria for ankylosing spondylitis used so far depend on the proof of X-ray changes in the sacroiliac joints and do not respect, on the other hand, magnet resonance imaging as sensitive method to detect inflammation.

Martin RUDWALEIT from Berlin (Germany) presented new criteria for *axial spondyloarthritis* which were likewise developed in the frame of ASAS.

Conventional X-rays are evaluated most reliably with the *modified Stokes Ankylosing Spondylitis Spinal Score (mSASSS)*. In this assessment instrument, the lower part of the thoracic spine is, however, not regarded because of its

limited visibility in lateral X-rays. Xenofon BARALIAKOS from Herne (Germany) presented a new assessment method called *Radiographic Ankylosing Spondylitis Spinal Score (RASSS)* which includes the lower part of the thoracic spine and thereby regards, on average, 30% more new *syndesmophytes* than regarded with the mSASSS.

### Anti-TNF-alpha therapy

Martin RUDWALEIT from Berlin presented predictive factors for a good response to a therapy with TNF-alpha inhibitors. These predictive factors include the extent of inflammation signs visible in magnet resonance images.

Likewise Martin RUDWALEIT demonstrated that in an evaluation of magnet resonance images also the back-side parts of the spine should be regarded (Figure 2).

Johan ASKLING et al. from Stockholm (Sweden) showed data of a Swedish biologics register (ARTIS) containing adverse side effects of TNF-alpha inhibitors. According to these data the risk of an infection needing hospitalized treatment decreases after one year of anti-TNF therapy. Likewise according to J. ASKLING et al. the existing information on the incidence of solid tumors in connection with anti-TNF therapy (growth of an existing tumor or induction of a new tumor) is still unclear. Observations of patients with rheumatoid arthritis and with a malign lymphoma indicate that more the disease activity and not the anti-TNF therapy plays a role in the induction of a malign lymphoma.

Joachim SIEPER from Berlin presented new therapeutic approaches for the treatment of ankylosing spondylitis. *Abatacept*, *Rituximab* and medications against the cytokines IL-6R, IL-17, IL-23 and regulatory T-cells are being tested in patients not treated with TNF-alpha inhibitors as well as in patients who did not respond sufficiently to TNF-alpha inhibitors.

### Conclusions

We expect that new findings in genetics and immunology will bring light into the *pathogenesis* (disease origin) and *pathophysiology* (disease mechanisms) of the spondyloarthritides and thus lead to new concepts. Already now a longstanding suppression of the disease activity and an improvement of the mobility is possible in patients with ankylosing spondylitis with the help of TNF-alpha inhibitors. Nevertheless, a large number of open questions is still to be answered which were extensively discussed at the 6th Spondyloarthritis Congress in Gent. ◀

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**Source:** Shortened patient-adapted translation by Ernst Feldtkeller of a scientific article published in *Zeitschrift für Rheumatologie* volume 68 (2009) pages 420–422

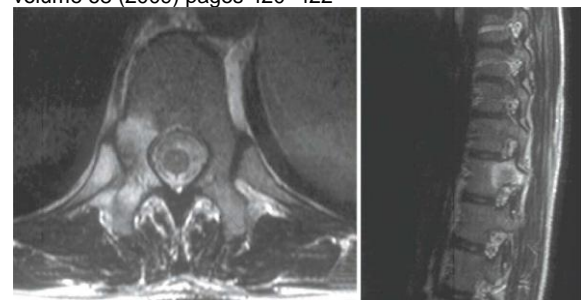


Figure 2: Typical inflammatory signs in magnet resonance images of the middle thoracic spine with involvement of a costovertebral joint and the posterior (back-side) part of a vertebral body, according to RUDWALEIT



## From bench to bedside!

Extracted from a report by Claire O'Connell in the Irish Times of November 10<sup>th</sup>. A major funder of health research in Ireland is moving its focus away from basic research and towards the patient.

HOW DO you turn scientific research into something that helps a patient? It's a question that has received considerable attention in Ireland as our basic research in life sciences has grown.

But a new strategy announced by one of the State's largest funders of medical research stands to boost

that process of translating discoveries from laboratory bench to bedside by shifting its focus away from basic research and towards applying that research knowledge.

Make no bones about it, we are making a clear statement that we will no longer be funders of basic, biomedical research, says Enda Connolly, CEO of the Health Research Board, which last week launched its new strategic plan.

So much health research can end up just being in the basic research to increase understanding, but increasingly if you are going to get the benefits you must also invest in its application and translation and how it is used, and how you actually create mechanisms for using it within your systems and care processes. That's where our focus will be over the next 3 to 5 years.

The strategy is a conscious shift by the agency, which currently has investments of about €200 million across hospitals and third-level institutions, and its aim is to bolster the Republic's health research infrastructure, according to Connolly.

The really big gap identified was that we had an underperforming clinical and health research environment.

Academia and industry in life sciences was not able to exploit the possibilities because they don't have the proper access to the clinic, the patients, the knowledge that being close to the bedside delivers in new products, new services and new activities.

That's the huge gap that Ireland has, and that's the gap the HRB sees itself trying to fill over coming years.

The plan itself sets out a number of goals: driving clinical and applied biomedical research, building up our understanding of population health and how health services are delivered, developing and managing high-quality health information systems and generating evidence that can support policy-making.



## [www.labtestsonline.ie](http://www.labtestsonline.ie)

There is a patient website providing up to date and reliable information about laboratory tests and how they are used. Labtests online was launched in St Vincent's Hospital Dublin in January 2009 by Mr. Mike Hallworth, President of the European Federation of Clinical Chemistry and Chair of Labtests Online UK. "Users of this site can

search for conditions and diseases and find how laboratory tests can help in diagnosing and managing them and can also search for tests directly. There are now 200 tests and 102 conditions listed and the whole site contains over 2,000 webpages.

This site is based on the very popular Lab Tests Online US and the Irish website has direct links to the Lab Tests Online UK site. The Irish site will contain information which has been customised for Ireland.

A group of pathologists and senior laboratory scientists have worked to ensure that all the information on this site is accurate and helpful said Ms Geraldine Collier, Chair of the Republic of Ireland Association for Clinical Biochemistry. The site will prove a great resource to the Irish patient in the understanding of blood tests and demystifying why they are done she commented".



## World Spondylitis Day

Folks we are trying to establish a World Spondylitis day to supplement the existing World Arthritis day that happens around October 12<sup>th</sup> each year and focuses on a different aspect of living with a rheumatic disease. This year's theme was "Let's Work together".

Our plan is to ask the World Health Organisation to ratify a World Spondylitis day at the beginning of May.

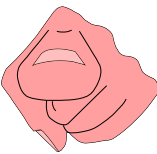
**Why are these two days going to be important in 2010?** The United Nations endorsed this decade (2000 to 2010) as "The bone and joint decade".

The Bone and Joint Decade was formally launched on 13 January 2000 at the World Health Organisation in Geneva, Switzerland. It is recognised and implemented in 56 countries.

The goal of the Bone and Joint Decade was to improve the health-related quality of life for people with musculoskeletal disorders throughout the world. These disorders are the most common causes of severe long-term pain and physical disability, affecting hundreds of millions of people across the world.

Each year a huge network of patient, professional and scientific organisations work together to draw national, regional and global attention to the burden of bone and joint disorders.

We have seen many changes in the world of AS over the last few years including a refocus of attention from patient, scientific and research organisations globally so we really should ensure that the Bone and Joint Decade goes out on a high of continued focus and does not end with a "whimper".



## ASAI Membership!

**The membership situation has further degraded this year with by far our lowest response on subscriptions in all the years I have been helping run ASAI.**



**We have been very lucky in recent years with the financial support & practical help we have received from the pharmaceutical companies which means our finances have not been under too much pressure.**

**However, the success or failure of this organisation is dependent on us having an active membership which gives support to people who need it, gives advice when possible, contributes to research when possible and voices our concerns to those who need to hear it (e.g. politicians, health care professionals, pharmaceutical companies etc.). So it's not all about the money!**

## THE EDGAR STENE ESSAY PRIZE 2009

organised by People against Arthritis/Rheumatism in Europe (PARE),  
the patient arm of the European League Against Rheumatism (EULAR)

### RARE BUT NO LESS SERIOUS –

*the challenge to cope with a rare rheumatic disease (Re-printed from the NASS Autumn 2009 newsletter)*

**“The rarity of a disease bears no relation whatsoever to its severity. A disease is what it is irrespective of its prevalence but rarity itself can be a key exacerbating factor.”**

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

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

Following a food poisoning episode when I was 24 I was told I had ulcerative colitis, a reasonable pronouncement given my symptoms and drastic weight loss. From that point of diagnosis – in this case by a young gastro-enterologist – I was boxed in. No matter what other symptoms I reported to my GP over the years there was only one response: a repetition of the diagnosis and an insistence on treating it. While crippling symptoms took hold and the “eye infections” and gastric problems worsened, with appalling fatigue and headaches, no new investigations were deemed necessary. Once an authoritative diagnosis is made, a patient who does not get better under the treatment regime risks being told, as I was, that the “failure to respond” is deliberate. I was subverting my own health.

Who does such a thing but the wicked or the mad? There’s not much a state healthcare system can do about wickedness but it can refer one to psychiatrists so various professionals were given the task of plumbing my depths to uncover the roots of my alleged desire to be ill. We didn’t get far.

After 14 years a new colleague at work persuaded me to push for a review with her former boss, the local professor of gastro-enterology. He established that the original diagnosis had been wrong due to his colleague’s inexperience at the time (the biopsies taken then did not support the diagnosis) and told me that I was also in a minority of patients who could not tolerate the carrier of the sulphasalazine I’d been prescribed. A load lifted from my shoulders! I had not invented nor imagined the horrible reactions. I was not mad!

Or at least not completely. He assured me that I did have some – unidentified – physical problem so he referred me for

“physiotherapy” which turned out to be more psychotherapy! A rheumatologist I saw privately told me he was puzzled too and I had better order a wheelchair because soon I would be unable to walk. I was a mother of three, in my thirties.

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

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

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

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

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

### Angela Graham

*We extend our Congratulations to Angela who has been named as a UK runner up for the Stene prize. This is now an annual competition. The object of the prize is to stimulate the interest of the many people with rheumatic disease in the work of EULAR and their national organisation.*

## Evidence of therapy forms in treating AS

by Prof. Dr. Edward Senn, specialist in physical therapy, Lucerne (Switzerland) and Munich (Germany) and Prof. Dr. Uwe Lange, Kerckhoff-Klinik Bad Nauheim, Germany published in ASIF News October 2008

The ASAS/EULAR recommendations for the management of ankylosing spondylitis are focussed on drug therapy because only these are regarded as “based on evidence” due to large randomised double-blinded studies. In some countries funding for patient education is refused by the health system using the argument that they are not “evidence-based”.

We asked Prof. Dr. Edward SENN, until 1996 the chair of Physical Medicine at the University of Munich, Germany, then medical head of Rehaklinik Bellikon, Switzerland, and Prof. Dr. Uwe LANGE, Department of Rheumatology, Clinical Immunology, Physical Medicine and Osteology, Kerckhoff- Klinik Bad in Nauheim, Germany, how “evident” the usefulness of patient education, of disease-specific advice on patient behaviour, and of physiotherapy options really is for patients with ankylosing spondylitis.

### Introduction

We agree that medical therapy should concentrate on therapeutic options the usefulness (efficacy and relative innocuousness) of which is *evident*. In this connection one has to distinguish between: therapeutic options the usefulness of which is logically obvious and thereby so *evident* that the evidence can almost not be increased by any studies (examples are disease specific patient education, disease-specific postural training, physiotherapy appropriate to the stage of the disease); therapeutic options the usefulness of which is *evident* by experience over many decades, the evidence of which can, however, be further increased by controlled studies (examples are radon therapy and other spa interventions); therapeutic options the usefulness of which can only be made *evident* by randomized studies (examples are all kinds of drug therapies).

This means that the need for randomized studies as proof of usefulness must not be generalized, as if evidence could generally only be based on randomized studies.

The following recommendations which should be carried out regularly, do not need statistical substantiations expressed in success rates by (in many cases impossible and ethically impermissible) double-blinded studies, because their usefulness is *evident* already without such studies.

1. When patients are first given the diagnosis of **ankylosing spondylitis (AS)**, extensive advice should be given on practicing good posture at all times. Patients with AS should be taught about dynamic, resting, and occupational postures. Later in the course of the disease, disease specific patient education should be repeated from time to time.

**Substantiation:** Only when they have such advice and education, can patients adapt their behavior, habits and their living and working environment in a way which will favorably influence the disease outcome.

2. Patients with AS should sleep on a level firm bed with a pillow just thick enough to allow a horizontal position for the face. They should make a habit of sleeping on their back. A saggy mattress or waterbed and a pillow which reaches under the shoulders should be avoided.

**Substantiation:** Hip joints and back can thus be prevented from becoming bent, and the tendency for curvature can be decreased. A small pillow may be necessary to prevent pain from overextension of the neck.

3. Good posture should also be maintained while sitting. Sitting for prolonged periods in low soft sofas or in chairs where the seat tilts backwards should be avoided.

**Substantiation:** While sitting on a soft surface which inclines backwards, the pelvis and sacrum tend to tilt backwards (humpback) leading to back pain when the patient tries to stand up again.

4. The work place should allow patients to alternate between sitting, standing and walking. Physical activity with prolonged strain on back and neck muscles and prolonged stooping and bending should be avoided.

**Substantiation:** Prolonged periods in an unfavourable posture tires the muscles primarily responsible for an upright posture and shortens their antagonists.

5. Sports (choose an activity you enjoy), endurance activities (strengthening fitness) in a deliberately upright posture should be performed regularly (4–5 times a week or even, better daily).

**Substantiation:** Each training session leads to a positive adaptation of structure: for muscles adaptation of their length, force, endurance, coordination and flexibility; for connective tissue structures (ligaments, capsules, tendons, cartilage) adaptation of their strength, loading capacity and freedom from pain.

6. Exercises to fight the humpback and the limitation of hip extension should be performed daily, for instance repeated lifting of the upper trunk and the angled elbows from a prone position.

**Substantiation:** Such exercises train the back muscles which straighten the back. The exercises also help mobilize the thoracic spine and simultaneously train the patient’s own perception of how to correct poor posture.

7. Respiratory capacity should be maintained by regular sports activities and by daily rotation training in the lying stretch position according to Schaarschuch-Haase, for instance on a stability ball or on a rolled up blanket, preferably in combination with deep breathing.

**Substantiation:** Rotation in the lying stretch position effects mechanically (as a reflex) a widening of the thorax and thereby of lung sections. Stretching, activation and training of muscles is the precondition for maintaining the mobility of the costovertebral and costosternal joints.

8. Annual rehabilitation stays should be made possible for patients with AS, with the full range of physical therapy (primarily physiotherapy). Also stimulating balneotherapy (moor baths, radon baths, radon gallery therapy, sulphur springs, thermal baths) are indicated if inflammation activity is not too high.

**Substantiation:** Pain due to inflammatory processes leads to muscle overloading, shortening of muscles and ligaments and limitation of the functions of spine and joints.

Balneotherapy acts to help with pain control, and to some extent is also anti-inflammatory. Intensive exercise therapy and other elements of a complex rehabilitation program make it easier for patients to keep their muscles strong and flexible.

9. Exercise and training activities which have to be performed autonomously by the patient, should be repeated regularly.

**Substantiation:** Regular motivation and corrections are essential.

10. Local painful inflammation processes (sacroiliac joints, entheses) should be eased by means of heat (however this is contraindicated in states of acute inflammation) or cold (repeated cold compresses, cold room).

**Substantiation:** Since cold diminishes the sensation of pain, intensive exercise is easier afterwards. Heat increases the blood circulation and thereby eases muscular tensions.

## Ankylosing Spondylitis International Federation (ASIF)

The 9th ASIF Council meeting took place between Twenty-seven delegates from AS patient organizations in 18 countries met in October 2009 for the 9th ASIF Council meeting in the radon spa Bad Hofgastein (Austria). The meeting was hosted by Österreichische Vereinigung Morbus Bechterew (ÖVMB) and supported by the Gasteiner Heilstollen, a therapy centre in a former mining gallery where patients with AS and other rheumatic diseases coming from many countries are treated by a natural combination of radon inhalation and hyperthermia. ASIF was founded in 1988 to intensify the international cooperation among their presently 28 member societies who represent about 54,000 patients with ankylosing spondylitis as their individual members. The Council meeting takes place every 2 years.

### Recent activities of ASIF Member Organisations

Delegates from Ireland, France, and Switzerland gave reports on interesting awareness campaigns.

In **Ireland** in 2008 and 2009, a country-wide campaign "Get Your Back Up" was launched in the presence of a well-known sportsman. Television and press journalists were invited to a national photo call. Key statistics about AS and case studies were distributed. A "touch-points" booklet was distributed to general practitioners and patients, with hints to additional information in the internet.

The AS society in **France** after their campaign "A Fond contre la Spondylarthrit" held another campaign to make the public aware of the "misunderstood invisible disease".

The **Swiss** AS society held a large bicycle tour through several regions in 2008. In connection with this, they travelled with a number of tents through four towns offering a back *parkour* (path with training stations), a diagnostic test, lectures, discussions, and advice.

### Information for emergency first-responders

ASIF president Dr. Jon Erlendsson, being a rheumatologist and a patient with AS himself, gave a lecture on why it is so important to know about spinal fractures. He mentioned the prevalence of spinal fractures in AS patients being 14% after a long disease duration.

## AS News

Under the headline "We are not like the others!" he pointed out that health personnel and also emergency first-responders often do not know what has to be taken into account in the case of an accident of a patient with AS, and that a spinal fracture is often not visible in initial X-rays.

He showed a DVD by which the Spondylitis Association of America explains the problem to emergency first-responders

The DVD was introduced by Laurie Savage (director of SAA) via a video presentation as she could not come to this Council meeting. She provided all delegates with a copy of the DVD which represents a good example for similar activities in other countries.

Jon Erlendsson also showed the Danish emergency card from which the ambulance service may detect how high the head of a patient has to be bedded during transportation to ensure that a fracture is not worsened by wrong bedding. Ernst Feldtkeller distributed an English version of an emergency leaflet designed by anesthetists for the German AS society.

With this leaflet, patients with AS can make first-responders and anesthetists aware of their special needs in bedding and narcosis

In three workshops on future ASIF activities, the following topics were amongst those discussed:

- Collaboration with PARE and the possibility of national AS societies to submit a "shopping list" to our members in the Standing Committee of PARE,
- How to make use of a World Spondylitis Day,
- Distribution of information on the management of patients with AS in an emergency case,
- Influencing hotels and restaurants to provide and announce equipment suitable for patients with AS (e.g. pillows, walk-in showers etc.),
- Exploring possibilities to improve ASIF funding that would allow upgrading of our methods of communication



This year saw the ASIF president since 2005, Dr. Jon Erlendsson of Denmark (pictured left), retire from his post.

His position has been taken on by Seoirse Smith from the Ankylosing Spondylitis Association of Ireland.

Also retiring from his position of Vice-President was Prof. Ernst Feldtkeller of Germany (pictured right), perhaps the longest serving member of the committee. He will however remain as the ASIF Scientific advisor. We are indebted to both of them and also another outgoing committee member Coby Otter of Belgium



The ASIF Committee is now (left to right) Hedley Hamilton (UK), Seoirse Smith (Ireland), Torben Jorgensen (Denmark), Jane Skerrett (UK), Cor Van Droogen (Netherlands) and Ken Mullholland (Canada)

## Dublin area Swimming Pools.

The following pools are all heated & suitable for arthritis patients.

- 1. Cheeverstown House, Templeogue**  
Swim Classes for people with joint problems.  
Monday nights: 7.15 p.m./ 8.00 p.m. / 8.45 p.m.  
No booking required - Anne McCabe, Ph: 4905988
- 2. Enable Ireland, Sandymount**  
Swim Therapy - 2:30 pm / 3:30 pm Monday & Tuesday  
Places on a first come first served basis.  
Contact 01 2695608 for details.
- 3. St. Vincents, Navan Road**  
General hours available.  
Contact 01 8384906 for times or collect a list at the pool
- 4. Central Remedial Clinic (C.R.C.), Clontarf**  
General hours available.  
Contact 01 8057445 or 01 8339458 for details.
- 5. Stewart's Hospital, Palmerstown**  
Adult Hours - Phone for times - Ph: 6269879

## North Dublin Hydrotherapy

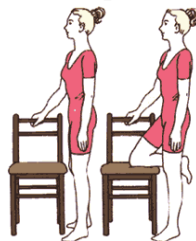
Hydrotherapy programme group sessions of 1 hour per week over 10 – 12 weeks.  
For details contact Lisa Staines at 8 Castle Road, Clontarf, Dublin 3 or telephone 01 8337809.

## Exercise Class for People with Ankylosing Spondylitis



Monday nights  
Cheeverstown House  
Templeogue  
Dublin 12

7 pm until 8 pm



For more Info contact:  
[info@ankylosing-spondylitis.ie](mailto:info@ankylosing-spondylitis.ie)

or

Hugh Cassidy 01 8316678  
Seoirse Smith 01 8376614

## Mater Hospital, Eccles Street.

The Physiotherapy Department, in the new building, have a class every Wednesday from 11.00 AM to 12.30 PM. There is no charge, but a letter from your doctor is required. Both pool (which is currently closed for repairs) and floor exercises are completed.

## A S News

### Cork Regional Hospital.

Details are available from Oonagh Hurley in the Physiotherapy Department. Phone: 021 – 546400

### Cork University Hospital.

Karen Buckley in the Physiotherapy Department has tried to get a group going in the area.  
Details on Phone: 021-4922406

### Cavan General Hospital.

Details from the Physiotherapy Department.  
Phone 049 - 61399

### Adare Physiotherapy Clinic.

The Adare Physiotherapy clinic is running Hydrotherapy Courses in the Dunraven Arms Hotel & Leisure Centre.  
Details from Gay Murphy on 061-396888 or e-mail on [adarephysio@esatclear.ie](mailto:adarephysio@esatclear.ie).

## Ennis Exercise Class for People with Ankylosing Spondylitis

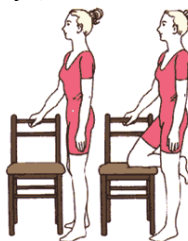
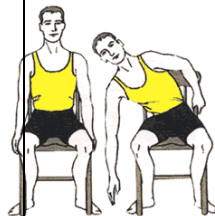
Mid-Western Regional Hospital, Ennis  
Physiotherapy Dept.

Mondays 7pm until 8 pm  
(except Bank/Public Holidays)

For more Info contact:  
[info@ankylosing-spondylitis.ie](mailto:info@ankylosing-spondylitis.ie)

or

Hugh Cassidy 01 8316678  
Seoirse Smith 01 8376614



## Exercise Class for Ankylosing Spondylitis

The good news is that we have increased the number of classes by 50%, see above. However, this is still a problem for us with now only three groups exercising.  
Two in Dublin, Cheeverstown house and the Mater Hospital and one in Ennis, County Clare.

Have you thought about getting together with other patients in your area? We will help find a physiotherapist to organize the group exercises. ASAI would be willing to help in whatever way we can to set-up and organize any local exercise groups.

