



SUMMER 2009 ISSUE

Editor's Letter

Welcome to our Summer 2009 edition of AS News. We hope that this edition finds you making the most of the recent warmer (if wet) weather and getting out there to exercise.

We have had a busy first half of 2009 particularly with;

- ✦ planning what currently appears to be another successful awareness campaign,
- ✦ attending an international conference on Immune Mediated Inflammatory Diseases (IMIDs),
- ✦ Talking to patients at the MATER Hospital's MASTER programme,
- ✦ Trying to set up an exercise group in the West of Ireland
- ✦ planning for attendance at the next ASIF meeting.

Later in this newsletter we will expand a little on each of these topics.

Recently we have seen an increase in international cooperation for our condition through organisations like Ankylosing Spondylitis International Federation (ASIF), European League Against Rheumatism (EULAR) and particularly its patients section People with Arthritis and Rheumatism in Europe (PARE) and Assessment of SpondyloArthritis international association (ASAS) amongst others.

There is also another group now taking a greater interest from the point of view of the pathology of our condition and its relationship to others, through the IMID Summit conference. We should take heart from the number of groups actively looking at living with AS and related conditions. It's all good news to someone with AS!

We hope you gain some knowledge, information and enjoyment from reading the newsletter. All that remains is for Hugh and I to wish you all a Healthy and active Summer.



Ireland scores low in patient empowering!

It has recently been revealed that Ireland ranked 20th out of 31 European countries in a comparison of 'patient empowerment'.

A Health Consumer Powerhouse survey measured empowerment across all European countries.

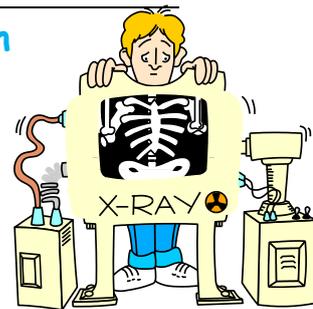
Empowerment was defined by four categories –

- patients' rights;
- information;
- health technology assessment;
- financial incentives.

Ireland scored relatively poorly in terms of patients' rights, with no healthcare law based on patients' rights; no right to choose among EU providers; no direct access to specialists; no no-fault malpractice insurance and a weak voluntary national screening programme.

It was recommended that Ireland produce a provider catalogue with quality ranking to enable patients' choice and open up to cross-border care.

Denmark ranked first in patient empowerment. The UK ranked first in the area of health technology assessment.



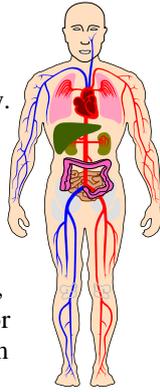
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What is an IMID?

“IMID” refers to a large group of long-term diseases that affects millions of people globally.

For example, Crohn’s disease, rheumatoid arthritis and ankylosing spondylitis are all IMIDs.

Normally the immune system helps your body fight and eliminate foreign molecules and cells, such as viruses and bacteria. But sometimes, for reasons that remain unclear, the immune system fails: instead of fighting the intruders, it also starts to attack cells that are a natural part of the body.



This “self-attack” gives rise to disease. It causes and creates a long-term (aka chronic) state of inflammation in the body.

In some people, the inflammation gives rise to one (or more) diseases with visible symptoms – e.g. psoriasis and psoriasis arthritis. In other cases the symptoms are less visible such as Crohn’s or early Ankylosing Spondylitis.

It has been described by one patient as “*when your body becomes your enemy*”.

The battle starts in the blood vessels. It is led by the cells that are part of the body’s immune system and normally involved in protecting the body. Among these cells are the macrophages, the B-cells and the T-cells. Like many other cells, these cells communicate via signaling molecules; the so-called cytokines. Cytokines are proteins that can be thought as “voices”; voices that tell cells what to do.

Normally, cytokines play a central role in mobilizing the immune cells attack on pathogens – such as virus and bacteria. The attack is executed for example by the macrophages, B-cells and T-cells in a collaborative manner.

Cytokines also play a central role in the previously mentioned “self-attack”. One cytokine in particular, has a central role in all of them; it is called TNF-alpha.

Inside the body of the people with Crohn’s disease, rheumatoid arthritis, psoriasis, psoriasis arthritis and ankylosing spondylitis, the level of TNF-alpha is elevated. As a consequence, a state of “hyper interaction” is going on between central cells in the immune system.

Nobody knows what originally causes this up-regulation of TNF-alpha. But we do know that the “silencing” of TNF-alpha offers one way to reduce - and sometimes entirely remove – the symptoms experienced by patients who, as a consequence of the elevated level of TNF-alpha – have developed one or more IMID. The silencing of TNF-alpha involves the introduction of tailor-made molecules; molecules that are produced outside the body, and represent the result of modern science and understanding of the human body.

Once inside the body, these tailored molecules find and bind TNF-alpha. Once bound, TNF-alpha’s ability to signal, for example facilitate the self-attack executed collectively by the “immune-quartet” (the macrophages, the B-cells, Helper T-cells and Killer T-cells) and others, is impaired.

Consequently, the premises of the self-attack are compromised. This typically leads to a reduction – or total relief – of the symptoms felt by the patient.

This is information gathered whilst attending an international summit on Immune Mediated Inflammatory Diseases. The positives for ASAI is that this is yet another international group aiming to increase collaboration across our diseases and countries. The topics for consideration at this summit were:

- Internet collaboration & e-Communication
- Best Disease Management for patients
- Mentor/Mentee programme
- It takes a patient to educate a patient
- Branding of IMID's

At the heart of these discussions (this is the first one we have attended) is how we can best run our respective disease & country specific organizations to achieve common goals for patients.

How rare is a rare disease?

A short extract from a piece in the Irish Times.

AS is regularly classified as a rare disease and there are all sorts of implications for us as people with the condition but also in how the condition is seen and treated. So what makes it rare? To be considered rare, a disease must have an incidence of no more than 5 in 10,000 people. Some of these diseases are quite well known such as cystic fibrosis, Duchene muscular dystrophy and Huntington's disease. Others are less well known like cystinosis, Pompe disease, sarcoidosis, retinitis pigmentosa and ankylosing spondylitis.

In Ireland, 6-8% of the population are/ will be at some time in their lives affected by a rare disease. Between 6,000 & 7,000 rare diseases have been identified worldwide and it’s estimated that a further 5 are described each week. Most cancers, including all affecting children, are rare diseases.

Because so little is known about many rare diseases, accurate diagnosis is often made late, often when a patient has already been treated for months or years for another more common disease.

Once an accurate diagnosis has been made, patients may have difficulty sourcing appropriate information and identifying qualified specialists.

Access to treatment can be a big hurdle as treatments for rare diseases are often expensive and relatively inaccessible because pharmaceutical companies do not consider it economically viable to trade in these medicines.

A figure of up to 44,000 possible patients is being used in relation to AS in Ireland.

This figure is an extrapolation of "likely" affected people.

These numbers are based on an approximate AS incidence rate of the total population.

Part of the problem is no-one can seem to agree to an actual incidence rate and one normally gets anything from 0.8 to 1.6% of total population remembering of course this would include mild, moderate, severe and, (crucially), undiagnosed patients. So using an approximate incidence rate of 1% of total population gives 4.4m /100 or 44,000.

AS on the internet

Occasionally we come across a website that has some interesting points of view on our condition and its management.

Over the last number of months we have come across the websites below.

(Please note that our inclusion of these sites in this newsletter is not an endorsement of their content).

- We are regularly asked about diet and AS. Whilst there is no empirical evidence that diet has significant impact there is certainly a lot of people who believe it has which makes the following an interesting site;

www.AnkylosingSpondylitisDiet.com

- Another topic that is discussed regularly with AS patients is "how to share information and experiences". This website is an on-line community dedicated to educating, encouraging and empowering people with an interest in managing AS.

www.EraseAs.com

As always please use some caution when reviewing information and before embarking on any new or changed approach to managing your condition talk to your medical team first.

Pain perception of people with chronic diseases

Research in patients suffering from a rheumatic condition

From an article by the Work Group Pain Survey: Jo Ampe, Bruno Mattelaer, and Miriam Uytendhouwen, Belgium. Translated from Dutch language arranged by Coby Otter, ASIF Executive Committee and published in ASIF News #9, April 2009

Main messages

Results

- 3 out of 4 patients are daily in pain despite satisfactory treatment
- Prominent presence of fatigue in nearly all patients
- Personal cost of pain medication presents a major problem for a third of patients

Expectations

Patients expect their doctor to pay more attention to their pain!

Preliminary remarks

Contacts with rheumatic patients and patient associations revealed the necessity for a better insight into pain perception of people with a rheumatic condition. After some preliminary contacts, the non profit organisation Rheumanet (Belgium) started drafting a questionnaire in 2007, which resulted in a pain survey on the internet and in several magazines. Rheumanet organised the survey in cooperation with its Dutch counterpart, Rheuma in Beweging, as well as the pharmaceutical company Pfizer. Other patient associations that contributed are: Vlaamse Reuma liga vzw, Chronische Inflammatoire Bindweefselziekten liga vzw, Vlaamse Vereniging voor Bechterew-patiënten vzw, Psoriasis liga Vlaanderen vzw, Vlaamse liga voor fibromyalgiepatiënten vzw, Reumatoïde Artritis liga vzw.

For the interpretation of the results, we need to take the following elements into consideration:

- The survey was distributed by the different patient organisations. We can assume that only motivated patients participated.
- The indicated use of medication, and especially that of the new anti-TNF medication, is higher than in reality: we presume that the questions were mostly answered by patients with a more severe pathology.
- More women responded: the percentage of participating men is significantly lower than could have been expected according to the patient population.
- Pain perception is highly subjective, which makes it hard to quantify. Statistical research however has shown that the average pain indicated by patients on a VAS scale amounts to 60%.
- In view of the relatively high number of participating fibromyalgic patients, clearly patients from that group were more actively encouraged to take part in the survey.

All this however does not alter the fact that the results of the survey are highly relevant to what those suffering from rheumatism think and feel. Further research is necessary.

The response

Apart from being permanently available via the internet, the survey was sent 3608 times by E-mail, and 2407 times in paper form enclosed with a magazine. A link to the internet version of the form could be found on 13 different websites.

A total 1624 patients participated in the survey (electronically or on paper).

The Patients Profile:

- 4 out of 10 patients suffer from rheumatoid arthritis (RA in fig. 1–4)
- 3 out of 10 from fibromyalgia (FIB in fig. 1–4)
- 2 out of 10 from ankylosing spondilitis (or AS, or Bechterew's disease)
- 1 out of 10 from psoriatic arthritis (PSA in fig. 1–4)
- 1 out of 10 suffers from chronic inflammatory connective tissue disease (CICT in fig. 1–4), arthrosis, osteoporosis or another clinical picture

The average patient's age lies between 45 and 54. The "youngest" patients suffer from fibromyalgia, the "oldest" from rheumatoid arthritis.

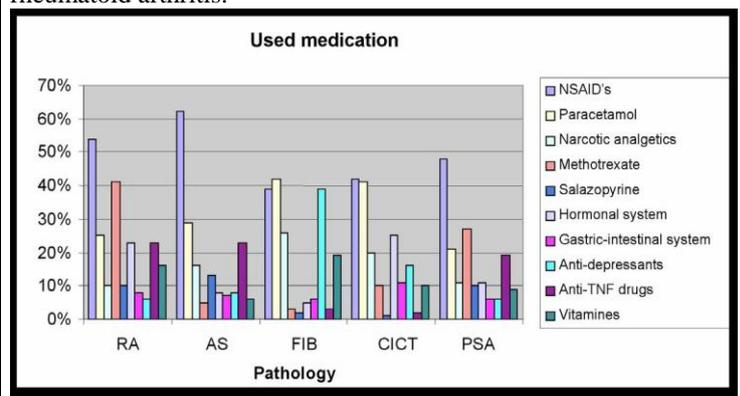


Fig. 1: Use of medication by patients

Patients with AS were diagnosed at an average age of 33.

For fibromyalgic patients the average age of diagnosis was

39. For those who suffer from fibromyalgia, an average of 6.6 years lies between the diagnosis and their current age, while patients with rheumatoid arthritis have known their diagnosis the longest: 14.3 years on average.

The time that lies between the first symptoms and the actual diagnosis is the shortest for rheumatoid arthritis, while the diagnosis of chronic inflammatory connective tissue disease takes the longest time.

Almost half of those suffering from AS and psoriatic arthritis are still professionally active, 2/3 of whom still work full-time. 3 out of 10 of the patients with rheumatoid arthritis, fibromyalgia or connective tissue diseases still work, and half of those occupy a full-time position.

The highest number of patients drawing to benefits through their illness (3 out of 10) we find among those with fibromyalgia and chronic inflammatory connective tissue disease; the highest number of pensioners (again 3 out of 10) among those with rheumatoid arthritis.

Doctor's visits

Almost all patients have seen several care givers over the past year. The GP takes up an important place: rheumatic patients see their family doctor 8 to 12 times a year; fibromyalgia patients see him more often than others suffering from a rheumatic condition.

On average, patients see a rheumatologist 3 or 4 times a year; those with rheumatoid arthritis and AS visit him more often than others.

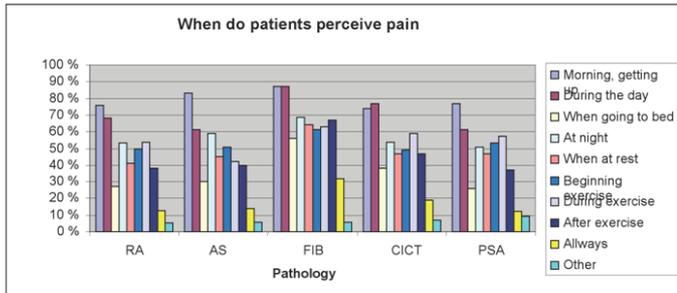


Fig. 2: Moments of Pain

A large number of patients sees a physical therapist once a week: patients with AS and fibromyalgia the most often, and those with rheumatoid arthritis the least often. The psychologist scores the highest with sufferers from fibromyalgia, the neurologist with patients with chronic inflammatory connective tissue disease or fibromyalgia.

Other care givers were, among others: the ophthalmologist, the cardiologist, the dermatologist, the gastroenterologist, the osteopath and the homeopath.

Another important aspect of the treatment is the level of satisfaction. 8 out of 10 patients with AS or rheumatoid arthritis are satisfied with the treatment they receive, followed by those suffering from psoriatic arthritis or connective tissue diseases. The lowest score is found among those with fibromyalgia: 6 out of 10.

However, even when patients are satisfied with their treatment, only 6 out of 10 think that the physician pays enough attention to the phenomenon "pain", half of the patients think it is up to the doctor to initiate a conversation about this.

Treatment

Almost all respondents use medication. NSAID's are used the most, followed by the painkiller paracetamol. Modern drugs like anti-TNF medication is used mostly by those suffering from rheumatoid arthritis, AS and psoriatic arthritis: almost 2 out of 10 patients. Methotrexate is mainly used by those with rheumatoid and psoriatic arthritis, corticosteroids by patients with rheumatoid arthritis and chronic inflammatory connective tissue diseases. Striking is the use of antidepressants by 4 out of 10 fibromyalgia sufferers.

Less than a quarter of all respondents uses a non-conventional or other non-medicinal treatment. Mostly these are patients with fibromyalgia, while people with rheumatoid arthritis choose the least for such treatment.

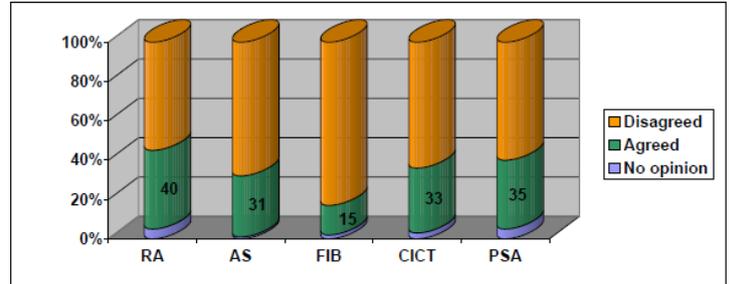


Fig. 3: % of Patient's agreement with "My pain is under control"

Pain perception

At least 3/4 of the patients experience pain on a daily basis. Practically all fibromyalgia sufferers experience significant pain almost all over their body and at every moment of the day. Those with rheumatoid arthritis report significantly more pain in their joints, while in patients with AS the pain is mostly located in the neck and spine. Psoriatic arthritis patients experience the most pain in their skin.

Over 2/3 of all patients described the pain as "gnawing". With fibromyalgia the pain was more often reported as "pain when touched", "electric shocks" and "pin pricks". Other problems that go hand in hand with pain are extreme fatigue, less sleep, a feeling of tension, moodiness, anger and depression. At least half of the respondents experience other problems than those that are purely attributed to their illness. Pain is clearly one of the most important symptoms in rheumatic patients. It is alarming that the majority of patients states that their pain is not really under control. In all patient groups, pain plays an important role in daily life. This is even more so for the fibromyalgia sufferers.

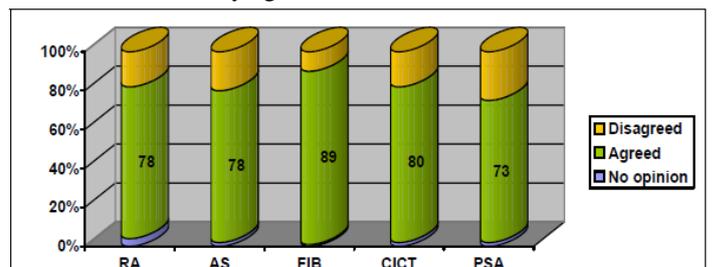


Fig.4: % of Patient's agreement with "My pain largely influences the way in which I live"

Living with pain

Patients with chronic inflammatory connective tissue diseases most often use help for personal care. Those with AS mostly ask for help from a third person for housekeeping.

Social activities have had to be given up by 2/3 of all respondents, although this does not mean that they just sit around at home.

Many patients indicated that they have learned to live with the pain, even if it has a significant impact on their working life.

Cost

Especially to patients with fibromyalgia and chronically inflamed connective tissue disease, the cost presents a major problem. For 2 out of 10 other patients this is also the case.

General conclusions

Pain is an important phenomenon in rheumatic diseases, and this is especially true for fibromyalgia, the “newest” disease for which the pain is clearly not under control in comparison to other conditions. Half of all patients expect the physician to initiate a conversation about pain. Also: more than half of the patients with pain find that this pain is not under control!

Painkillers only partially resolve the problem.

The most important additional symptom in rheumatic patients is fatigue, a phenomenon which is neither sufficiently known nor studied. The impact of rheumatism on daily and professional life should not be underestimated.

Last of all, 1/3 of the patients think that the costs for treatment are too high.

Our conclusion

To improve the quality of life of patients with a rheumatic disease, there is need for:

- More attention
- More communication
- More research

Patient organisations as well as the medical world should work at finding solutions for all of the above mentioned problems.

Famous people with AS:

I was reading a book recommended by one of our members (Anatomy of an illness) by Norman Cousins the late political journalist, author, professor and world peace advocate when I thought about famous people who may have had AS.

So far some famous people I have found with AS are;

- **Robert Alan Deal** – aka Mick Mars guitarist with Rock group the Motley Crue - diagnosed when he was 19 and which increasingly impacted his work.
- **Ian Woosnam** – Welsh professional golfer who has won a number of majors, part of the 8 Ryder cup teams and captained it in 2006.
- **Chris Small** – Scottish professional snooker player who had to retire in 2005 due to his AS
- **Mike Atherton** – former English cricket captain, journalist and broadcaster
- **Lee Hurst** – English stand-up comedian and TV personality
- **Rico Brogna** – former US Major League Baseball player and AS advocate/ambassador for the US Spondylitis Association

Allowing for the fact that Norman Cousins AS diagnosis has had some doubt cast on it (it may have been reactive arthritis) we still have half a dozen well known people with AS. I am sure there are more. Do you know of any?

“Get Your Back Up” -

ASAI's National Awareness Campaign

There is a feeling that there is a low awareness of AS – not just in the major demographic (young males) but also amongst medical professionals who appear to be slow to diagnose or refer to Consultant Rheumatologists.

Also, there is a feeling that the options for managing the condition are not well known.

In 2007 ASAI were looking at the possibilities for addressing these issues. With some help and advice it was decided an awareness campaign was the best solution. However, the expertise to get the coverage necessary for a successful campaign would be hard to get and expensive. Through a contact in Wyeth Pharmaceuticals we got an introduction to a Public Relations company operating in Dublin.

Our objectives were:

- To increase general awareness and education around key symptoms and treatment of AS,
- To create a “call to action” for people experiencing these symptoms to seek diagnosis at primary care level from their GP or physiotherapist, and then referral to a Rheumatologist,
- To mobilise patients who have already been diagnosed to visit their Rheumatologist to review their current treatment,
- Utilise core media to ignite the debate around AS,
- Build awareness of the treatment landscape.

The strategy that we decided upon was:

- To create an Ankylosing Spondylitis Awareness Week. Entitled “Get Your Back Up,” the campaign would work to provide a platform on which to talk about AS in mainstream consumer media.
- The campaign would be driven by celebrity and case study-led media relations, underpinned by the re-launch of the ASAI website and a celebrity-fronted radio infomercial.
- The campaign would run through the Ankylosing Spondylitis Association of Ireland (ASAI), endorsed by the Irish Society of Rheumatology (ISR) and the Irish Society of Chartered Physiotherapists (ISCP) with financial support through an educational grant from Wyeth Pharmaceuticals.

The key tactics to deliver the strategy were:

- **Celebrity Endorsement:** Leverage media opportunities by engaging a high-profile Irish sporting figure to front the campaign, in order to appeal to the key male demographic,
- **National Photo-call:** “Get Your Back Up” week was launched with a national photo-call with the sporting celebrity. All national newspapers would be invited, as well as TV and radio outlets,
- The sporting celebrity would also be the “voice” of the infomercial,
- We proposed developing and launching “Touchpoints” booklet to the public via the re-launched website and a nationwide GP mail-out with an accompanying campaign explanation leaflet coinciding with the launch of the consumer campaign/photo-call.

Celebrity Endorsement '08

John HAYES (right), the Ireland rugby international was selected as the celebrity spokesperson. As a professional sportsman in a very physical sport like rugby his awareness of injury and seeking proper and prompt diagnosis are important to him. Allied to this is the fact that lots of men diagnosed with AS seem to initially think their problems are related to sporting or work injuries to their lower back. Obviously, he is newsworthy in his own right.



Campaign Launch

The campaign was launched on June 25th 2008 with a photo-call in St Stephen's Green. This coincided with a re-launch of the ASAI website which could be accessed using the campaign strap-line "Get Your Back Up" www.getyourbackup.ie.

Impact

The campaign was a success striking a cord with the general public (shown by the extra email & telephone contacts) and the GP's (market research confirmed GP's noted the campaign).

We cannot underestimate the importance of gaining the support of organisations like the Irish Society of Rheumatology, Arthritis Ireland, the Irish Society of Chartered Physiotherapists and the Irish Rheumatology Health Professionals Society.

Equally important was the support, practical and financial, from Wyeth Pharmaceuticals.

Without them we would not have made the contacts necessary to engage with the wider print media, make a radio infomercial, get interviews on radio with Matt Cooper or on TV with Mark Cagney and Sinead Desmond.

Where to from here?

Given the obvious success of the '08 campaign we decided to use the same formula for '09.

The same objectives, strategy and similar tactics to deliver that strategy were employed. With Touchpoints and the Clinicians guide already been developed we just reused them.

We added some analysis tools to the website that would allow us check the site traffic.

The celebrity endorsement would be from by a different sporting hero in a similar manner to the '08 campaign.

Celebrity Endorsement '09

Joe Canning (right), the Galway inter-county hurler was selected. As a young man playing one of our national field games at the highest level his awareness of injury and seeking proper and prompt diagnosis are important to him. Again this is allied to the fact that lots of men with AS seem to initially think their problems are related to sporting or work injuries to their lower



back. Lastly, given the point in the championship season we were at and his talent he is newsworthy in his own right.

Exercises for the car - A one minute workout!

A few simple exercises for when you are driving.

Sitting half way forwards in your car seat:-

1. Pelvic tilts; encouraging flexion and extension of your lower back area so that the small of your back moves towards and then away from the back of the car seat. Repeat 5 times.
2. Twisting in your seat to touch your left hand above your right shoulder onto the car seat; look around too to encourage neck rotation. Repeat 3 times.
3. Twisting in your seat to touch your right hand above your left shoulder onto the car seat; look around too to encourage neck rotation. Repeat 3 times.
4. Bend sideways over the right edge of car seat reaching as far as you can and coming back up to starting position again. Repeat 3 times.
5. Bend sideways over the left edge of car seat reaching as far as you can and coming back up to starting position again. Repeat 3 times.

Sitting back into the car seat:-

6. Reach hands up over your shoulders to hold onto the headrest and stretch the top of your back and your neck into the seat and headrest where possible trying to increase the area of contact with the seat/headrest so that you are getting retraction or straightening of your back and neck. Repeat 3 times.
7. Retract your shoulders back into the car seat. Repeat 3 times.
8. Pull your chin in trying to straighten the top of your back/neck and try to make the contact with the headrest without tipping your head back. Repeat 3 times.

When travelling by car, try not to be travelling for long periods of time as this makes you more likely to stiffen up. Try to break up journeys into shorter by components and get out of the car and move around. The more energetic or vigorous this movement the more beneficial it will be to you.

Alternatively, try a little work out in the car while you are travelling. Some of the above exercises are suitable for this. The above exercises can be done in a very short period of time, in as little as one minute when you are familiar with the movements. You could do this when you get into the car; when you stop the car before you get out. You may find other times you can do it all or some of it; in a traffic jam; waiting to exit a car-park; at traffic lights; waiting in the car for someone to join you or waiting with a sleeping baby. When you do these exercises you are trying to maintain the range of movement you have and if possible trying to increase the range you have. If you improve your range of movement try then to use that extra range in a functional activity like putting on your seat belt or looking around to reverse or check for traffic before turning.

An Englishman in Gastein's "Heilstollen"

by Matt Homfray, London, member of the National ankylosing spondylitis Society (NASS) and published in the ASIF Newsletter in April 2009

I am by nature rather sceptical of treatments that fall into the complementary medicine category, and usually prefer to stick to peer-reviewed evidence-based medicine. This is the way that most patients are encouraged to think by their doctors, whose opinions are quite rightly formed according to clinical trial data and best-practice guidelines.

Last April I stumbled upon an article by Dr Albrecht Falkenbach, previously chief physician at the Gasteiner Heilstollen (literally 'healing gallery of Gastein') in an Alpine spa resort near Salzburg, Austria. I was immediately intrigued, as the article described how around 2800 patients with AS return to this former mining gallery annually or biannually to undergo radon therapy to relieve their rheumatic pain.

The Radhaus mountain in Gastein's valley is not the only place in the world where the noble gas radon can be found, but the lack of toxic impurities in the gas make it quite unique and safe to breathe. The Gasteiner Heilstollen's own literature claims that it 'activates the body's own cell messengers, which promote healing and reduce inflammation, with long lasting effects'. Their brochure also claims that AS patients can expect reduced pain for around 9 months post treatment, with reduced need for medication, and is littered with positive testimonials from loyal cave-dwellers.

Dr Falkenbach's article featured a study he and some fellow rheumatologists had carried out comparing 2 cohorts of patients with AS. One cohort received radon therapy (plus adjunctive therapy such as massage and physiotherapy) in the Gasteiner Heilstollen, and the other cohort attended a rehabilitation spa programme in Holland featuring similar adjunctive therapy, but without the radon. Efficacy was measured by various standardized flexibility parameters for both cohorts, and in the Gasteiner Heilstollen cohort only, also by blood testing for various inflammatory markers. I was not entirely convinced by this research but I decided to try radon therapy for myself.

The Gasteiner Heilstollen recommend that AS patients do a 2 or 3 weeks course of treatment to obtain the maximum pain relieving effect, which means around 10 sessions in the caves (a rest day must be taken after 2 consecutive days of treatment). I only had a week to spare, so could only fit in 4 sessions.

On arrival at the Heilstollen, every new patient has a consultation which includes taking a medical history and brief physical examination, with one of their resident doctors.

Blood pressure is measured, as patients with hypertension are not allowed into the caves. Patients with claustrophobia are also advised not to enter the caves. The doctor explains the procedure fully, and helps to build a program around the cave sessions,

featuring individual or group physiotherapy, massage and so on. Patients are then issued with a bath robe and make their way to the little train that transports them to the caves. The train does a circuit of the cave system, stopping at various stations that vary in temperature and humidity where the patients disembark. Each station has male and female caves, where patients lie naked on beds in silence for three quarters of an hour, until the train returns to collect them.

Anyone who finds saunas unpleasant may struggle with the length of time spent in each cave. It is impossible to leave a cave until the train returns, unless you press the panic button and raise the alarm! The climate ranges from 37°C to 41.5°C and from 75% to 100% humidity. You sweat profusely. After the cave sessions, patients are encouraged to snooze in the quiet rooms for an hour before starting physiotherapy or massage sessions. When I flew back to London at the end of the week, I felt more supple than I had in months, if not years. I have no doubt that this was largely due to the excellent physiotherapy that I received from professionals who specialized in AS, such is the volume of AS patients that go there. I was also aware from my research that the supposed pain relief after radon therapy does not kick in for several weeks, so I was not expecting immediate results. However, the fellow AS patients I had met at the Heilstollen (most of whom were recurrent visitors rather than first timers like myself) were so positive about the radon therapy that I couldn't help believing that I would shortly be pain free. I wondered whether this positive attitude could somehow contribute to a placebo effect, but decided to remain completely open minded. After 3 weeks back at home, the positive effects of the physiotherapy had begun to wear off but a week or so later I started to realize that the stiffness was slowly improving.

Since then, I have been able to reduce my medication from the level it was pre-radon therapy. Could this be chance?

Yes it could. But I had tried to do this several times before going to Austria and failed. I don't know if radon therapy really does work, but I will be going back to the Gasteiner Heilstollen next year for further sessions without doubt.

Another English patient with AS (right) who was almost unable to walk before he read the report on Gastein's radon gallery by Ernst Feldtkeller (left) published in the NASS newsletter of Spring 1983. After several stays in Bad Gastein he was able to propose a common hiking tour to the main crest of the Hohe Tauern in Summer 1989.





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

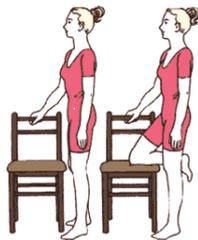
Adult Hours - Phone for times - Ph: 6269879

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

or

Hugh Cassidy 01 8316678
Seirse Smith 01 8376614

New Exercise Class for People with AS in the West of Ireland

A new physiotherapist led exercise class is starting on September 7th in the Mid-Western Regional Hospital, Ennis, Co. Clare Physiotherapy Department.

The intention is to run the class every Monday (except bank holidays) between 7 and 8 pm.

For more Info contact: info@ankylosing-spondylitis.ie
Or phone Hugh Cassidy on 01 8316678 or Seirse Smith on 01 8376614

Another Exercise approach for Ankylosing Spondylitis

Arising from our radio ads in the "Get you back up" campaign we have been contacted by Steph Grey at Live and Breathe Pilates.



Steph tells us that she already has clients with AS that find her classes beneficial and we have heard from physiotherapists that Pilates are a good exercise option. Contact details are on

www.liveandbreathepilates.com.

(When undertaking any exercise remember to let the class leader know about your AS and any limitations it imposes on you.)

Need A Break?



Again arising from our radio ads in the "Get you back up" campaign we have been contacted by **Topflight** in relation to their "wellness holidays" specifically they mentioned their trips to Gastein in Austria. Yes the same location where the Ankylosing Spondylitis

International Federation pays its second visit and the subject of the earlier article in this newsletter.

The climate of the Healing Galleries in the area of the Hohen Tauern and the Gasteiner Valley, in the Austrian Alps is unique.

The extraordinarily potent effect it has on varied symptoms of disease is put down to a combination of 3 healing factors:

- The Radon content from up to 4.5 NanoCurie per litre of Gallery air (**the same quantity in all stations**)
- The air temperature from 37.5°C to 41.5°C according to station
- The relative air humidity from 70 to 95% according to station

Interesting discoveries were made that led to scientific research into the gallery system after WWII. In a particular part of the mountain naturally high stone temperatures of 44° degrees Celsius and high air humidity was found. Apart from this there were many miners who claimed to have gained relief from their rheumatic complaints while they were working inside the mountain. The University of Innsbruck carried out extensive scientific research from 1946. This found that apart from the high degree of warmth and air humidity the content of Radon in the gallery air was also an effective factor.

Then in 1952 the Healing Gallery Company Limited was founded and in 1954 the first Gallery Cure House was built. This was then extended from 1970 to 1971 until they were able to open the Cure House in its present state in 1989.



Topflight