



AUTUMN 2011 ISSUE

**Editor's Letter**

Welcome to our Autumn 2011 edition of AS News.

We hope that this edition finds you all safe, healthy & active.

This year we have tried to develop both existing and new relationships with organisations that have a mutual interest in supporting chronic, often unseen, conditions like AS. Some of the connections we have made and are making may not initially appear obvious. However, in the current social and economic environment we need to ensure our voice is heard in whatever way we can and that we get support and assistance from as many quarters as possible.

We have developed or become involved in a number of campaigns that all help with these aims over the last few months;

- Can you feel my pain?
- Fit for work
- Watch your back

More details of which are covered later in this edition.

By direct contrast to those highlights mentioned above, we once again have had a disappointing year when it comes to membership renewals and, perhaps more importantly, involvement of members in running the organisation.

All of the work is now falling to a reducing number of individuals and our efforts are diluted by too few people trying to do too many things, for example the delay in producing this newsletter.

I must acknowledge the help that we now receive from other organisations. Whether it is ideas, financial support or just someone to chat to about what we are doing the help of **Arthritis Ireland, Abbott Laboratories, Pfizer** and **Merck Sharpe & Dohme** is critical in ASAI embarking on and delivering all of our work now.

Thank to all for your help.

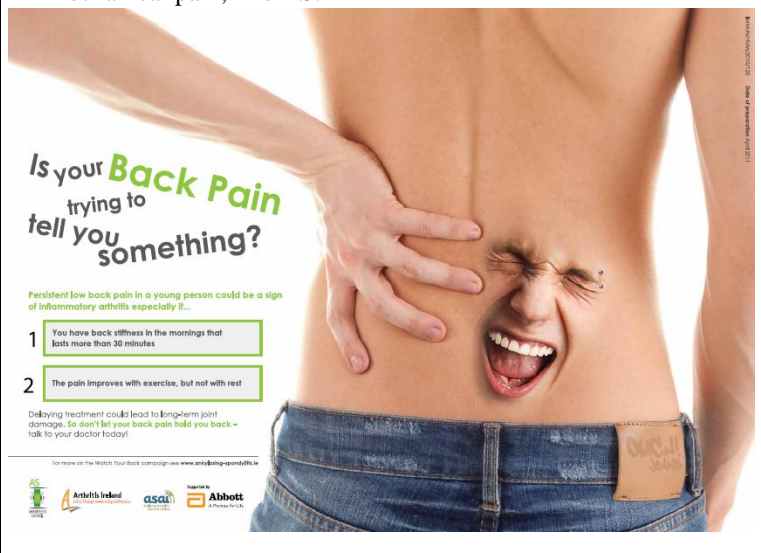
*Seserise*

**Ankylosing Spondylitis Awareness**

Last year with the help of the ASAC and Abbott Pharmaceuticals, and the support of Arthritis Ireland, we launched a campaign for GP's called "*Back in Action*".

This year, helped and supported by the same people, we have followed up with the "*Watch your back*" campaign.

This is a poster campaign targeting the waiting room in your local GP's surgery or clinic that focuses on the individual with persistent low-back pain and the need to pay attention to such pain as it might be something more significant than mechanical pain, like AS.



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## Risk factors for back pain

Taken from an article in Arthritis Ireland's summer 2011 lifestyle magazine "arthritis life".

Musculoskeletal pain, obesity and smoking are all linked to an increased risk of work disability among people with lower back disorders, according to new research. People with pain in their neck, shoulder or back were twice as likely to suffer disability than those without says the findings published in the Journal of Occupational and Environmental Medicine. Painkillers, manual labour and chronic disease were also associated with an increased risk of work disability. Musculoskeletal disorders (MSDs) are the most commonly reported cause of work-related ill health in Ireland so in response to these issues, Arthritis Ireland are heavily involved in 'Fit for Work', a Pan-European campaign focused on raising awareness in the workplace so that small adjustments can be made to reduce the impact of MSDs on employee attendance, making significant savings to the business and state. The study suggests that health interventions early in work-life may be of importance both to improve workability and prolong working career, particularly in occupations including physical loading.

## Fit For Work

Taken from an article in Arthritis Ireland's summer 2011 lifestyle magazine "arthritis life".

### Did you know...?

It is estimated that the annual cost of lost productive time due to RA and other forms of arthritis is €1.6 billion per annum.

*With musculoskeletal disorders (MSDs) on the rise, and accounting for up to seven million lost working days at a cost of €750m to the Irish Exchequer, it is little wonder that this is an area of increasing importance in our ailing economy.*

The 'Keeping Ireland Fit for Work' forum which took place in April in Dublin Castle, is the latest in a collaboration between Arthritis Ireland and Abbott Ireland to investigate the impact of MSDs on the Irish workforce and the potential interventions that could be used to ensure better outcomes for workers with MSDs.

The good news is that by making a few small adjustments to the workplace, Irish companies can reduce the impact of musculoskeletal disorders (MSDs) on employee attendance – which will make

significant savings for their business and the State, not to mention making for a happier workforce!. These findings were stated at the recent 'Keeping Ireland Fit for Work' at the forum.

### What kind of changes do Irish companies need to make?

Keynote speaker at the forum Dame Carol Black, National Director for Health and Work in the UK, outlined the recent approach in the UK to reducing work absenteeism.

She told the forum that employers need to be flexible and Ireland has to change its perceptions about working with an MSD, revealing that in the UK 25% of those currently employed have a health condition or disability but only 2.4% are actually on sick leave.

Dame Carol pointed out that those affected by MSDs and other chronic conditions want to work and can continue to do certain things while leaving aside those they are unable for. She said the 'sick note' culture is unhelpful and excludes people from the workforce when they become incapacitated, offering no rehabilitation or opportunity to contribute. Dame Carol is an advocate of the 'fit note' and has been instrumental in its introduction in the UK

### What is a fit note?

Last year, in the UK the sick note was replaced by the fit note. Evidence shows that work is generally good for your health and that often going back to work can actually aid a person's recovery. On the other hand, staying off work can lead to long-term absence and job loss with the risk of isolation, loss of confidence, mental health issues, de-skilling and social exclusion. The new fit note can help. Doctors are able to advise people who are on sick leave for over seven days whether, with extra support from their employer, they could return to work earlier. Research has found that since the introduction of a 'fit note' in the UK last year, half of GPs had sent more people back to work, while three quarters felt it helped their patients make a phased return to work.

### What did the panel say?

The 'Keeping Ireland Fit for Work' forum was attended by representatives from patient associations, employer groups as well as policy makers and healthcare professionals, all of whom spoke of the benefits and

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### Background to Fit for Work Ireland

The Fit for Work campaign is based on a groundbreaking pan European study, conducted across 25 countries, which examined the impact of musculoskeletal disorders (MSDs) on an individual's ability to work, the cost to the economy and society as a whole.

The research looked in great detail at the adequacy of treatment and support provided to workers, their experiences at work, the effect of their condition on family and colleagues and the human and financial costs of such musculoskeletal disorders. The research in Ireland produced significant findings, all of which have implications for Irish policy makers, employers and health professionals.

### 3

the implications of the on the implementation of a 'Fit for Work' strategy in Ireland.

Keynote speaker Dr Steve Boorman, Director of Health and Safety at the UK's Royal Mail, informed the forum how the Royal Mail, through application of the 'Fit for Work' principles, successfully reduced an overall absenteeism rate from 9-10% in 2002 to around 4% today, resulting in savings of €227 million from 2004-2007. His decision to implement 'Fit for Work' practices was based on the premise that it made financial sense.

Tina Corcoran, HR Absence Management Coordinator, Dublin Airport Authority (DAA), explained how the DAA's efforts in the last couple of years have reduced its absenteeism rate from 6.7% to 4.5% this year showing that targeted intervention reaps dividends for the employer and benefits of well-being for the employee.

Richard Wynne, of the Work Research Centre Ireland told the forum that Ireland, like the rest of Europe, has an ageing workforce that it is likely will have to work to later in life in the future. Mr Wynne said providing support to allow workers experiencing ill health continue their career is absolutely vital as people are more likely to develop a chronic condition as they age. Mr Wynne noted the commitment to providing occupational therapy services in Ireland is "very weak" compared to other countries, with 2,000 occupational therapists in Finland compared to fewer than 200 in Ireland, despite both countries having similar labour markets.

Identifying solutions, he highlighted the benefits of introducing disability management programmes, and return to work policies with an emphasis on consistency, support and clear recognition of the line of responsibility.

#### Fast facts from Fit for Work Report

- MSDs are the most commonly reported cause of work related ill health in Ireland.
- The direct cost of MSDs at work in Ireland is estimated to be at least €750 million.
- Ireland spends more per capita (40.9%) on sickness and healthcare benefits than 24 other countries featured in a Europe wide study.
- 860,000 people in Ireland have arthritis, with 30% of all GP visits each year being attributable to arthritis or other musculoskeletal conditions.

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### ASAI collaboration with Arthritis Ireland paying dividends!

The Ankylosing Spondylitis Association of Ireland has joined forces with Arthritis Ireland to assist in the implementation of an important service that will ultimately help people with AS.

Arthritis Ireland is an active member of the latest HSE Rheumatology Clinical lead program headed up by Prof. Oliver FitzGerald of St. Vincent's University Hospital.

One of the exciting initiatives emerging from the work is the creation of 24 new physiotherapist posts specially trained in the treatment of Musculoskeletal Disorders (MSD's).

These posts will initially be deployed to help clear outpatient waiting lists and will hopefully help spot any new AS patients waiting to see a rheumatologist or orthopaedic surgeon.

Over time these posts will form an important first line intervention in the area of all MSD's such as back pain and arthritis.

ASAI is an active participant in Arthritis Ireland's Fit for Work Program that aims to address the issue of work absenteeism due to MSD's.

With MSD's being the biggest contributor to workplace absenteeism, accounting for 7m lost working days per year, this is an important program.

The Fit for Work Program will educate employers, employees, union representatives and health professionals in this area by ensuring speedy and appropriate intervention when a worker goes out sick due to an MSD.



## Arthritis Ireland

Little Things make a Big Difference



## BILL OF RIGHTS TO GIVE VOICE TO 400,000 IRISH PEOPLE LIVING WITH CHRONIC PAIN

In April of this year Chronic Pain Ireland, with the support of Pfizer Healthcare Ireland announced its support for Can You Feel My Pain? - This is a new Europe-wide campaign which aims to raise awareness of the burden of chronic pain.

The far-reaching initiative seeks to give a voice to 13 per cent of the Irish population (400,000) who are living with the debilitating condition.

The campaign urges Governments and health systems across the continent to recognise the problem of unresolved pain and for it to be accepted as a genuine health priority.

A core outcome of the Europe-wide campaign is to drive change in health services through the development of a chronic pain **Bill of Rights**, shaped by those affected by chronic pain. The public are encouraged to show their support for change by signing the online Bill of Rights hosted on [www.chronicpain.ie](http://www.chronicpain.ie)

Chronic Pain Ireland was aiming to obtain 5,000 signatures of support for the campaign which will be presented to the Dail alongside a recent hard hitting report (Pain Proposal) into the impact of chronic pain in Ireland. Together, it is hoped that this will promote change to ensure that the right patient receives the right treatment at the right time.

Despite the burden that chronic pain places on individuals and their families, healthcare systems, employers and the economy, it is not yet formally recognized as a disease in its own right or as a medical specialty in Europe.

The awareness programme is also supported by leading patient advocacy groups including Arthritis Ireland, Ankylosing Spondylitis Association of Ireland and MS Ireland. Patient support organisations across Europe have also joined up to fight for this recognition.

Developed by European patient organisations including Chronic Pain Ireland, the Bill of Rights outlines five key rights that campaigners believe will improve the lives of those affected by chronic pain. These include:

- Right to be Understood;
- Right of Access to Information;
- Right to Professional Support;
- Right to Early Intervention & Optimal Pain Management;
- Right of Pain Relief as a Fundamental Human Right

### **Ms Gina Plunkett, Chairperson of Chronic Pain Ireland**

**said:** "Chronic pain affects many people and the lack of awareness of Chronic Pain is unacceptable leading to serious issues and problems for individuals, for carers and for society as a whole. Our hope is that giving a new, shared voice to people affected by chronic pain will give us a fresh impetus for action.

"We are appealing to individuals, carers and other advocacy groups to speak out for the rights and needs of people with chronic pain, by pledging their support for the Bill of Rights today [www.chronicpain.ie](http://www.chronicpain.ie)"

The impact of chronic pain is widespread. According to the Irish Pain Proposal report, more than fifty percent of chronic

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pain sufferers felt their chronic pain impacted directly on their employment status and 31% worry about losing their jobs. Chronic pain is also associated with a loss of mobility and depression. The report argues that treating chronic pain with the same seriousness afforded to other major conditions or disease, can deliver both cost savings and better outcomes for patients through more efficient pain management.

**Eimear Kearney**, who suffers from chronic pain for almost a decade pointed out that: "Living with chronic pain can be isolating and frustrating and sometimes I feel like no one understands it. The "Can You Feel My Pain?" campaign will give me an opportunity to reach out to other people with chronic pain across Ireland. By sharing our stories and encouraging the public to sign up to support the Bill of Rights we can fight for change for people in our situation."

To show your support for people living in chronic pain and to sign up for change, please visit our website [www.chronicpain.ie](http://www.chronicpain.ie)

### About the "Can You Feel My Pain?" Campaign

In partnership with Pfizer, patient advocacy groups and citizen organisations across Europe have joined forces to develop the "Can You Feel My Pain?" campaign. The campaign will harness the huge opportunity presented by the Internet and social networking sites to reach a wide audience, raising awareness and generating support for real change in the field of chronic pain.

The Bill of Rights draws upon content from the European Charter of Patients' Rights and Chronic Pain Ireland's Charter of Rights. The Bill of Rights is hosted online allowing people to log on, add their name and encourage other people to support the rights.

### Who is involved?

Chronic Pain Ireland [www.chronicpain.ie](http://www.chronicpain.ie)  
Arthritis Ireland [www.arthritisireland.ie](http://www.arthritisireland.ie)  
MS Ireland [www.ms-society.ie](http://www.ms-society.ie)  
Ankylosing Spondylitis Association of Ireland  
[www.ankylosing-spondylitis.ie](http://www.ankylosing-spondylitis.ie)

### About Chronic Pain

- Chronic pain can be experienced in a number of locations in the body; however, the back is the most common. Other common sites include neck, joints and headaches.
- Certain conditions are more commonly associated with chronic pain, such as arthritis, cancer, diabetes and multiple sclerosis (MS) however it can develop without any specific cause.

### About the Pain Proposal Report:

- In July 2010, the Pain Proposal Steering Committee led a Pain Proposal Executive Committee meeting of 50 experts from 15 countries in Europe, including Ireland, in order to generate debate around what steps should be taken to improve chronic pain management.
- The Pain Proposal initiative seeks to drive recognition of the personal, social and economic impact of chronic pain on the European population. It aims to highlight issues, inefficiencies and challenges in current chronic pain management and offer recommendations to support better delivery of care, affording greater value for the same resources currently available.
- The initiative has been spearheaded by the Pain Proposal Steering Committee, a group of high profile European experts in the fields of chronic pain, policy and economics, who held an initial meeting in January 2010.
- The insights from this meeting fed into a Pain Proposal European Consensus Report – written by medical writers in consultation with the Pain Proposal Steering Committee and Pfizer.

## Time to Diagnosis of AS in an Irish group of patients.

We do not have the details of this study to publish but we have been told that the Department of Rheumatology in St. Vincent's University Hospital have completed a study on this important aspect of managing AS.

Delay in diagnosis is a significant factor in AS management with the time delay at one time being up to 15 years. More recently that diagnosis delay had reduced to be in the range of 8 to 11 years.

The outcome of this study in Ireland is now suggesting that the average time from symptom onset to diagnosis was 7.25 years.

Still a lengthy time for diagnosis (given it is an average) but also an improvement on the previous averages.

## New EULAR President

**EULAR is the European League Against Rheumatism.**

Maxime Dougados is Chief of the Department of Rheumatology at the Cochin Hospital in Paris as well as a teacher of rheumatology at the Rene Descartes University, Medicine Faculty Paris V. He is the new President of EULAR. The important point for the AS community at large is that he is also Vice President of ASAS (Assessment of Ankylosing Spondylitis).

He has stated that his priority is to try to maintain the excellent quality of the major EULAR initiatives in the fields of research, education and lobbying. He has also stated that he will try to improve the communication between the EULAR committees and each national EULAR member society.

He has also stated that one of the main objectives of EULAR is to improve the recognition of the burden of Musculoskeletal diseases by the different national health care systems and in particular by the politicians working at European community level. In doing so the aim is to improve the daily lives of rheumatic patients and also convince politicians to financially support basic, translational and clinical research in the field of rheumatology.

Maxime Dougados has stated that it is amazing to see the recent importance of patients in the different ongoing EULAR initiatives. This has been facilitated by the fact that EULAR is not only a scientific society for rheumatologists but also an umbrella institution including doctors, patients and health professionals. Currently patients are invited to participate in studies/initiatives proposed by doctors and are also a part of the team in charge of such studies/initiatives.

## Spondylitis Terminology

The medical terms that describe symptoms, medications and more when reading or talking about ankylosing spondylitis and related diseases can be confusing. The following are some of the terms frequently used in relation to AS;

### Axial Spondyloarthritis

Axial spondyloarthritis is a more recently used term for inflammatory arthritis affecting the spine. Physicians can make a diagnosis of axial spondyloarthritis in the absence of radiographic (x-ray) sacroiliitis, which is traditionally used to diagnose ankylosing spondylitis.

### Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)

The Bath Ankylosing Spondylitis Disease Activity Index is a self-assessment tool that was created to determine disease activity and tonrate effectiveness of treatment for those with AS. The BASDAI consists of 6 questions related to the major symptoms of AS, which are rated on a 1 through 10 scale (1 being no problem and 10 being the worst problem). The resulting 0 to 50 score (2 questions are averaged to provide 1 of the 5 scores) is divided by 5 to give a final 0 n-10 BASDAI score. Scores of 4 or greater suggest suboptimal control of disease, and patients with scores of 4 or greater are usually good candidates to change their medical therapy.

### Bath Ankylosing Spondylitis Metrology Index (BASMI)

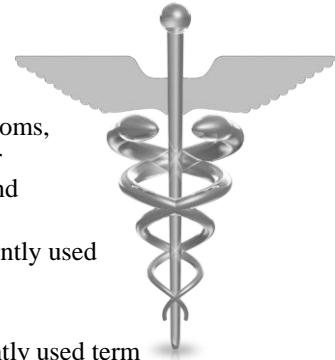
The Bath Ankylosing Spondylitis Metrology Index consists of 5 clinical measurements to assess the spinoal mobility in ankylosing spondylitis patients. These measurements include cervical rotation (average of Left & Right); tragus (ear) to wall (average of Left & Right); lumbar side flexion (average of Left & Right); lumbar flexion (modified schober's test) and intermalleolar (the distance between the ankles bony protusions). Scores are calculated using the BASMI scoring table, which results in a number out of 10. The higher the BASMI score the more severe the patient's limitation of movement is due to their AS.

### Bath Ankylosing Spondylitis Functional Index (BASFI)

The Bath Ankylosing Spondylitis Functional Index (BASFI) is a set of 10 questions designed to determine the degree of functional limitation in those with AS. The 10 questions were chosen with input from patients with AS. The first 8 questions consider activities related to functional anatomy. The final 2 questions assess the patients' ability to cope with everyday life. A visual analogue scale (with 0 being "easy" and 10 "impossible") is used to answer the questions on the test. The mean of the 10 scales gives the BASFI score – a value between 0 and 10, with a higher score correlating to more functional limitation.

### NSAID

NSAIDs are Non-Steroidal Anti-Inflammatory Drugs. This is the term used to describe a selection of drugs used to treat the inflammation experienced during an AS flare. These are often the first medications used to treat AS.





There are two interesting initiatives for younger people with AS or arthritic conditions that have been around for a little while but have recently gathered pace;

- Arthritis Ireland's "Young Arthritis Network" – you can get the contact details through the Arthritis Ireland website at [www.arthritisireland.ie](http://www.arthritisireland.ie)
- Spondylitis Association of America's "SWIFT – the Spondylitis Web Info For Teens". You can catch them at [www.teens.spondylitis.org](http://www.teens.spondylitis.org)

All too often arthritic or rheumatic conditions are seen as something affecting "older people". Not true. These are both worth checking out.



### World AS Day

The first Saturday after May 1st has been designated world AS day by the Ankylosing Spondylitis International Federation (ASIF). This provides the international AS community with an opportunity to stand up and be heard raising awareness of AS.

There were special events held in Canada, Hungary, the United Kingdom, Portugal and Turkey to name a few. In the USA there was an humorous campaign launched as GASP – Global Ankylosing Spondylitis Project - "There are over 33 million people with Spondylitis world-wide. In a sense, we're all Fusing Together. The mission of GASP is to bring people with AS together so that our united voice can raise AS awareness." In Canada, Portugal and Hungary special patient meetings were held to discuss various topics affecting AS management and patient issues. In Turkey the president of the national patients group (ASHAD) appeared on television to give information on AS and in the UK there was a sponsored walk involving 160 people on 5km or 10km walks.

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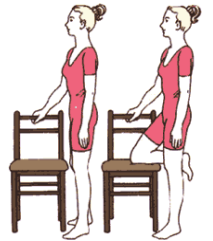
### Ennis Exercise Class for People with Ankylosing Spondylitis

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



### 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](mailto:info@ankylosing-spondylitis.ie)

or

Hugh Cassidy 01 8316678  
Seoirse Smith 01 8376614

