



AUTUMN 2010 ISSUE

Editor's Letter

Welcome to our Autumn 2010 edition of AS News.

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

Once again we have been busy since our last newsletter with some of the highlights being;

- The planning and execution of a new sort of online awareness campaign, "Back in Play", which is fun, European-wide and particularly relevant with this year's Soccer World Cup
- The planning and execution of a second awareness campaign, "Back in Action", this time for primary healthcare professionals
- Cooperation with an on-line global survey by ASAS on a Health index

More can be read about each of these later on in the newsletter.

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.

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 the Wyeth staff who joined as part of the global acquisition) and **Merck Sharpe & Dohme** is critical in ASAI embarking on and delivering all of our work now.

Thank to all for your help.

Severise

Meet the Ankylosing Spondylitis Awareness Council (ASAC)



- Professor Oliver FitzGerald
Consultant Rheumatologist,
Department of Rheumatology, St Vincent's University Hospital
- Dr Donncha O'Gradaigh Consultant Rheumatologist, Department of Rheumatology, Waterford Regional Hospital
- Ms Martina Fitzpatrick
Physiotherapy Clinical Specialist in Rheumatology, Allied Therapy Suite, St Vincent's University Hospital
- Dr Patrick Davern GP Surgery, Kyle Court Clinic, Tipperary
- Dr Jeremiah O'Flynn GP Surgery, Mullingar Road, Co Westmeath
- Dr Conor McCarthy Consultant Rheumatologist, Department of Rheumatology, Mater Private Hospital
- Dr Eanna Falvey Director of Sports and Exercise Medicine, Sports Surgery Clinic, Santry Demense
- Dr Philip Carolan The Clontarf Clinic, Dublin 3
- Dr Catherine Sullivan Specialist Registrar, Department of Rheumatology, St Vincent's University Hospital

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Infusion or injection?

Patients' preferences for tumor necrosis factor inhibitors

by Dessy W. Fajri, Caroline A. Brand, Shyamal i C. Dharmage, Belinda J. Martin, Russell R. C. Buchanan and Lionel Schachna, Victoria, Australia

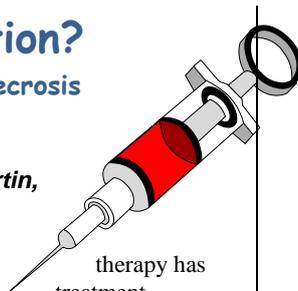
Tumor necrosis factor inhibitor (anti- TNF) therapy has set a new standard for an acceptable treatment outcome of patients with severe ankylosing spondylitis (AS). There seems to be almost no difference for axial disease in the efficacy of infliximab (trade name remicade) administered by intravenous infusion and etanercept (enbrel) or adalimumab (humira) administered by injection which can be done by the patient himself. Head-to-head trials have, however, not been performed. In many countries, insurance reimbursement policies of the health insurance companies strongly influence prescribing patterns of TNF inhibitors. In other countries, universal access to these medicines for citizens with severe AS is the rule, with no differential reimbursement for infusions or injections.

Thus the patients themselves may be involved in the decision.

Patient survey for preferences and their motives

For finding out which factors influence patients' preferences of intravenous versus subcutaneous TNF blockers, an unstructured phone survey was first conducted among 20 randomly selected AS patients treated with either intravenous or subcutaneous TNF blockers. The patients were asked to provide three reasons for their choice.

The responses were then used to create a self-administered questionnaire in which the patients were asked to rate their response to each of 19 possible reasons for choosing intravenous or subcutaneous TNF blockers using a five-point scale reaching from strong agreement to strong disagreement. The statements were presented in the questionnaire in no specific order. Patients who had received more than one TNF blocker were asked to consider only the reasons for choosing their first TNF blocker. All AS patients receiving TNF blocker therapy at the Austin Spondylitis Clinic, the only AS referral centre in the Australian state of Victoria, were invited to participate. Excluded were patients with inflammatory bowel disease (because infliximab was generally the TNF blocker of choice among this subset) and patients treated before 1 April 2005 (when infliximab was the only available TNF blocker and there was no choice between more than one).



Results

The response rate was 74 out of 93 patients (80%). The first prescribed TNF blocker was infliximab in 39%, etanercept in 43% and adalimumab (introduced as the latest of all three) in 18% of the patients responding. 66% stated that they were very satisfied with their AS treatment, 30% were satisfied and 4% neither satisfied nor dissatisfied. Responses to this question were similar for patients choosing intravenous or subcutaneous therapy. 80% agreed with the statement "My doctor gave me a choice and I made a decision based on my personal preference". 11% agreed with "My doctor gave me a choice and I let him/her decide for me", and 9% agreed with "I didn't know that there were any choices; my doctor made the choice for me". The results of the survey were unchanged when the latter two groups were excluded from the analysis.

Patients administered intravenous or subcutaneous therapy as their first TNF inhibitor did not significantly differ by demographic covariates or the disease severity. There was, however, a tendency favouring intravenous therapy in the following subgroups: males, Australian-born, reduced disease activity and those with an associated peripheral arthritis. There was also a tendency towards shorter travel time to an infusion centre for patients who received intravenous therapy. The number of participants who either agreed or strongly agreed with each of the proposed statements is displayed in *Table 1*. Few patients within either group identified errors with dosing or administration of treatments major determinants of their choice of therapy.

Conclusions

Apparently, the administration time and flexibility with the timing of treatment play an important role in the choice of treatment. Also safety aspects – for one group the administration of treatment by trained professionals in a hospital setting, for the other group a sense of control over their treatment through the use of self-administered treatment – were major determinants of choice. The high level of satisfaction with treatment response in our clinic suggests that shared clinical decision making between clinicians and patients may be desirable for AS patients commencing anti-TNF therapy.

The results of the study strongly imply that when therapy options with similar efficacy but differing impact on lifestyle are available, clinicians should proactively discuss these options with their patient and should offer the choice of therapy to the patient.

Address of the author mentioned last:

Austin Spondylitis Clinic, Austin Health, P.O. Box 5555, Heidelberg, Victoria 3084, Australia

Source: Shortened patient-adapted version of a scientific article originally published in *Clinical Rheumatology* vol. 28 (2009) p. 599–602 published in ASIF News #10

Table 1: Percentage of patients who either strongly agreed or agreed with the decision motive mentioned, among the patients treated with intravenous or subcutaneous TNF-alpha inhibitors, respectively.

Decision motives mentioned by a majority of patients treated with intravenous TNF blockers:	Percentage
An infusion is more convenient than injections. Once the infusion is done, I can forget about medication for 6 weeks.	97%
I feel more secure visiting an infusion clinic where a trained professional can supervise the delivery of my medication.	90%
I would be able to use the infusion time productively by reading, listening to music, etc.	86%
Visiting the infusion clinic allows me to see trained personnel who can answer any question that I may have about my medication	69%
I don't like needles and I don't feel comfortable with self injecting.	62%
I feel anxious about preparing the medication for self injecting.	52%
Decision motives mentioned by a majority of patients treated with subcutaneous TNF blockers:	Percentage
Injections allow me to have a lot more flexibility and independence by choosing the time of the day to have my medication.	80%
Injections only take a few minutes once or twice a week and are far less disruptive than attending an infusion clinic for half a day.	73%
An infusion time of 4 hours (plus travel time to and from the infusion clinic) takes too much out of my day.	73%
By injecting the medication myself, I feel more in control of my treatment	62%

FOOTBALL STARS UNITE TO TACKLE BACK PAIN

Throw-in legend Rory Delap urges fans not to dismiss lower back pain

This year saw us take a different approach to the last two year's awareness campaigns whilst still keeping with a sporting theme.

We joined forces with other European AS organisations to start a Europe-wide awareness campaign using the internet and a fun on-line game to get our message across – that is still running. The following is an excerpt from the press releases that accompanied the campaign launch.

June 2010: UK Premiership & former Irish international footballer Rory Delap, renowned for his devastating throw-in, has joined forces with a number of football heroes across Europe to support 'Back in Play', a European wide campaign to reach young men and women and raise awareness of ankylosing spondylitis (AS), a poorly understood condition which can affect the lower back.

AS is a type of inflammatory arthritis, characterised by low back pain and stiffness, which is most common in young men. The symptoms can be subtle and are often overlooked or confused with common back pain or sports injuries meaning it can take a long time to be accurately diagnosed. The campaign, supported by the Ankylosing Spondylitis International Federation (ASIF) and national organisations across Europe (like the Ankylosing Spondylitis Association of Ireland), kicked off with the launch of the Back in Play website, www.back-in-play.com. The site is home to a football game with a competitive European league, which tests a player's throw-in skills whilst highlighting the symptoms of AS that can differentiate it from other back pain. In addition to watching a throw-in master class from Rory Delap, visitors to the site can review the AS symptom checklist compiled by AS patient groups, find out more information about the condition via patient and doctor interviews and links to patient support groups.

Website sections:

- Hear from the professionals – This section of the site focuses on the professional footballers that have chosen to support the *Back in Play* campaign, most notably Premier League footballer Rory Delap.
- Video centre – A collection of campaign videos to entertain website visitors, including experts on AS discussing the condition and the importance of accurate diagnosis, a word from Rory Delap about the campaign and his tips on taking a successful throw-in
- About the campaign – Information on the *Back in Play* campaign and its partners
- Back pain and AS – Background information on back pain and AS with downloadable material and links to patient organisations for further information about the condition and treatment.

The Stoke City player, whose flexibility and back strength is a key part of his enviable skill, believes Back in Play can help raise awareness of this little known condition and its symptoms. Lending his personal support to the initiative, Delap comments: "Most football fans will not have heard about AS, yet the stats show up to 1 in 200 will have it." Reflecting on the importance of early diagnosis and



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treatment he continues: "It is understandable that some of the symptoms like lower back pain are often written off as a sports injury or bad posture, however there are some key subtleties such as the pain getting better with exercise and painful, red eyes, that can indicate AS. Test your throw-in skills with the game and check out the symptoms at the same time."

Most commonly, but not exclusively found in young men, AS symptoms typically start in the late teens and early twenties, causing severe, chronic pain and discomfort.

"A lack of awareness of the condition and the gradual onset of symptoms means that it can take years for sufferers to get an accurate diagnosis" said Seoirse Smith, President of the Ankylosing Spondylitis International Federation (ASIF) and Secretary of the Ankylosing Spondylitis Association of Ireland. "I know from personal experience that the earlier the condition is diagnosed the better the outcome for the patient. If AS is not correctly diagnosed or treated, over many years, the spine can become rigid as it may fuse together, and fixed in a bent position making it increasingly difficult to move around freely and undertake day-to-day activities with ease."

Although there is no cure for AS, Professor Désirée van der Heijde, from the Department of Rheumatology at the Leiden University Medical Center in Leiden, The Netherlands, says patients can be managed effectively. "There are a number of treatment options available to help reduce the pain and stiffness experienced by sufferers, from traditional anti-inflammatory drugs which are usually the first line of treatment, to the newer biologics." She concluded, "In addition to taking medication, maintaining a good posture and a regular exercise routine has also been proved to be beneficial."

As in the previous two years' campaigns the help of a sporting ambassador (Rugby's John Hayes in 2008 and hurling's Joe Canning in 2009) helped us to generate interest from national media which also helps with the general awareness message.

There are further national launches due soon in what is regarded as a wave 2.

I am told that the total number of game players for Back-in-Play has now reached 1.7 million and approximately 110,000 visitors to the website, hopefully this move into "wave 2" launches should push us our total to over 2m.

Check out the on-line game and see if we can get Ireland up the league table at;

WWW.-Back-in-Play.com



ANKYLOSING SPONDYLITIS PATIENT ORGANISATIONS - WHAT ARE THE BENEFITS OF MEMBERSHIP?

I. Song 1, C. Brenneis 1, L. Hammel 2, E. Feldtkeller 2, J. Listing 3, J. Sieper 1, M. Rudwaleit 1.

1 Charité Rheumatology, 3 German Rheumatism Research Center, Statistics, Berlin, 2 German Ankylosing Spondylitis Society, DVMB, Schweinfurt, Germany

Background: Patient organisations for ankylosing spondylitis (AS) exist in many countries. The aims of these patient organisations are to inform and to educate patients in order to help them better deal and cope with the disease, to organize supervised physiotherapy groups, to support the exchange of experiences, and to represent the interests of patients in society and law (see www.spondylitis-international.org).

Objectives: To evaluate differences between AS patients who are members of a patient organisation and AS patients who are not such members.

Methods: The German Ankylosing Spondylitis Society (DVMB) is a large patient organisation with more than 14,000 members in Germany. A cross-sectional survey based on a questionnaire was performed between December 2008 and April 2009. The questionnaire consisted of 82 questions regarding demographics, diagnosis, smoking, acquisition of information about the disease, disease activity, mobility, functional status, patient satisfaction, quality of life, treatment and disability to work and educational level. The questionnaire was distributed to AS patients by rheumatologists in 51 hospitals and/ or private practices. In addition, the questionnaire was sent to 3400 randomly selected members of the German AS society. Data collection and analysis was done anonymously.

Results: In total, 1273 patients responded (1068 members of a patient organisation & 205 non-members). As DVMB members and non-members were not comparable by age (54.9 vs. 46.6 years) and disease duration (30.2 vs. 20.1 years) we performed a 2:1-matching of members to non-members regarding age, disease duration and sex. In the matched population (n=549), members (n=366, mean age 47.0 years, mean disease duration 21.1 years, 63.9% male, HLA-B27 positive 89.0%) and non-members (n=183, mean age 46.3 years, mean disease duration 20.1 years, 63.9% male, HLA-B27 positive 94.6%) differed in the following aspects: members more often felt that they were well informed (62.2% vs. 35.4%, $p < 0.001$), more often used the information provided by the patient organisation shortly after the diagnosis (58.5% vs. 11.5%, $p < 0.001$) and also later on during the course of the disease 66.7% vs. 5.5%, $p < 0.001$), and more often had a positive family history for AS (34.4% vs. 23.3%, $p = 0.004$). There were neither differences regarding disease activity (BASDAI 4.0 vs. 4.2, $p = 0.172$), nor any difference in the percentage of patients taking NSAIDs, DMARDs or anti-TNF-blocking agents, or in the percentage of patients not performing physiotherapy on a regular basis (19.9% vs. 23.0%). However, members as opposed to non-members had a better functional status (BASFI 3.4 vs. 3.9), $p = 0.021$), had less work days missed during the last year (15.1 days vs. 31.2 days, $p = 0.003$), had less smokers (55.9% vs. 71.0%, $p = 0.001$), and felt less often unsatisfied with the current situation (11.7% vs. 23.0%, $p = 0.001$).

Conclusion: There are numerous benefits associated with the membership of an ankylosing spondylitis organisation. AS patients who are members feel better informed about AS, have a better functional status and a healthier life style. Overall they seem to cope better with the disease than non-members.

BACKinaction



Is an awareness campaign that was launched this year for GP's. In order to support GP's in referral decisions in this complex area, the Ankylosing Spondylitis Awareness Council (ASAC) has developed a simple tool, the "Ankylosing Spondylitis Action Pathway" (ASAP), to assist them in the assessment of low back pain patients. This tool has been circulated to GP's and is also available to online on the ASAI website. As part of the distribution of the ASAP tool to GP's a patient hand out called "A Guide to Managing your Back Pain" was also distributed. The following is an excerpt from that leaflet.

What is Back Pain?

Back pain is a familiar problem that can range from a dull, constant ache to a sudden, sharp pain that leaves you incapacitated. Most people, around 80%, will have back pain at some stage in their lives. Usually the best way to deal with this pain is to stay active.

Causes of Back Pain

Most back pain is caused by muscle, ligament or joint sprain. This can cause discomfort and stiffness. Other reasons can include:

- A slipped disc or a trapped nerve
- Arthritis caused by wear and tear
- Fracture caused by osteoporosis
- Stress
- Pregnancy

Acute vs Chronic

1. Pain that hits you suddenly is acute pain. To be classified as acute, pain should last no longer than six weeks.
2. Chronic pain, on the other hand, may come quickly or slowly, and it lingers a long time. In general pain that lasts more than three months is considered chronic.

Managing Pain

- Managing your pain and staying active will help you recover.
- Painkillers and anti-inflammatory medications may help control your pain. A pharmacist or GP can advise on suitable medication.
- Local application of warmth (e.g. hot water bottle) can be used for the relief of acute lower back pain.

Posture

- Sit well back into the chair. It should support your lower back.
- Do not sit for long periods whether you are at home, in the office, in school or driving.
- Your feet should be flat to the floor. If your feet do not reach the floor, adjust the height of the chair.

Sleeping

- Find a position that helps relieve your pain. Lying on your side with a pillow between your knees may help.

Stay Active

- At the beginning you may need to rest, but the sooner you get back to normal activities and work the better.
- Build up your activity level gradually.
- When sitting, use an upright chair and get up and stretch or walk around every 15 minutes.
- Try not to do much lifting. If you must lift, please follow these instructions:

Lifting

1. Lift only what you are able to lift safely
2. Bend hips & knees so that your legs, not your back do the work
3. Keep a firm grip on the load
4. Keep the load close to your body
5. When turning, move your feet instead of twisting your body.

Work

- You may need to change how you do your work for a short time, so speak to your boss and co-workers.

Occasionally back pain may be a sign of another illness, if your back pain persists over 3 months please consult your GP.



ASAS - The Assessment of SpondyloArthritis International Society.

An important part of AS research programmes is trying to understand all the

myriad ways in which this disease impacts the lives of patients.

Increasingly, we are asking patients to play a more active role in developing standardized questionnaires that can be used all over the world. A current important initiative by ASAS, an international group of experts & specialists, is the development of a "Health index" called "ASAS HI".

It might be used to assess the effectiveness of new treatments for our disease. It will also become the international standard for all manner of research in spondylitis. So I just want to emphasize that the assistance you provide is truly important.

The impact of disease on functioning is the essential information for our medical teams when reporting on and managing the health problems of individuals. The attached questionnaire is based on the ASAS/WHO International Classification System for Functioning, Health and Disability core set for AS. This is a framework and a classification system to define the spectrum of problems in functioning. The spectrum ranges from restricted mobility, over impairment in activities and participation (eg social participation) to the influence of environmental factors.

Thus, the health index will go beyond of questionnaires for measuring quality of life. In addition, the aim of ASAS is to produce licence-free assessments to improve the care of patients with AS.

Progress in Ankylosing Spondylitis Genetics

This article was printed in The Spondylitis Association of America's Summer 2010 newsletter and is an excerpt from Dr. Matt Brown (Professor of Immunogenetics, University of Queensland) article published in AStretch Australia.

In the past 3 years major advances have been made in the ability to identify genes that cause common human diseases, such as arthritis, diabetes, obesity and so on. Studying thousands of individuals for hundreds and thousands of genetic markers each, we can now identify many, but not all, of the genes that influence the risk of developing conditions. These studies are expensive (min. \$1 million per study), complex, and generally involve multinational consortia to ensure the skills and patient cohorts are available to complete the studies.

Our group in Brisbane is now well skilled in performing these sorts of studies and has become an Australasian centre for this type of research. Although we research several different diseases, AS has been a long-standing focus. We are the main genetics centre for an international consortium termed "Australo-Anglo-American Spondyloarthritis Consortium" (TASC). This group involves more than 20 researchers, and is engaged in studies aimed at identifying genes involved in AS, and also non-genetics factors, such as work, lifestyle and psychological factors which influence the severity of the condition and how it affects patients. We have now completed 2 major studies which have identified 4 definite

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new genes/genetic regions involved in AS, and several others that are very likely to be true AS-genes.

The first big breakthrough came in 2007, when in collaboration with another group (the Wellcome Trust Case Control Consortium), TASC identified 2 genes, called **IL23R** and **ERAP1**, as being involved in AS. These were really exciting findings because of the known function of the genes, and neither had been suspected of having been involved in AS previously. Both tell us a lot about the processes which lead to AS developing.

Since the discovery of the association of IL23R with AS, several genes involved in determining the activity of TH17 lymphocytes have been demonstrated to be involved in AS of the related conditions, inflammatory bowel disease (IBD) and psoriasis. This tells us that this lymphocyte-type is really important in the process by which AS develops. What we don't know yet is if the genetic variants that lead to AS cause the lymphocytes to be underactive or overactive.

The other gene we identified, ERAP1, most likely works to increase the risk of AS by influences on HLA-B27. We don't yet know how HLA-B27 causes AS (despite LOTS of research), but one leading theory suggests that HLA-B27 presents short proteins to cells called T-lymphocytes. These T-lymphocytes normally serve to protect us from infection and cancer, but can cause disease themselves if the control of their activity gets upset. It is thought that HLA-B27 may cause AS because it presents particular proteins which induce these lymphocytes to become excessively active, leading to inflammation and arthritis.

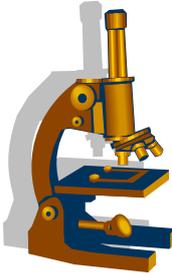
The other 2 genetic regions we have shown to be involved in AS are what we call "gene deserts", which are regions of the genome where the DNA contains no genes. These regions used to be called "junk DNA", but are now known to contain areas which control the expression of other genes. We don't yet know what the other genes are that these genes control, but we are working at it, and hope that by working this out, we can use the information to develop new therapies for AS.

Many more genes have yet to be identified which cause AS, and there are other large studies underway in Europe, Canada and China that will report findings in the next 12-18 months which will increase the list further. In particular, the International Genetics of AS consortium (IGAS), will be performing a study with about 13,000 samples from all over the world, which we will also be genotyping in our lab in Brisbane. So the next 2 years will be a very exciting time for discovering genes in AS.

Mater Hospital, Eccles Street.

The Physiotherapy Department, in the new building, have a class Mondays from 10.30 AM to 12.30 PM. There is no charge, but a letter from your doctor is required and you need to meet with a physiotherapist for assessment first. Both hydrotherapy and floor exercises are available.

Contact bwhite@mater.ie.



The Birds, the Bees & TNF's

This article was printed in The Spondylitis Association of America's Summer 2010 newsletter and originated with "Talk Back" the newsletter of the Canadian Spondylitis Association in Fall 2009.

Although some pregnant women with inflammatory arthritis may experience an improvement in disease activity during their pregnancy, others may need to continue therapy throughout pregnancy and during lactation as well. Information on the safety of these drugs during pregnancy is limited.

Anti-TNF drugs have demonstrated efficacy in reducing disease activity and joint destruction and improving health-related quality of life in patients with AS and other inflammatory diseases such as rheumatoid arthritis, psoriatic arthritis and juvenile idiopathic arthritis. The anti-TNF agents commonly used include infliximab, adalimumab, etanercept and golimumab. These drugs fall into the United States FDA category B concerning foetal risk, indicating that while animal studies have not shown a risk to the foetus, adequate studies of pregnant women have not been conducted. Consequently, and probably for legal reasons, drug manufacturers have recommended that these agents be avoided during pregnancy and lactation.

A survey of rheumatologists in the USA showed that fewer than half of those questioned agreed that anti-TNF drugs should be avoided in pregnancy. Almost half stated that they were uncertain about their safety during pregnancy. The respondents generally agreed that recommending effective birth control for women taking these drugs was important.

It is interesting that women of reproductive age suffering from inflammatory arthritis who are being treated with anti-TNF therapy may increase their chances of reproduction and pregnancy. It is still controversial if anti-TNF agents have a positive impact on fertility but it has been noted that pregnancy rates have increased in women with rheumatic diseases during the last few years. While most pregnant women with rheumatoid arthritis experience an improvement in disease activity, the picture is different for most women with AS. Ankylosing Spondylitis tends to demonstrate persistent disease activity during pregnancy that decreases only in the later months. Disease activity in pregnant women with AS tends to equally either be unchanged, improved or worsened. A post-partum flare of disease activity is experienced by 60-90% of AS patients, generally within 6 months of delivery. Most often, the post-partum flare is experienced by those who had active disease at conception.

It is considered important to explore the safety of anti-TNF therapy exposure in those women who experience worsening of their disease either during or after pregnancy. Current data do not seem to support a large excess risk of adverse pregnancy and/or foetal outcomes in women exposed to anti-TNF therapy at some point in pregnancy. Evidence is limited by the small number of published case studies and by differences in the type and amount of anti-TNF agents, possible use of other drugs and the timing of exposure during pregnancy. Most of the data relate to exposure in the first trimester and a few patients have been exposed during the entire pregnancy or during the second or third trimester. No long-term follow-up studies are yet available on the possible effects of exposure to the offspring. Some effects of in utero drug exposure may not be observed for decades.

To date, anti-TNF agents have been shown to be transferred via placenta to the unborn child. The agents can be found in breast milk but are probably digested in the gastrointestinal tract of the child. No large excess risks of foetal or maternal

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adverse outcomes have been reported following exposure to anti-TNF therapy during pregnancy compared with the general population. Sporadic cases of congenital malformation have been reported, but do not seem to be in excess of what is expected in the general population.

More data is expected over the next five years which will allow for assessment of the post in utero exposure to anti-TNF drugs.

The European Science Open Forum (ESOF) 2010 took place in Turin, Italy from 2-7 July. ESOF is a biennial pan-European meeting dedicated to scientific research and innovation.

IPPOSI

Irish Platform for Patients' Organisations,
Science and Industry

Dr Ruth Barrington, CEO of Molecular Medicine Ireland, was invited to chair an interactive session at the event on 6 July that explored the theme - Improving Patient Partnership in Clinical Research. The speakers were Professor Jacques Demotes-Mainard, Coordinator of ECRIN, Dr Paola Mosconi of the Instituto Mario Negri, Milan and Eibhlin Mulroe, CEO of the Irish Platform for Patients' Organisations, Science and Industry.

The objective of this session was to highlight the importance of patient involvement in clinical research, the need for a strong clinical research capacity and for appropriate funding mechanisms in Europe.

The session featured presentations on how patients are being encouraged to participate in clinical research in Italy and at a European level. Using the example of Ireland - Eibhlin Mulroe of IPPOSI presented the findings of a survey of public attitudes to clinical research - the session explored how patient organisations, working closely with the clinical research community, may address barriers to greater patient involvement in clinical research.

Dublin will host the Euroscience Open Forum in 2012 and to create awareness of the event a group of six young Science Ambassadors travelled on a Science Communications Bus from Dublin to Turin stopping off at cities of scientific interest along the route. Ronan Lyne, a Neuroscience student in Trinity College Dublin, and Michelle Dunne, a science and chemistry teacher at St. Joseph's College, Presentation Convent in Lucan were selected out of 50 applicants to make the journey across Europe on the specially commissioned bus.

Ennis Exercise Class for People with Ankylosing Spondylitis

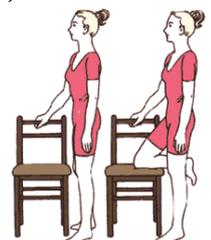
**Mid-Western Regional Hospital, Ennis
Physiotherapy Dept.**

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

**For more Info contact:
info@ankylosing-spondylitis.ie**

or

**Hugh Cassidy 01 8316678
Seoirse Smith 01 8376614**



“As patients with ankylosing Spondylitis we have to be more careful than others”

From an interview with Ernst Feldtkeller (left), scientific advisor to ASIF and scientific editor of the membership journal of the German AS society, by Reto Baliarda, editor of the membership journal of the Swiss AS society and published in “vertical”, membership journal of the Swiss AS society, issue 45 of August 2010.

Throughout 60 years with the disease, Ernst Feldtkeller took care day and night of having a straight posture. As a result he is stiffened relatively upright. The vigorous 78 years old living in Munich, has thus lived many decades a cognisant life with the disease. A small inattention however was sufficient to cause him a spinal fracture.

In Garching near Munich he was making music with other hobby musicians in a new unfamiliar building where one of his friends had moved. When he left the flat, situated in the first floor, he did not notice a very narrow step at the corner of the staircase, which had been designed apparently to sell more square meters as living space by the architect. Also no grab rails were provided along the other side of the staircase. At this corner Ernst Feldtkeller slid down, hit the open front door with his head and had to be transported to a hospital with a spinal fracture.

Dr. Feldtkeller, would you say that your fracture was caused by a high energy level/impact of the fall?

No, the energy level was not high. I fell from the second lowest step of a staircase and could break my fall on hands and knees. I would not have had any injury if I had not hit the open front door with my head.

Did you suspect a vertebral fracture immediately after the fall?

Yes, I had the suspicion immediately since I knew that I have no intervertebral discs to absorb the push along my body axis. I also could hear the crack.

How did you behave? Did you remain lying?

No, it would have been difficult for me to lay down anywhere without a head support. I sat down on the lowest step of the staircase and waited for the ambulance.

Were you transported lying or sitting?

When lying I would have needed a head support carefully adapted to the shape of my neck. In sitting I could keep my head and neck in the natural position. Also I had the feeling that it was easier for me to resist the street unevenness in sitting which caused me severe pain. In the hospital I asked for a wheelchair for the transport to the examination room.

How was your mood immediately after the accident? Did you have severe pain?

I could tolerate the pain as long as I was able to keep my head quiet. Since the X-rays did not show any instability, I worked at home on my computer on the day after the accident. On the second day after the accident, however, I could not stand up in the morning and was obliged to ask a doctor for strong painkillers.

Thus it lasted some time until the fracture was diagnosed?

Yes, on the evening of the accident the radiologist said that there is no indication of a fracture. After the severe pain did not improve during the following days, I asked to be transported on a vacuum stretcher to a computed tomography. I had to tell the ambulance man very clearly that he must not support the stretcher under my head but only under my shoulders. Otherwise he would have bent my already broken neck. The computed tomography then revealed that the deck plate of the seventh cervical vertebra was broken down.

You were confined to bed for five weeks. Did you spend this time in a hospital?

No, my wife took care of me at home, although she is now 74 years. I am infinitely thankful to her for this. Only once every day I was able to stand up with severe difficulty for a short time.

Did you have any neurologic complications like nervous deficits, for example?

No, I was happy to have had no neurologic deficits. After five weeks, however, Dr. Heinrich Böhm, orthopedic advisor of our AS society, told me after a view on a new magneticresonance image that the deck plate is not really stable. He told me that without surgical stabilization the severe pain could last another long time and in worst case I would even risk paraplegia. After this advice I agreed immediately to a surgical stabilization.

With 2 titanium bars and 10 screws 5 vertebrae were interconnected from the fifth cervical vertebra to the second thoracic vertebra. Will this stay?

I do not need the metal instrumentation anymore, after the bones have healed completely. A removal would, however, mean another surgery. Therefore all will be left where it is.

Do you, more than one year after the accident, still feel any consequences of the spinal fracture?

Yes, I have become stiffer than before and feel by years older than before the accident. Bending forward and all efforts are more difficult for me than before.

Back to the accident on the staircase: Would you say that your ankylosing spondylitis played a twofold role? Due to your mobility restrictions you had difficulties to detect the dangerous step. And the collision with the door would probably not have caused a fracture in a person without Ankylosing spondylitis.

Yes, such a staircase is especially dangerous for patients with ankylosing spondylitis. This is the case not only because the spine of a patient with ankylosing spondylitis is at a higher risk of being fractured, but also because patients with almost complete ankylosis have difficulties to look directly in front of their feet. They therefore depend more than other people on a riskless state of a staircase.

Do you now behave different when you step down a staircase?

Yes, more than before I always step down with at least one hand at the grab rails if available (though this was the cause that I took the inner curve on the staircase on the fatal evening). When there are no grab rails, for instance in front of a historical building, I step down sideward in order to see which is the next step.

Is it true that the staircase, did not fulfil the building regulations?

Yes, this is true. I took measurements and found that the step width at the end of the step at the corner is only 8 cm, measured perpendicular to the edge of the step. In such a building it should be at least 10 cm. Nevertheless, I should have stepped down more carefully and should not have trusted that the staircase is constructed correctly and can be used without danger. As patients with ankylosing spondylitis, we have to be more careful and perhaps also more suspicious than other people.

Where do you see the largest dangers for an accident with a spinal fracture as consequence of a long-standing AS?

I see the largest dangers in a traffic accident (whether as a pedestrian, cyclist or in a car), and in a fall from a high level, for instance from a ladder.



Sleep-on-it

This heading should not be construed as a call on our members to put this newsletter away and go to bed! On the contrary, it should serve as inspiration for you to participate in an upcoming survey to investigate if we as AS patients experience general problems in

connection with overnight hotel stays.

The background is an inquiry to the Danish AS association from a member as to whether they had a list of hotels with beds, pillows, etc. which are appropriate for AS patients. Finding hotels with good beds was a problem for him as he travelled a lot and had many overnight hotel stays both domestically and abroad.

Unfortunately, they do not have such a list of hotels which they could recommend members to use but it caused the executive committee to discuss how big this problem is in general for AS patients with somewhat stiff joints in oblique angles. We all know how important it is to us all to get a good night's sleep, particularly if we have work-related overnight hotel stays.

Many of us know of hotels where the pillows in the beds are big, firm, and foam-filled. It is an impressive sight when the beds are made but such pillows are hardly comfortable to rest on. And worst of it all is probably that folding, pushing or nudging the pillows does not help shaping them comfortably for AS patients. If the AS patient's neck is not perfectly stiff at bedtime, it certainly will be in the morning after a night on a pillow like that.

ASIF, hopefully with the co-operation of all national associations, with financial support to the project from Abbott, have decided to investigate the extent of the problem/problems for AS patients. If the problem is big and general, it is the intention to try to encourage/inspire hotels all over the world to have some "arthritis-friendly" rooms available, and smaller hotels to have some AS-friendly pillows and/or mattresses available for people like us.

In the first place, we will attempt to find out whether there are problems and, if so, to which extent. Identical questionnaires will be presented to the member associations to circulate to their members in order to get an overview of what the extent might be. The data from the survey will be the basis for the decision as to whether we will continue the project or not.

The questionnaire will be sent to you as a URL link in an email for posting on your association's web site and distribution via email from mid-October for one month, so please keep an eye and help us collect data on the extent of the problem.



A S News

We encourage all our members to fill in the questionnaire, whether you have problems with overnight hotel stays or not, in order for us to get a picture of the potential problems which is as realistic as possible.

Once the result of the survey is available, you will of course receive feedback with thanks for your assistance.

The spin-off of this sort of project, assuming it goes ahead of course, is an increased level of awareness of our condition is generated.



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

