



## SUMMER 2013 ISSUE



### Editor's Letter

Welcome to our Summer 2013 edition of AS News. We hope that this edition finds you all safe, healthy & active.

I must apologise for the delay in this issue but we wanted to have this issue coincide with the relaunch of our website, our new iPhone app and our new booklet. These are all taking place as part of our SUAS project, see page 2 for all the details.

We also need to note the collaboration with Arthritis Ireland which sees us changing our contact address and phone numbers, see the details on the right of this page.

The membership situation continues to decline with the last year being one of the lowest responses on subscriptions in all the years I have been helping run ASAI.

We were extremely fortunate to have a significant bequest made to us by the late Brian Lynch, a member of many years and we also continue to be very lucky with the financial support & practical help we have received from the pharmaceutical companies which means our finances have not been under too much pressure.

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

*Seserise*



# SUMMER

From May this year we have changed both our postal address and our contact telephone numbers.

In order to improve the service we deliver and make ASAI more accessible and responsive to calls and contacts we have reached an agreement with Arthritis Ireland that we can use their contact address and phone numbers.



We should stress at this stage that we are maintaining our independence but partnering with Arthritis Ireland to avail of their resources and align with any advocacy work, service development and potentially fundraising opportunities that arise from time to time to benefit ASAI further.

Over recent years we have built a relationship with the excellent full-time personnel within Arthritis Ireland that has helped us in addressing some of our challenges. Whilst we are very grateful for the support and advice they have given us so far this is an opportunity to improve the relationship and potentially build a greater advocacy voice for ASAI going forward.

In the immediate future the ability for people with concerns over AS to get their telephone call answered or have their post addressed quicker is of obvious benefit

### In This Issue

- 2 **SUAS** (Supporting & Understanding AS) our iPhone App
- 3 **Inhibiting Progression:** Can TNF-a Inhibitors Reduce Radiographic Progression in AS? ; The Impact of TNF-inhibitors on radiographic progression in AS
- 3 **The Tumor-Necrosis-Factor Alpha (TNF-a) Blockers:** An Overview
- 4 **Research News:** Hip disease in AS ; Long-term outcome for patients with active AS with etanercept
- 5 **Spreading the word on AS,** - How technology is being used to raise awareness of AS with GP's



## ASAI's iPhone App

We have been extremely fortunate to establish an excellent working relationship with a number of organizations that has allowed us develop an iPhone App for people living with AS - **SUAS** (Supporting & Understanding AS).

The **SUAS** app, developed in partnership with the Waterford Regional Hospital Rheumatology Team, supported by Pfizer Healthcare Ireland with the technology design, build, test & deployment managed by Publicis D Healthcare is the first of its kind in Ireland. It provides AS patients with educational information, guided exercise videos and the ability to monitor their progress over time.



Using the fact that regular exercise is an essential aspect of managing AS because the fitter and more flexible you are, the better able you will be to deal with the stiffness and pain associated with this chronic condition.

To assist people with AS exercise safely while also allowing for a diverse exercise programme which can be conducted on an ongoing basis, the ASAI in partnership with the Rheumatology Team at Waterford Regional Hospital have developed SUAS. It contains a library of instructional exercise videos, from beginner to advanced levels, with the ability to track and monitor the user's progress over time.

The SUAS app can act as a 'physio-in-the-pocket' for those with AS, which is particularly important for patients living in areas of the country with limited access to fitness or health amenities.

Dr Claire Sheehy, Consultant Rheumatologist at Waterford Regional Hospital explained: "Exercise is an essential part of managing AS. When carried out regularly, exercise can reduce pain and stiffness, as well as optimise movement and posture for those with AS."

"SUAS is a flexible, on-the-go tool designed to support people living with AS learn about all aspects of their condition while also teaching them daily exercise techniques. People can fill in simple surveys within the app to establish their level of functionality and track their 'score' over time as they exercise and improve strength and flexibility. They can keep a record of this to discuss with their healthcare professional to better inform their treatment" she said.

The app also contains support information and tips for those living with AS to manage key aspects of daily life, including condition symptoms, maintaining posture, working with AS and daily lifestyle.

## A S News

But it does not stop there, **SUAS** – which is free to download – is part of a newly-developed suite of support and information resources for patients living with AS and is available to download from the iTunes store.

In addition to the **SUAS** app, an educational booklet has also been developed to replace the old Touchpoints book. It is a few years since the Touchpoints booklet was developed as part of a wider awareness campaign and we have continued to use it as a patient guidebook.

However the amount of information that it provided was limited in certain areas. Now that we have all of this extra information drawn together for the iPhone App we decided to reuse it in producing a new booklet – the booklet will have "tabs" to allow easy access to the key sections with the information easier to access.

Finally, having collated a lot of excellent information that was now being used in the iPhone App and the booklet we decided to take all of that great information and let it "flow" through into a redesigned and redeveloped website.

The is still at the same location or domain name and it will continue to provide the same sort of functionality but will now have the same design and look as the iPhone App and booklet. See it at [www.ankylosing-spondylitis.ie](http://www.ankylosing-spondylitis.ie).



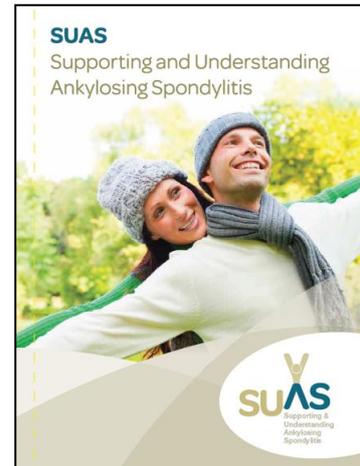
The last critically important development in this suite of information resources was again on the website. This was the ability for the website to be mobile ready – with the increasing use of mobile devices, (smartphones, tablets

etc.) being used to access the internet this is an important development for us.

So, it now means we have a strong fourth mechanism for people interested in AS to access the information and interact with us.

A big thank you is due to all of those involved in delivering this exciting set of communication tools for us.

Last but not least we must specifically acknowledge the bequest received on the sad passing of Brian Lynch. Brian's kind bequest has enabled our final print & dispatch of the booklets to our membership.





## ***Inhibiting Progression: Can TNF- $\alpha$ Inhibitors Reduce Radiographic Progression in Ankylosing Spondylitis (AS)?***

By Chris Miller from an article in the July edition Spondylitis Association of America's eSun, electronic Spondylitis Update Newsletter. [www.spondylitis.org](http://www.spondylitis.org)

Consensus on the effectiveness of TNF- $\alpha$  inhibitors has been evolving and changing each year since they were introduced over a decade ago. But the biggest question has yet to be decisively answered: Can the TNF- $\alpha$  inhibitors slow or halt disease progression in AS?

The latest study published in Arthritis & Rheumatism concludes that they appear to do so when they are used to treat ankylosing spondylitis.

TNF- $\alpha$  inhibitors are medications that target and attempt to block TNF- $\alpha$  in the body. TNF- $\alpha$  is a cytokine involved in the inflammatory process. Excess amounts of TNF- $\alpha$  have been associated with various forms of inflammatory arthritis. These medications are either injected or, in the case of remicade, given by an IV.

Currently, there are four anti-TNF therapies used in the US that have an indication from the Food and Drug Administration (FDA) to treat AS (presented in order of initial FDA approval):

- Enbrel (etanercept)
- Remicade (infliximab)
- Humira (adalimumab)
- Simponi (golimumab)

The new study, "The Impact of TNF-inhibitors on radiographic progression in Ankylosing Spondylitis" looked at the "effect of Tumor Necrosis Factor-Alpha (TNF)-inhibitors on progressive spine damage in Ankylosing Spondylitis (AS) patients" by examining x-rays of patients over time.

The authors conclude that, "TNF-inhibitors appear to reduce radiographic progression in AS, especially with early initiation and longer duration of follow up." Thus, it appears that better results are achieved when the TNF- $\alpha$  inhibitors are started earlier.

### ***The Impact of TNF-inhibitors on radiographic progression in Ankylosing Spondylitis.***

Haroon N, Inman RD, Leach TJ, Weisman MH, Lee M, Rahbar MH, Ward MM, Reveille JD, Gensler LS.

**Source:** University Health Network, University of Toronto, Toronto, ON, Canada.

*This piece, from the American College of Rheumatology is recommended reading from the preceding article in the July edition Spondylitis Association of America's eSun, electronic Spondylitis Update Newsletter. [www.spondylitis.org](http://www.spondylitis.org)*

#### **INTRODUCTION:**

We studied the effect of Tumor Necrosis Factor-Alpha (TNF)-inhibitors on progressive spine damage in Ankylosing Spondylitis (AS) patients.

#### **METHODS:**

All AS patients (satisfying the modified New York criteria) prospectively followed and with at least two sets of spinal radiographs at a minimum gap of 1.5 years were included (n=334). Patients received clinical standard of care, which included non-steroidal anti-inflammatory drugs and TNF-inhibitors. Radiographic severity was assessed by the modified Stokes Ankylosing Spondylitis Spine Score (mSASSS). Patients with a rate of progression more than 1 mSASSS unit/year were considered progressors. Univariable and multivariable regression analyses were done. Propensity score matching (PSM) and sensitivity analysis were performed. A zero-inflated negative binomial (ZINB) model was used to analyze the effect of TNF-inhibitor on change in mSASSS with varying follow-up periods. Potential confounders like Bath AS Disease Activity Index (BASDAI), ESR, CRP, HLA-B27, gender, age of onset, smoking and baseline damage were included in the model.

#### **RESULTS:**

TNF-inhibitor treatment was associated with a 50% reduction in the odds of progression (OR: 0.52; CI: 0.30-0.88; p=0.02). Patients with a delay in starting therapy of more than 10 years were more likely to progress compared to those who started earlier (OR=2.4; 95% CI: 1.09-5.3; p=0.03). In the ZINB model TNF-inhibitor use significantly reduced progression when the gap between x-rays was more than 3.9 years. The protective effect of TNF-inhibitors was stronger after propensity score matching.

#### **CONCLUSIONS:**

TNF-inhibitors appear to reduce radiographic progression in AS, especially with early initiation and longer duration of follow up.

© 2013 American College of Rheumatology.

### ***The Tumor-Necrosis-Factor Alpha (TNF- $\alpha$ ) Blockers: An Overview***

*This article is from a piece by Chris Miller, posted on the Spondylitis Association of America's (SAA) web site in April 2013. We greatly appreciate SAA allowing us reproduce these pieces here. [www.spondylitis.org](http://www.spondylitis.org)*

#### **Overview**

The Tumor-Necrosis-Factor alpha (TNF- $\alpha$ ) blockers are biologic medications that have been shown to be highly effective in treating not only the arthritis of the joints but the spinal arthritis associated with ankylosing spondylitis (AS) and related diseases.

As of this writing, there are four anti-TNF therapies used in the US that have an indication from the Food and Drug Administration (FDA) to treat AS and other diseases in the spondyloarthritis family (presented in order of initial FDA approval):

**Enbrel (etanercept)** - Originally approved in 1998 for rheumatoid arthritis (RA), Enbrel is self-injected and normally administered 1-2 times weekly. It has received indications for use in the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Rheumatoid Arthritis



## 4

- Juvenile Idiopathic Arthritis
- Plaque Psoriasis

**Remicade (Infliximab)** - Approved in 1999 initially for RA. Remicade is given by infusion - through an IV drip - thus one must visit a doctor's office or infusion clinic to receive the medication. The infusion can take around 2 hours. The infusion cycle varies per individual, but is commonly done every 6-8 weeks. It has been approved by the FDA for the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Crohn's Disease
- Ulcerative Colitis
- Rheumatoid Arthritis
- Plaque Psoriasis

**Humira (adalimumab)** - Humira was given its first indication in 2002 for RA. Humira is self-injected and normally administered 2-4 times each month. It has received approval for use in the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Crohn's Disease
- Ulcerative Colitis
- Rheumatoid Arthritis
- Juvenile Idiopathic Arthritis
- Plaque Psoriasis

**Simponi (golimumab)** - Approved in 2009 for rheumatoid arthritis, psoriatic arthritis, and ankylosing spondylitis. Simponi is the newest TNF-a blocker to become available. Simponi is self-injected and administered once each month. It has received approval for use in the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Rheumatoid Arthritis

### Quick Reference Table

Trade Name	Generic or Brand Name	Dose	Frequency	Total Dose (Range)	Route of Administration
Enbrel	Etanercept	25-50 mg	1-2 times/week	50 mg/week	Subcutaneous injection
Remicade	Infliximab	3-6 mg/kg	Given at variable intervals	NA	Intravenous
Humira	Adalimumab	40 mg	2-4 times/month	NA	Subcutaneous injection
Simponi	Golimumab	50 mg	1 time/month	NA	Subcutaneous injection

### How do anti-TNF therapies work?

Each of the above mentioned medications target and attempt to block TNF-alpha in the body. TNF-alpha is a cytokine involved in the inflammatory process. Excess amounts of TNF-alpha have been associated with various forms of inflammatory arthritis.

The National Institutes of Health describes cytokines as follows: "Cells of the immune system communicate with one

## A S News

another by releasing and responding to chemical messengers called cytokines. These proteins are secreted by immune cells and act on other cells to coordinate appropriate immune responses."

It should be noted that each TNF-a inhibitor works in a slightly different manner within the body to block TNF-a.

Thus, if one does not have a positive effect in a particular individual, a different one might.

### What are the Potential Side Effects?

The most serious known side effect of the TNF-a blockers is an increased frequency of infections, especially tuberculosis. Thus, a TB test is usually required before starting any of the TNF therapies.

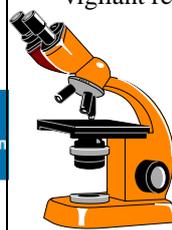
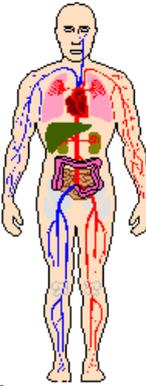
Fungal infections have also been reported, such as pulmonary and disseminated histoplasmosis, coccidioidomycosis, and blastomycosis.

A very rare possible complication is increased frequency of cancer, especially of the blood (leukemia) or of the lymphatic system (lymphoma). However, this has not been fully substantiated.

In an April 1, 2013 article titled, "TNF Inhibitors: Safer than we thought," Rheumatologist Dr. Irwin Lim states that, "The good news is that there has been no definite signal, after a decade of widespread use, in patients all over the world, of an increase in incidence of solid cancers. By that I mean breast cancer, colon cancer, etc.

"Lymphoma was always a worry. Patients with rheumatoid arthritis already have a higher risk of lymphoma...To date, there has been no increase in lymphoma seen in patients on TNF inhibitor therapy."

Dr. Lim adds, however, that rheumatologists should remain vigilant regarding side effects.



## Research News

### Hip disease in ankylosing spondylitis.

Vander Cruyssen B, Vastesaeger N, Collantes-Estévez E.

**Source:** Department of Rheumatology, OLV Hospital Aalst, Bornem, Belgium. Bvcruyssen@Gmail.com

#### PURPOSE OF REVIEW:

Hip disease occurs in about one-third of patients with AS and can often be disabling, necessitating total hip replacement in young adults. There have been recent articles on a number of aspects of this problem, including the epidemiology and pathology. The most recent studies on diagnosis, prognosis and therapeutic management are reviewed here.

#### RECENT FINDINGS:

Several large studies have evaluated the prevalence and outcome of hip involvement in AS. Hip involvement can be diagnosed clinically, radiologically, by MRI or by ultrasonography. These examinations highlight different aspects of hip disease in AS. Hip disease is more prevalent in patients with a younger disease onset and seems to be

associated with more severe axial disease. Antitumour necrosis factor (TNF) agents are helpful for pain relief and improvement of function in patients with active axial and active hip disease. However, it is not clear whether this treatment option can prevent progression of structural damage. In case of end-stage hip disease, total hip replacement should be considered.

#### SUMMARY:

In patients with AS, the hips should be routinely assessed, at least by clinical examination. Anti-TNF therapy should be considered in patients with NSAID-resistant active axial disease who have concomitant hip disease.

#### Long-term outcome of patients with active AS with etanercept - sustained efficacy & safety after 7 years.

Baraliakos X, Haibel H, Fritz C, Listing J, Heldmann F, Braun J, Sieper J.

#### INTRODUCTION:

Data from clinical studies on the long-term efficacy and safety of anti-tumor necrosis factor (TNF)-alpha therapy in patients with AS are scarce. This is the first report on continuous treatment with the TNFalpha fusion protein etanercept over 7 years (y).

#### METHODS:

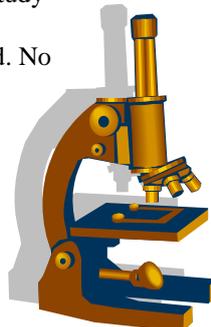
Overall, 26 patients with active AS were initially treated with etanercept 2x25mg s.c./week with no concomitant disease modifying anti-rheumatic drugs (DMARDs) or steroids. The clinical response was assessed by standardized parameters. The primary outcome was the proportion of patients in spondyloarthritis international society (ASAS) partial remission at 7y. AS disease activity scores (ASDAS) for status and improvement were compared to conventional outcome measures.

#### RESULTS:

Overall, 21/26 patients (81%) completed 2y and 16/26 patients (62%) completed 7y. In the completer analysis, 31% patients were in ASAS partial remission at 7y, while 44% patients showed ASDAS inactive disease status. Mean Bath AS activity index (BASDAI) scores which were elevated at baseline (6.3(plus/minus)0.9) showed constant improvement and remained low: 3.1(plus/minus)2.5 at 2y and 2.5(plus/minus)2.2 at 7y, while ASDAS also improved (3.9(plus/minus)0.7 at baseline, 1.8(plus/minus)0.9 at 2y, 1.6(plus/minus)0.8 at 7y), all  $p < 0.001$ . From the 10 dropouts, only 5 patients discontinued treatment due to adverse events. Patients who completed the study had lower baseline Bath AS function index (BASFI) scores vs. patients who discontinued. No other clinical parameter at baseline could predict any long-term outcome.

#### CONCLUSIONS:

This study confirms the clinical efficacy and safety of etanercept in patients with active AS over 7y of continuous treatment. After 7y, more than half of the initially treated patients remained on anti-TNF therapy, and 1/3 were in partial remission.



### Spreading the word on AS

*How technology is being used to raise awareness of AS with GP's as part of their continuous development & education programmes.*

In Spring 2011 it became compulsory for all GP's to achieve 50 CPD credits throughout the year, in the past this would have been achieved by attending evening educational meetings. However due to increased GP workload and time pressures, attendance at these evening meetings has been declining.

There was a need to think differently about how to provide this education, embracing innovative technologies and at a time which is convenient to both the audience and the speaker.

Abbvie pharmaceuticals facilitated the development of the "Rheumatology Toolbox", a disease educational initiative by partnering with Consultant Rheumatologist Dr Robert Coughlan. The aim was to bring the education to a wider GP audience via an innovative technology platform (GoToWebinar). The speaker, Dr Coughlan, remained in his office for the meeting and GP's linked-in remotely with the main host site being Ballina Medical Centre. There was also collaboration with the ICGP to ensure the meeting was CPD external points approved.

The benefit of using the GoToWebinar platform is that it allows the audience to both hear and see the speaker via live webcam as well as seeing the educational material.



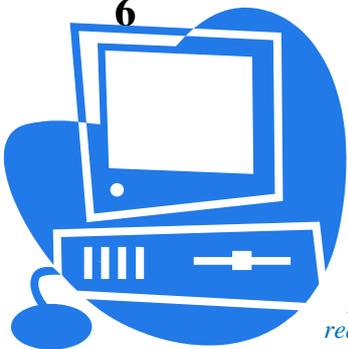
21 y.o. nurse  
pain and swelling in Rt Achilles Tendon "after night duty"  
Lt Achilles Tendonitis one year previous "walking on holiday"  
background low back pain "related to lifting"  
inflammatory features in back pain  
EXAM:  
Achilles Tendonitis  
tender SIs  
reduced lumbar range- forward and lateral

The initial webinar meeting was held in May 2013 and focused on updating GP's on Ankylosing Spondylitis, covering key areas of prevalence, symptom recognition and updating them on current treatment options. The ICGP approved the meeting for 1.5 external CPD points and 1 study leave hour. The GP's that registered and attended the meeting remotely and completing the 1.5 hour session then received their CPD certificates.

There was great positive feedback from those who attended, stating that it was a "convenient way of updating them with relevant educational CPD accredited material" using an innovative approach to solving an age old problem.

From ASAI's point of view it was great that AS was the first topic for these innovative webinars.

6



**Found on the internet:**

*What is Ankylosing Spondylitis?*

*There are many definitions of this disease online, but I find most of them lacking depth after talking with many people with AS, the disease can be very different from person to person and its effects far reaching. So I thought I would put together a picture of what AS looks like.*

*From the horses mouth;.....*

**Check out:**

<http://cigarettesandmeltedchocolate.wordpress.com/2013/07/19/what-is-ankylosing-spondylitis-from-the-horses-mouth/>

Both of the following were mentioned in our last edition of the newsletter but both are worth mentioning again as they are a good resource for younger people living with AS;

- 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)

## Break your Cycle of Arthritis Pain

Learn to break the cycle of arthritis pain by signing up for a Living Well with Arthritis course.

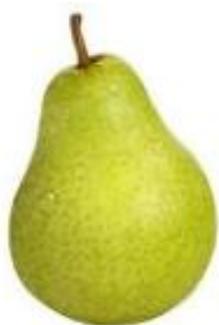


Registration is now open for the autumn round of courses where you will discover how to reduce your pain, decrease your reliance on health professionals and medication and improve your overall sense of wellbeing.

In just six weeks you can learn how to manage your condition and make a big difference to your quality of life.

Check out:

[http://www.arthritisireland.ie/go/programmes\\_events/living\\_well\\_with\\_arthritis](http://www.arthritisireland.ie/go/programmes_events/living_well_with_arthritis)



**P**osture  
**E**xercise  
**A**ctivity  
**R**egularly

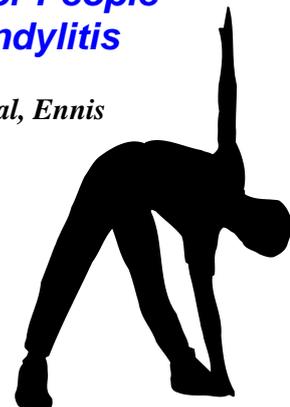
## Ennis Exercise Class for People with Ankylosing Spondylitis

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 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

## Waterford Exercise Class for People with Ankylosing Spondylitis

Monday nights  
Woodlands health & Leisure Club  
Dunmore Road  
Waterford

7 pm until 8 pm

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

or

Catherine Cullinane 087 3867845