



WINTER 2014 ISSUE



Editor's Letter

Welcome to our Winter 2014 edition of AS News.

We hope that this edition finds you all safe, healthy & looking forward to the Christmas break.

As previously mentioned the great response we had to our *SUAS* app meant that we took it onto the android platform. With this in mind we decided on a short publicity campaign to let people know it was now on android. We actually got more coverage this time round than we did first time round when it was originally launched – go figure!

Along with this publicity campaign we also launched “*Don't Turn Your Back On It*” with the help of Abbvie. There is more about this campaign inside.

I attended the Ankylosing Spondylitis International Federation's council meeting in Sofia, Bulgaria where once again I was elected President. More on this inside.

Finally, I would just like to say how pleasing it is that we continue to get such significant assistance and interest in AS from the Pharma industry, Media partners, Arthritis Ireland & now the researchers. Things are looking up!

Merry Christmas & a Happy, Healthy New Year.



Sevise

SUAS

The Publicis D Healthcare team did a great job promoting the app via a novel photo-call when I was joined by Pfizer's Declan O'Callaghan and the Irish National Youth Ballet.

Coverage this time round through October and November was via a number of specialist health publications.

The publications were;

- Irish Examiner Feelgood
- Irish Medical News
- Waterford News & Star
- Medical Independent
- Irish Medical Times
- Irish Pharmacist
- Irish Pharmacy News
- Nursing in General Practice



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DON'T TURN YOUR BACK ON IT

The “*Don't Turn Your Back on It*” awareness campaign has been very successful for us over the last couple of months.

This campaign started when a task force of stakeholders got together in late 2013 to ask some key questions about inflammatory back pain in general and also AS. The group consisted of Physiotherapists, Doctors, Rheumatologists, Patient support groups and some Pharmaceutical company representatives from 5 countries in Europe – France, Germany, Italy, UK and Spain. The task force was co-chaired by Prof. Joachim Sieper and myself, Seoirse Smith.

The focus of attention became “*Diagnostic delay*” (it still takes a long time to be diagnosed with AS for example) and “*Awareness*”.

With this in mind the decision was taken to develop an awareness campaign that would prompt people not to ignore back pain and to seek advice. The campaign, largely developed centrally, was then delivered in each of the 5 countries before being made available to other countries around the world.

As a result of this work ASAI teamed up with Abbvie here in Ireland to deliver the same awareness programme using some of the tools developed centrally but adapted for use in Ireland. This is the model of use all around the world now.

The end result was a website www.yourback.ie, a radio ad, a presence at a key physiotherapy event in Croke Park, Posters & Handouts in some of our universities, a twitter & facebook campaign and a photo-shoot to launch the initiative for media coverage.



Model Roz Purcell, Limerick Hurler & Physiotherapist David Breen and Sports Broadcaster Ger Gilroy launching the campaign.

A S News

The coverage was generated across Newspapers, Magazines and Websites but also Radio, TV and social media.

- The Don't Turn Your Back On It campaign has been featured in four of Ireland's top selling national publications
- The Irish Independent, Irish Sun, the RTE Guide and the Irish Daily Star, all featured the campaign - collective readership of 1,831,100 people.
- Some of Ireland's top online news sites have also coverage the initiative
- Ireland's national TV broadcaster RTE aired a DTYBOI feature on their news and current affairs TV show, Morning Edition. The piece featured a patient and a spokesperson from Arthritis Ireland
- The majority of the DTYBOI coverage to date has included a picture from the launch the campaign as well as a mention of the website and a quote from the campaign.

The total possible Readership / Listenership / Viewership / Unique Users is estimated at 5,934,322 people.

The Radio ad was on Newstalk for 2 weeks from Monday 10th to Monday 24th November and we also had a piece on RTE One – Morning Edition.

The Morning Edition interview was with a person living with AS, Cian Burgess and Grainne O'Leary from Arthritis Ireland.

It is also worth noting that we got support from the GAA and FAI for the campaign.

**BACK PAIN
HOLDING
YOU DOWN?
DON'T IGNORE IT.**

People who have back pain for more than 3 months should visit www.yourback.ie to complete a short symptom checker to assess if their back pain may be inflammatory.

abbvie

This initiative has been funded and organised by Abbvie and is supported by the following public organisations:

ASIF
asai
Arthritis Ireland

REGULATED
Date of registration: October 2014

A Work-able SOLUTION

Arthritis Ireland is calling for an early intervention strategy to keep Ireland "Fit for Work"

Compiled from Arthritis Ireland's Nov/Dec 2014 "Big News"

Turning 18 was certainly a milestone event for Aoife Weller, but not in the way she hoped. Shortly after her birthday, she was diagnosed with rheumatoid arthritis, a condition that affects every single joint from her jaw bone to her baby toe.

Pain and stiffness are her constant, unwelcome companions, and every day presents a new challenge.

In spite of these difficulties, Aoife managed to secure her first full-time job.

But she chose not to tell her employer about her condition and struggled quietly for nine months to keep it under wraps.

She admitted: *"It was a constant battle of hiding my painful and swollen joints from my coworkers. That, as well as hiding the constant colds, flus and infections I got as a result of my compromised immune system."*

Hit by a bad flare-up, Aoife was on sick leave for weeks.

Back at work, she told her employer about her condition and was delighted with his response. He offered her flexible working hours, re-located her desk to minimise the distance she needed to walk and ergonomically corrected her work station to ease the strain on her joints.

This arrangement worked for some time. But as the company expanded, Aoife's workload increased, with the added stress exacerbating her condition. She and her boss discussed moving to another role within the company or working from home.

Yet Aoife knew this wasn't viable for the company in the long-term.

With a heavy heart, she felt she had no choice but to leave. She recalled: *"I knew that both myself and the company had tried our best to come up with a solution which would help me stay. I loved my job and I particularly loved the people I worked with. Anyone who has had to give up work due to illness will tell you that the thing they miss most about working is the social aspect"*.

Unfortunately Aoife's dispiriting story is mirrored in workplaces nationwide. Arthritis is among a range of

To order
Arthritis Ireland's
Fit For Work booklets for
employers & employees
call the National Helpline
on
1890 252 846 or download
them on
www.arthritisireland.ie

A S News

musculoskeletal (MSDs) conditions which impact heavily on a person's ability to hold down a job. Every year, they account for seven million lost working days, costing the Exchequer €275 million. Add the cost of overtime payments to cover absence, lost productivity and costs to the healthcare system, and the true bill is closer to €750 million.

But despite this annual haemorrhaging of finances, nothing has been done to tackle illness-related workplace absenteeism – until now.

Arthritis Ireland is a founding member of the Fit For Work coalition, a group of organisations calling for an effective early intervention plan which will keep more people in work and save €55 million a year. It's an ambition that is based on research.

A survey by Arthritis Ireland shows that 77 percent of unemployed participants either lost or quit their job because of their MSD. The fall-out is devastating.

Aside from the loss of earnings, unemployment can leave people feeling socially isolated and without a sense of purpose. As the illness increases its grip over a person's life, returning to employment or training becomes even more difficult.

Yet in many cases, this sorry situation can be avoided. And Arthritis Ireland is leading

the way, producing two booklets which offer practical advice for employees and employers. They also provide information on how experts like

occupational physicians, occupational therapists and occupational health nurses can help people to manage their condition in the workplace.

Had this support been available for Aoife Weller, life today could be very different.

The 26-year-old explained: *"If I'd known or my employer had known about the Fit for Work principles like early intervention, if I'd known to go and see an occupational health specialist, then I believe there may have been a chance for me to stay in that job. That is why I believe that it's so important for the Government to adopt and promote early intervention so employees and employers know the full breadth of options available."*

Today, she's looking for a part-time job, and hopes that she – with the support of her future employer – can gradually build up to full-time hours.



Yet for this to happen, we need Government support so that organisations nationwide can adopt an early intervention plan.

It's a "no-brainer" money-saving idea, but more importantly, it will make a positive difference to the lives of thousands of people living with arthritis and other conditions.

About Fit for Work

Fit for Work aims to better align the work and health agendas in Ireland, bringing together key stakeholders to drive important policy changes.

We believe that governments, business, the healthcare community and patients need to collaborate to deliver policies that enable those living with musculoskeletal disorders (MSDs) to maintain active healthy lives and participate in the workforce, which also serves to maintain the economy's productivity and competitiveness.

The Fit for Work project has a particular focus on the impact of MSDs and work participation and absenteeism. We examined the impact of MSDs on an individual's ability to work and the adequacy of treatment and how this impacts on Ireland's economy and society as a whole. We are now working to ensure that these findings and recommendations are used to inform both policy and practice by government, healthcare professionals and employers in Ireland.

The Fit for Work project has looked in some detail at the impact that MSDs have on the working lives of thousands of Irish workers, the adequacy of the treatment and support they receive, their experiences at work, the effect of their condition on their family and colleagues, and the human and financial costs involved.

More specifically, this project has sought to address each of the following questions:

1. *What is the impact of MSDs on employment and economic performance in Ireland?*
2. *How is this likely to change in the context of future demographic, workforce and lifestyle changes?*
3. *What is the relationship between work and MSDs?*
4. *What impact do biological, psychological and social factors, including workplace factors have on MSDs?*
5. *How well do employers, governmental bodies, GPs and occupational health professionals understand and deal with MSDs as they relate to the workplace?*
6. *How well equipped is the health sector to provide early intervention, rehabilitation and other support for people with these conditions?*
7. *What early interventions can policy-makers and employers deliver to ensure that those with MSDs retain their jobs, maximise their quality of*

working life and their contribution to society and maintain access to employment?

It is well documented that an individual's ability to work is of vital importance to both their own personal health but also to the health of the wider economy. Yet conventional measures to improve productivity fail to take account of one of the most serious barriers to growing prosperity: poor workforce health. Ill-health, even in a favourable economic climate, can reduce the aggregate level of labour productivity in an economy and damage the competitiveness and effectiveness of private and public sector organisations.

That is why Arthritis Ireland is leading the development of the Fit for Work programme in Ireland. We are advocating that improvements in early intervention, treatment and return to work practices could help people with even severe Musculoskeletal Disorders (MSDs), such as arthritis, either stay in work or return to work sooner.

Fit for Work Coalition members

Name	Institution / Company
Dr. Don Thornhill	Independent Chairperson
Mr. John Church	Arthritis Ireland
Dr. Joe Clarke	HSE Primary Care Clinical Lead
Dr. Maurice Collins	Irish College of General Practitioners
Ms. Christina Doyle	Irish Rheumatology Nursing Forum
Prof. Oliver Fitzgerald	HSE Rheumatology Lead
Ms. Martina Fitzpatrick	Irish Society of Chartered Physiotherapists
Dr. David Gibney	HSE Rheumatology GP Lead
Ms. Paula Guerin	AbbVie
Mr. David Harney	Irish Life Corporate
Dr. Martin Hogan	Royal College of Physicians in Ireland
Ms. Esther Lynch	Irish Congress of Trade Unions
Ms. Eimear Lyons	Association of Occupational Therapists of Ireland
Dr. John McDermott	VHI Corporate Solutions
Ms. Kara McGann	Irish Business & Employers Confederation
Ms. Grainne O'Leary	Arthritis Ireland
Mr. Francis Power	Health & Safety Authority
Dr. Robert Ryan	Royal College of Physicians in Ireland
Mr. Seoirse Smith	Ankylosing Spondylitis Association of Ireland
Dr. Frances Stafford	Irish Society of Rheumatology



ASIF Council Meeting

The 11th ASIF Council meeting took place in Sofia Bulgaria between the 6th and 8th of November with delegates from 20 countries.

It seemed such a short time since the last Council meeting was held in the Izmir Turkey, hosted by our good friends and colleagues from ASHAD.

In fact it had been three years since our last Council meeting and those years have been eventful both within the global AS community and the world at large.

President's Report

As the President I delivered a short report on the activities of the Executive Committee in those 3 years highlighting;

- The Executive committee continue to “meet” regularly, usually monthly, using internet technology to have virtual meetings
- We had very successful booths at the EULAR conferences in Berlin in 2012, staffed by DVMB, in Madrid in 2013 staffed by CEADE and in Paris in 2014 staffed by ASAI
- World AS day continues to gather momentum with more member organisations holding events in early May and with ASIF endorsing the “Walk Your AS Off” initiative leading up to World AS day
- As an executive we have continued to try and work with the connections we have made with a number of other similar organisations in related areas – IFPA, EFCCA & AGORA. We hope we can develop these relationships further
- We have had discussions with a lot of the major pharmaceutical companies, which we hope to develop further over the coming years;
 - Abbvie, Cellegene, Janssen & Pfizer
- We have rebranded of ASIF and given it a sharper identity
- We have redesigned and rebuilt the main website which is now delivered in a number of different languages
- We have started to talk about ASIF and its future

Council Meeting Workshops

On the topic of ASIF and its future, we conducted some workshops at this Council meeting to look at the next steps for ASIF as an organisation;

- What need or needs does ASIF fill?
- Should it change?
- If so how?

The workshops were very effective as it presented the opportunity for all of the delegates to meet in smaller groups to discuss and contribute on each of these topics.

These are topics that are of interest to all AS associations including ASAI.

The normal Meeting activities

As well as the other usual meeting activities, e.g. minutes or previous meeting, matters arising etc. etc. there was the election of Executive Committee. The executive for the next period is;

Executive Committee Members (left to right):

- Dr. Tuncay Duroz – Turkey
- Mr. Zhivko Yankov – Bulgaria
- Mr. Raj Mahapatra – United Kingdom
- Ms. Ruta Grigiene – Lithuania
- Seoirse Smith (President) – Ireland
- Michael Mallinson (Secretary) – Canada
- Hedley Hamilton (vice President) – United Kingdom



There were also presentations in support of applications to join ASIF from Russia, Netherlands and Lithuania.

Other Topics

There were a number of other very interesting presentations on a NASS Patient Survey in the UK, NASS Research Priorities in the UK and ASIF & Social Media.

The key note presentation was from Prof. Peter Taylor from the University of Oxford on "Biosimilars in rheumatic disorders: the science behind them and their place in clinical practice".



Physical Activity in Your Area

Compiled from Arthritis Ireland's Nov/Dec 2014 "Big News".

AQUA AEROBICS AND HYDROTHERAPY						
	Location	Day	Time	Class	Cost	Contact
Longford	Longford Arms Leisure Centre	Tuesdays	11.30am	Aquafit	7 sessions for €45 or €10 per class	Marta on 085 7341790
	Longford Arms Leisure Centre	Wednesdays	8pm	Aquafit	7 sessions for €45 or €10 per class	Marta on 085 7341790
Sligo	Avena Leisure Centre, Ballisodare	Tuesdays	11.50am - 12.45pm	-	-	Mary on 086 8609311
	Sligo Park Hotel	Friday	11.30am	-	€30 for 6 sessions	Maura on 086 0711843
Kerry	Aqua Jogging, Aqua Aerobics and Mobility exercise	TBC	TBC	Aqua-jogging Aqua-aerobics	-	Tom on 087 6723442
Kildare	St Raphael's Hydrotherapy Pool, Celbridge	Wednesdays	5 - 6pm	Swim & Aqua Exercise	€5 per class	-
	Westgrove Hotel, Clane	Wednesdays	11pm	Aqua Class	-	-
	Westgrove Hotel, Clane	Fridays	2pm	Aqua Class	-	-
	The Gables Leisure Centre, Newbridge	Wednesdays	2 - 3pm	-	€10 including swim/aqua class and use of Jacuzzi, leisure centre.	-
Louth	Energie Gym, Drogheda (M1 Retail Park)	Thursdays	12pm	Arthritis Aqua flex	€10 per class	Marie on 087 6336 (after 6pm Mon-Fri)

SEATED EXERCISE CLASSES						
	Location	Day	Time	Class	Cost	Contact
Kildare	Newbridge	Mondays	11am	Seated Exercise	-	Claire on 045 433803
	Kilcullen Parish Centre	Tuesdays	10:30am	-	-	Claire on 045 433803
	Suncroft Community Centre	Tuesdays	2:30pm	-	-	Claire on 045 433803
Dublin	Johnstown Parish Pastoral Centre, Killiney (in association with Siel Bleu)	Thursdays	12:30 - 1:30 pm	Adapted Physical Activity	-	01 2831504
	St Brigid's Parish Centre, Killester	Fridays	11.30am - 12.30pm	Adapted Physical Activity	€4 per class	Mary on 086 1037009
Mayo	Newman Institute Ballina	Mondays	7pm	Seated Exercise	-	-
	TF Royal Hotel Castlebar	Tuesday	7.15pm	Seated Exercise	-	-

Arthritis Ireland Walking Groups



You should also check out the walking groups in your area on www.arthritis.ie.

Remember that physical activity & exercise is a critical part of managing your AS effectively for the best outcomes. The advantages of all these groups is that you will have help/assistance with your exercise to make sure you are being careful with the added advantage of a social dimension of exercising together.

Don't forget the ASAI weekly exercise groups in Ennis & Dublin and the Mater Hospitals weekly physio session!

Remember PEAR!

Posture - **E**xercise - **A**ctivity - **R**egularly

