



THE MAGAZINE OF THE NATIONAL ANKYLOSING SPONDYLITIS SOCIETY

# ASNews

SPRING 2018

## My Great British Bake Off Experience

James Hillery shares his experience. Page 17



## Join us for Members Day 2018

Page 4

## The Summer Raffle is back!

Page 5

### ALSO IN THIS ISSUE:

- First steps to university
- NASS Branches win award
- Research update

## Who said you had to hang up your boots?

Walking football is an excellent way of staying fit and healthy. Page 11



[WWW.NASS.CO.UK](http://WWW.NASS.CO.UK)



## All About **NASS**



**Dr Dale Webb**  
Chief Executive  
dalewebb@nass.co.uk



**Sally Dickinson**  
Information, Communications  
& Helpline  
sally@nass.co.uk



**Amardeep Gill**  
Supporter Engagement  
amardeep@nass.co.uk



**Jill Hamilton**  
Campaigning, Policy & Projects  
jill@nass.co.uk  
Jill mainly works from home in  
Wales so if you do need a chat  
please call her on 07875 107 747



**Paul McGowan**  
Branches and Helpline  
paul@nass.co.uk



**Jakub Ochmanski**  
ASone and AService Near You  
jakub@nass.co.uk



**Justyna Potiopa**  
Finance and Administration  
office@nass.co.uk

## Welcome!

Welcome to our new-look Spring 2018 issue of AS News, my first as NASS CEO. And what a great way for me to start to understand how AS impacts on your lives.

James's article on taking part in the Great British Bake Off is a fantastic insight into what it's like to take part in a demanding TV show while holding down a busy job and family life and living with pain and stiffness. And David's article is a searingly honest account of the impact AS has had on his life.

Over the past few months I've been out meeting our Trustees and members to understand what they want from NASS as a charity. I'm looking forward to meeting lots more NASS Members at Members Day in June. Do make sure you reserve your place in plenty of time as we always have a full house.

I'd love to chat about what you want from NASS so, if you can't make it to Members Day, do drop me a line.

Dr Dale Webb

### You can find us at:

172 King Street  
Hammersmith  
London W6 0QU

**You can call us on:** 020 8741 1515

**You can see our website at:** [www.nass.co.uk](http://www.nass.co.uk)

### You can chat and share experiences on:

#### Facebook

NationalAnkylosingSpondylitisSociety

#### Twitter

@NASSchiefexec  
@NASSexercise

**Editor:** Sally Dickinson email [sally@nass.co.uk](mailto:sally@nass.co.uk)

**ISSN:** 1357-4698

Produced by Wells Printing

The copy date for the Autumn 2018 edition of AS News is Friday 7 September 2018



# NEWS IN BRIEF

## Changing times at NASS

Raj Mahapatra, NASS Chair

In November we said goodbye to Debbie Cook as CEO. Under Debbie's leadership NASS was able to achieve significant impact in so many ways.

We were able to influence policymakers to introduce national clinical guidelines for AS and better access to a broader range of biologic therapy.

Across the UK we engaged parliamentarians, GPs and other clinical communities. We opened new branches, developed new information and resources and set research priorities based on the needs of people affected by AS.

Debbie worked hard to build effective relationships and earned the respect and admiration of all who worked with her. Debbie has left behind an impressive legacy and on behalf of staff and trustees we want to thank her for her outstanding commitment to helping improve the lives of people with AS.

Thank you Debbie and well done!



[www.nass.co.uk](http://www.nass.co.uk)



**Dale Webb joined NASS in November. Our goals now are to make AS more visible, strengthen the community of people interested in AS and ensure that we provide the best support and information that we can.**

Dale and the team are planning a series of NASS conferences across the UK over the next 18 months as the start of a rolling programme of events. We will bring together people affected by AS, NHS service providers and commissioners, researchers and other interested parties to look at the quality of AS care locally, forge new relationships and build our base of supporters so that we can raise public awareness.

In the summer we will launch a new NASS website. It will have an even stronger focus on providing support to newly diagnosed people, an interactive guide to the national clinical guidelines for AS and it will showcase the community of people who work with us in so many ways to help us achieve our mission.

It's simply not acceptable that the average delay to diagnosis for someone with AS is still 8.5 years. We're determined to renew our efforts

to tackle this. In the autumn Dale will be meeting with a range of clinicians to understand exactly where those delays are occurring, why and what can be done to reduce them. This will help us decide what we need to do to have the biggest impact. We will also hold a parliamentary event in November to raise awareness about this delay as well to thank those clinicians and health care professionals who are leading the way to improve care quality.

Thank you all for your continued support and encouragement. It really does mean a great deal to us to have such an active community of people affected by AS. We look forward to taking NASS to the next stage of its development, building on Debbie's legacy and identifying new ways to improve diagnosis, treatment and long term support.

AS NEWS Spring 2018 | 3



# Join us for MEMBERS DAY 2018

This year we will be holding our annual Members Day at St Mary's University in Twickenham.

We are delighted to be partnering up with Anxiety UK who will run a workshop, Middlesex Football Association who will be running a walking football tournament and Chi Running UK who will be adapting their techniques to give us a taster in Chi Walking.

There will also be workshops on Fatigue and a new feature Exploring AS, run by NASS Trustees Dr Andrew Keat and Claire Harris, ideal for those who are newly diagnosed, would like to discuss the condition in more detail or would like to know more about the latest in treatment and understanding of AS.

Regular features will return as well including the AGM, Friends & Family and Chat with an Expert. Refreshments and lunch are included free as part of the day. You can sign up online via the NASS website or complete the form on the back cover of the magazine.



<b>Venue:</b>	St Mary's University, Twickenham
<b>Date:</b>	9 June 2018
<b>Time:</b>	9.30am – 4.00pm
<b>Highlights:</b>	Workshops on Fatigue and Anxiety plus Chi Walking and Walking Football
<b>Who can attend:</b>	Paid up NASS members plus one guest
<b>Sign up:</b>	Online at <a href="http://www.nass.co.uk/members-day-2018">www.nass.co.uk/members-day-2018</a> or by post using the form on the back cover
<b>Cost:</b>	Free – with a £10 deposit per person, refunded on attendance



## Call for nominations to the Council of Management

Raj Mahapatra, NASS Chair



Every year at the NASS AGM and Members Day, NASS members get the opportunity to stand for election to the Council of Management. The Council of Management is the term we use to describe our board of trustees which includes both people living with AS and healthcare professionals.

The role of a trustee is to make sure the strategic aims and objectives of the charity are achieved. You will be responsible for the overall strategy of the charity along with other trustees, and will be asked to vote on important decisions.

You will need to attend four meetings per year which are held on Saturday mornings. If you are interested in becoming a trustee please email Jill for a full role description and nomination form. The closing date for nominations is 4 May 2018. You will then be asked to complete an eligibility declaration and provide a biography and photograph for the elections at the AGM at St Mary's University in Twickenham on 9 June 2018.

*Please note that you can only be nominated to be a trustee if you are a fully paid up member of NASS as set out in the Constitution.*

[www.nass.co.uk](http://www.nass.co.uk)

## The Summer Raffle is back!

**Enter for your chance to win £1,000!**

For your chance to win, simply complete and return your tickets to NASS along with your money. **We've enclosed one book of 30 tickets for you.** All we need on each ticket is your name, postcode and a phone number so we can reach you if you've won!

**TOP  
PRIZE  
£1,000**

**SECOND  
PRIZE  
£250**

**THIRD  
PRIZE  
4 X £50  
EACH**

The closing date for entries is 6 September, with the draw on 7 September. Good luck!

Every 10 tickets sold pays for a call to our helpline, providing vital guidance and support to anyone affected by AS.



## CONGRATULATIONS to the winners of our Christmas Cracker Draw

Our lucky winners are:

**1st prize - FitBit - Mr D Adamson**

**2nd prize - Amazon Kindle Fire - Mr A Howard**

**3rd prize - £50 Red Letter Day voucher - Mr P Rigg**

We hope you enjoy your exciting prizes!

Thank you to everyone who took part. You helped us raise a brilliant £2,350 - enough to provide information-packed guidebooks to over 1,000 people newly-diagnosed with AS.



# WHAT'S NEW AT NASS

## We need your consent to stay in touch



**With new General Data Protection Regulations (GDPR) being introduced in May 2018 we need your consent to contact you further on the work of NASS.**

We have emailed everyone and will send a letter to those who didn't reply or for whom we don't hold an email address. If you haven't responded yet do get in touch with your contact preferences. If you have not let us know about your contact preferences by 25 May 2018 we will not be able to contact you any further and your contact information will be withdrawn from our records

Please note consent can be withdrawn at any stage by contacting [data.officer@nass.co.uk](mailto:data.officer@nass.co.uk) or any member of the NASS team.

## Understanding the NICE Spondyloarthritis Guideline

The NICE Spondyloarthritis Guideline was published around a year ago. It sets out guidance on how AS should be managed and diagnosed. We produced posters to help GPs and hospital specialists understand how it should be used.

In May we hope to launch an interactive guide to the guidelines on the NASS website. It will have some great videos and will link to other areas of the NASS website.

## Rheumatology services near you

Our Helpline has always had lots of calls about what AS services are on offer in your area. Jakub has been contacting all the rheumatology departments in the UK and you can now search for services near you using your postcode. We are still busy adding new departments every week so it's an area we will build up over time.

[www.nass.co.uk/nass-branches/aservice-near-you](http://www.nass.co.uk/nass-branches/aservice-near-you)



## NEW website

The team are currently working hard on developing a new website for NASS. We hope that it will be ready for you by the end of the Summer, so keep an eye out.

*We have opened two new branches in 2018*

## New NASS Branches

**NASS Whittington** is based in North London at the Whittington Hospital. The branch meet every Wednesday 18:30 to 19:30 for gym exercise. Contact [whittington@nass.co.uk](mailto:whittington@nass.co.uk) if you'd like to get involved.



**NASS Belfast** meet every Tuesday from 18:30 to 19:30 at Queens Physical Education Centre. Each gym session is followed by a 30 minute time to chat. Contact [belfast@nass.co.uk](mailto:belfast@nass.co.uk)





## Dr Keat hangs up his stethoscope

Dr Andrew Keat's patients at Northwick Park Hospital were sad to hear that he retired from clinical practice at the end of 2017. He said ***"I am really sad to lose touch with so many people, some of whom I have known for many years but I have reached the stage when needs must"***.

After an academic career since the early days of HLA-B27, Dr Keat moved to Northwick Park Hospital in 1995. There he set up the Arthritis Centre including the Spondyloarthritis clinic run with physiotherapist Mrs Claire Harris. He was Clinical Director of Orthopaedics, Rheumatology and Rehabilitation at Northwick Park hospital for 5 years and was held in high regard and with great affection by many of his AS patients. His department won the Hospital Doctor Rheumatology Department of the Year award in 2004.

*Dr Keat has made a huge difference to my life. Just having someone that believes you, and treat you like a person and not like a number.*

*A brilliant and charming consultant who listens, gives freely of his time and knows me better than my GP. His sense of humour is a tonic in itself.*

*Dr Andrew Keat is a great source of comfort and reassurance. He works tirelessly to support myself and others with AS. I am so thankful for all he has done to improve my quality of life. Thank you Dr Keat.*

*It is very difficult to put into words how much Dr Keat has helped me out over the years. I have had many complications with my AS and his empathy and guidance have helped no end in my leading as much of a 'normal' life as I can for over 30 years.*

He has received many prestigious awards throughout his career, including the Michael Mason medal, the Lettsomian medal and the NASS-Frink award. He is a member of various learned societies and was a co-founder and chairman of the British Spondyloarthritis Society, a registered charity seeking to advance research and clinical service in the field. He lectures and writes extensively and widely on AS.

We are happy to report Dr Keat will remain very much involved in the work of NASS. He remains a NASS Trustee and much valued member of our Medical Advisory Board. He will be at Members' Day this summer, running the 'Exploring AS' session with Claire Harris. You'll also be able to book a slot with him in the 'Chat to an expert' session.



## A sad goodbye

Raj Mahapatra, NASS Chair

After ten years of going above and beyond in his service to NASS, our Treasurer, Simon Frost, is standing down. His preparation and presentation of the accounts has always been exemplary and those who have attended an AGM whilst he has been in post will have to agree that he has made understanding the accounts genuinely fun!

To the staff and Trustees, he has been dependable and insightful.

NASS has benefited greatly from his professional advice and guidance over the years. On a personal note, as Chair it has been of great comfort to know that I have had someone with such great depth of experience working by my side. He will be a very hard act to follow!

On behalf of all of us, I thank him for all that he has done



## MEDICINE NEWS

### NICE recommend golimumab as an option for non radiographic axial spondyloarthritis

NICE (National Institute for Health and Care Excellence) have announced golimumab (Simponi) is now recommended, within its marketing authorisation, as an option for treating severe non-radiographic axial spondyloarthritis in adults whose disease has responded inadequately to, or who cannot tolerate, non-steroidal anti-inflammatory drugs.

NICE already recommends adalimumab, etanercept and certolizumab pegol for treating non-radiographic axial spondyloarthritis. Because golimumab has similar overall health benefits and costs to adalimumab, etanercept and certolizumab pegol, NICE have recommended it for treating non-radiographic axial spondyloarthritis in the NHS.

It means that there's another option for people with non-radiographic axial spondyloarthritis.



### Cimzia can now be considered during pregnancy and breastfeeding

The European Medicines Agency (EMA) has approved the label change for UCB's CIMZIA® (certolizumab pegol), making it the first anti-TNF for potential use in women with ankylosing spondylitis during both pregnancy and breastfeeding.

Data submitted to regulatory authorities included first-of-their-kind clinical studies, including CRIB and CRADLE demonstrating minimal transfer of CIMZIA® through the placenta and breast milk from mother to infant.





# Biosimilars set to launch for adalimumab

**Back in 2016, a biosimilar for etanercept was launched. Lots of people on Enbrel were switched across to the biosimilar.**

Later this year we expect biosimilar versions of adalimumab (Humira) to be launched. We have attended meetings run by NHS managers and we believe rheumatology departments will be asked to switch people on Humira across to the biosimilar versions quite quickly.

## What are biosimilars?

Biosimilar medicines are developed to be highly similar to a biological medicine which has already been approved and made available for patients.

They can be developed by manufacturers once the original patent for the product has expired. They are called "biosimilar" because the molecular structures are so complex that it is not possible to produce an absolutely identical drug to the original - referred to as the "originator". With less complex drugs, such as non-steroidal anti-inflammatory drugs, it is common for different manufacturers to produce identical "copies" of the originator drug, known as "generic" drugs.

## Why make biosimilars?

Biosimilar medicines are developed to provide alternative products, usually at a lower cost than the original biological medicine.

Both Inflectra and Remsima have been approved as biosimilar versions of infliximab and Benepali and Erelzi were approved as a biosimilar of etanercept (Enbrel).

## What are the regulations for biosimilar medications?

Once approved, a biosimilar medicine is recognised to be a highly similar version of a biological medicine and should have comparable quality, safety and effectiveness.

Biosimilars introduced into the UK market first have to be approved by the European Medicines Agency (EMA). They go through a regulatory process which requires comparability studies that demonstrate equivalence to the originator product in terms of quality, efficacy and safety.

## Our recommendations

If you are contacted by your rheumatology department about switching we would expect:

- The initial letter or contact should include information about the new medication
- There should be an opportunity for you to discuss the switch in more detail if you want – whether that's in a group meeting or a one to one discussion with a member of your rheumatology team
- Training on the new device to be offered

Do get in contact with Sally or Paul on the Helpline if you have any concerns.



## NASS Fundraising choir concert in commemoration of Armistice Day

Dr Dale Webb, NASS CEO

**November 10 2018**  
**7.30 pm at the Welsh Church of Central London, W1W 8DJ**

As the new CEO at NASS I am keen to do my own personal fundraising for this incredible charity. The best way that I know how to do that is through music. In my spare time I'm a choral conductor and have the privilege of leading two choirs. So I have decided to put on a concert this autumn in support of NASS with my choir Vocalium.

The programme is called 1918: Remembrance, Peace and Light. It will commemorate 100 years since Armistice Day through music and readings. The programme will remember composers who fought during World War One or who served the war in some capacity – including George Butterworth, Ivor Gurney, Ralph Vaughan Williams and Maurice Ravel. We will perform Gurney's Since I Believe in God the Father which only come into print in 2018.

We remember these composers in more recent works including Kiss the Bairs. This was written in 2016 by BAFTA award winner and NASS supporter Jessica Curry in collaboration with Poet Laureate Carol Ann Duffy. It forms part of a larger work called The Durham Hymns. I'm delighted that Jessica will be attending the concert and she will explain the letter from a serviceman to his wife which forms the backdrop to Kiss the Bairs.

The timing and venue for the concert are poignant. First, it takes place on the eve of the 100th anniversary of Armistice Day. Second, the concert will be given in the Welsh Church of Central London where Prime Minister Lloyd George was a regular attendee. It is sobering to think that he sat in the pews 100 years ago with the very heaviest burdens of state resting on his shoulders. Lloyd George went on to establish the Cymanfa Ganu – a festival of sacred hymns – to commemorate those who died on all sides of the conflict.

I would love to see lots of NASS supporters at the concert. Please do come. A chance to support NASS and to pay our respects to those who fought and died for our freedom 100 years ago.



Tickets are £12.50 per head plus £1.25 booking fee: [www.wegotickets.com/event/428497](http://www.wegotickets.com/event/428497)



# MOVE TO IMPROVE

## Who said you had to hang up your boots?

Why not try walking football?! It's different to regular Association Football and is really taking off in the UK. It allows people who have loved the sport all their lives to once again safely get back to playing. Regular football is a high impact sport and many people with AS stop playing out of fear of injury or because it causes flares.

Walking Football has very specific rules that outlaw running and allows either no contact or only minimal physical contact between players. Over-head height restrictions and indirect free kicks ensure that the sport is played safely.

Teams are either 5 or 6-a-side and can include men and women. Games are played at a slower pace, often on state of the art 3G artificial grass pitches. This reduces the threat of pain, discomfort and injury, with players briskly walking through matches.

Walking football is an excellent way of staying fit and healthy. It's great to do something you enjoy rather than exercise being a chore.



## Fancy giving walking football a try?

We are running a walking football session at Members' Day this year. May the best team win!

# A Gardeners' World

David Joseph is 80 and has lived with AS for many years. He finds gardening a great way to keep active and help manage his AS, and has grown vegetables in his garden for 25 years.



We would also like to take this opportunity to thank David for his wonderful donation of £100 to help NASS support others like him

David has lived alone since his wife died, and while his AS has made it harder for him to get down on his hands and knees to tend to his vegetables, he has no plans to stop any time soon.

David says:

*"Whatever I want to do, I can find a way. And if I can't, I'll find someone who can do it for me! I've had both hips replaced, have asthma and high blood pressure but I'm still doing it. Years ago my neighbours used to grow vegetables too, but some died and I'm the only one still keeping it up."*

This summer, one vegetable in particular stood out.

*"I noticed this marrow at the beginning of July. It just kept growing. My daughter told me to leave it and see what happens so I did – and it just grew beautifully."*



## A mindful approach to **IMPROVEMENT** THROUGH MOVEMENT

Gray Caws, Master Instructor and Director of Chi Running UK

*The Chi Walking and Chi Running method aims to improve efficiency of movement, reduce the risk of injury and training enjoyable rather than a chore to be endured.*



**“True balance comes from perfect positioning of centres of gravity”**



Based on age-old principles of Tai Chi, key focuses include postural alignment and relaxation, optimal breathing, balance, and working with gravity. What I believe sets it aside from many other fitness programmes is that it considers not only physical but also psychological effects on movement. Through a mindful approach to practice and emphasis on body awareness, it highlights how bad habits are formed and good ones learned.

### **The foundation for efficient movement**

Good posture and optimal breathing form the foundation on which to build a safe, effect training programme. No-one will have perfect posture and the last thing you should do is try and force a specific posture. Rather, we should consider where we are at the moment and look to create a gradual, progressive change where possible.

### **Standing posture stance**

A good starting point is a standing posture stance.

Aim for your pelvis to be balanced over your feet (with a little more of the weight through the heels). Within the pelvic girdle area is the body's centre of gravity. In Tai Chi this area is referred to as the dantien – the energy centre.

Now balance your ribcage over your pelvis and the head on top of the spine.

Gait Analysis: Normal and Pathological Function focuses on human gait analysis by Perry and Burnfield (1992) describes good standing posture as ‘quiet standing’.

Consider also “Proper posture is believed to be the state of musculoskeletal balance that involves a minimal amount of stress and strain on the body” (Yip et al, 2008).

### **The Oxygen Advantage**

Alongside Chi Running and Walking, I also teach The Oxygen Advantage breathing method. This addresses breathing pattern disorders in everyday, looks at how to improve focus and concentration, aerobic fitness, and reduce breathlessness and exercise-induced asthma.

A common misunderstanding is that the bigger the breath we take, the more oxygen we deliver to the body. This is not the case. You only have to see someone hyperventilating or having a panic attack to realise this is not optimal breathing. We should not confuse a big breath with a deep breath. In general, the body requires a rhythmical breathing pattern of 10-14 breaths per minute.

You can find out more about Chi walking and running on these websites: [www.adventuresinmovement.com](http://www.adventuresinmovement.com) and [www.chirunning.uk](http://www.chirunning.uk) We are also delighted that a Chi Walking session at this year's Members Day run by Gray and NASS supporter Elaine Jackson



## MOVE TO IMPROVE

### Standing posture breathing exercise

In standing posture, bring your attention to your breathing. Keeping the lips lightly together, notice the slightly cooler air coming in through the nostrils, and slightly warm leaving. Don't over-breathe or take big breaths. Spend time following the breath, keeping it soft and light.

After a few minutes, change the focus of attention from the nose to the diaphragm. A nice visualisation is to sense that you are breathing into the heart. Again, don't push or force anything, just follow the breath.

### Take a step

When working on standing posture and breathing, take time to sense and feel the structural efficiency of your body. You can then take this sense into movement, walking and running. Maintaining structural integrity during movement will ensure minimal stress and strain on the muscles and joints at all times, allowing movement to be fluid, efficient and restorative.

### Posture exercise

This gentle neck flexion and extension exercise will help improve mobility of the neck and thoracic spine. Again, just to emphasis, please check with a health professional if you have fusion or kyphosis (forward stoop) with your AS.

1. Stand tall, with pelvis balanced over feet, ribcage over pelvis and head on top of the spine.
2. Gently raise your eyes and look up to the ceiling, tilting your head back as far as it will comfortably go. Think of your neck beginning in the thoracic spine and elongate from there.

3. Now gently tilt your head forwards and tuck the chin towards the chest, once again getting a sense of elongation of the thoracic spine.

This exercise should not be rushed or forced. You should maintain gentle, rhythmical breathing throughout. If you feel any pain stop immediately.

## National Institute for Health Research confirms exercise improves symptoms and function for people with AS

Although exercise has long been recommended for people with AS, there are few studies which have properly tested the effectiveness of exercise. Medications have also changed a lot in recent years and it's important to understand whether these new medications have altered the benefit of carrying out exercise.

This study looked at a range of exercise programmes, and examined whether exercise had a lesser or greater benefit in studies which included people receiving anti TNF drugs.

### Findings

- Exercise improved symptoms on the BASDAI scale. Exercise groups scored on average 0.90 points lower than control groups (95% meta-analysis of all eight studies).
- Exercise also improved day-to-day function on the BASFI scale.
- Exercise gave apparently greater benefit when limited to the four studies that included people who received anti-TNF therapies.

### What does current guidance say on this issue?

The NICE Spondyloarthritis Guideline which was published in February 2017 recommends people should be referred to a specialist physiotherapist to start an individualised, structured exercise programme. This should include deep breathing and aerobic exercise, stretching, strengthening and postural exercises, spinal extension and a range of motion exercises for the spine.

Exercise and stretching are also emphasised as a component of self-care during disease flare-ups.

### What does it mean?

The findings show that exercise gives measurable improvements in symptoms and physical function scores in people with AS.

The results support NICE guidelines that exercise should be a core component of care in people with AS.

It's important to keep exercising even (or especially!) if your symptoms are well controlled with anti TNF therapy.

It would be nice to know more about the type of exercises which benefit people with AS at different times, for example where there is extensive fusion or where people are having a major flare.

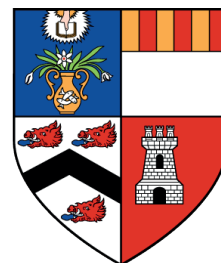


Trunk side stretch

Hamstring stretch

Lying down

# RESEARCH UPDATE



UNIVERSITY OF  
ABERDEEN

Dr Gareth Jones  
*Epidemiologist, University of Aberdeen*

## Results from the BSRBR-AS

The British Society for Rheumatology Biologics Register for Ankylosing Spondylitis (BSRBR-AS) has been collecting data since December 2012. Run from the University of Aberdeen, data is gathered from around 2800 AS patients from over 80 NHS rheumatology departments across the UK.

Data is collected from clinical notes, and by patient-completed questionnaires. We owe a huge debt of gratitude to the patients who complete the questionnaires (some, have completed more than ten!) but we are also enormously grateful to the consultants, research nurses and other clinic staff who assist in the data collection. Without these people the study – quite literally – could not go ahead.

Originally set up as a safety register – to monitor the long-term safety of biologic medication – the study is now a valuable resource to answer other important questions about AS.

Recruitment to the study ceased in December 2017 and the last patient will complete their final follow-up questionnaire in June 2018. It is sad that the register is coming to a close. However, scientifically, it's just starting to get exciting as we begin to analyse the data. Here, we outline a few of the recent analyses we have been conducting.

## Absenteeism and work withdrawal

For working age adults, the ability to work is important – not only from an economic standpoint but also for social and psychological health. Research has shown that, among those with AS who are employed, presenteeism (reduction in workplace productivity, due to ill-health) is more of a burden than absenteeism (time off work, due to ill-health).

Although it seems intuitive that these two concepts are related, the extent to which this is true is not well understood and it is unknown, for example, whether they relate to subsequent job loss, or not at all.

People with AS have identified the ability to stay at work as a priority. But despite this, relatively little is known about predictors of job loss generally. Identifying the specific risk factors that are related to leaving work (including health-related early retirement) are important.

In the baseline questionnaire (at the time of recruitment to the study), study participants were asked several questions about their working lives, including whether they were employed and, if so, how much work-time they missed due to their disease (not including clinic appointments). This information was collected again one year later.





## RESEARCH UPDATE

We found that, over a one-year period, 6% had left the workforce (after excluding those who had reached retirement age). The biggest predictor of withdrawal from work at one year, was absenteeism at baseline – the more absence that was recorded, the higher the risk of work withdrawal one year later.

In turn, a separate analysis showed that the major factor influencing job absenteeism was having previously reporting presenteeism (decreased productivity).

This might sound rather gloomy: decreased productivity today, leads to absenteeism tomorrow, which leads to job loss the day after. However, the fact that we are now better able to identify these patients – and to identify them early – should improve the management of employed patients and hopefully, ultimately, reduce the risk of withdrawal from work.



### Does biologic therapy help people stay in work?

Biologic drugs have revolutionised the treatment of AS over the last decade. Data from the Scotland Registry for Ankylosing Spondylitis (SIRAS) suggests that around one-third of patients are, or have been, on biologic therapy. This data related solely to anti-TNF drugs, although today with more drugs available, including some that target other biological processes (e.g. IL-17 pathway), this figure is likely to be even higher.

Randomised controlled clinical trials have shown that these drugs are effective in reducing disease activity (e.g. Bath Ankylosing Spondylitis Disease Activity Index; BASDAI) or objective measures of inflammation (e.g. c-reactive protein levels in the blood; CRP) but there is very little data on how well biologic therapy impacts on work. Do the benefits seen in terms of disease activity translate into real differences in the workplace? Do they result in a decrease in absenteeism and a return to normal productivity?

Nearly 500 study participants took part in this analysis: 70% were men, with an average age of 46 and average disease duration of 11 years. All were employed. Those who were prescribed biologic were younger, had higher disease activity (higher BASDAI), poorer function (higher BASFI) and were more likely to be smokers. They also reported more absenteeism and presenteeism in the week prior to the baseline questionnaire.

After adjusting for all of these things, patients on biologic therapy demonstrated significantly greater improvements in presenteeism, one year later, compared to those on conventional therapy. No difference at follow-up was seen in absenteeism. However, combining these results with those described above suggests that this reduction in presenteeism will translate into reduced sickness absence in the longer term, and a greater chance of staying in work.

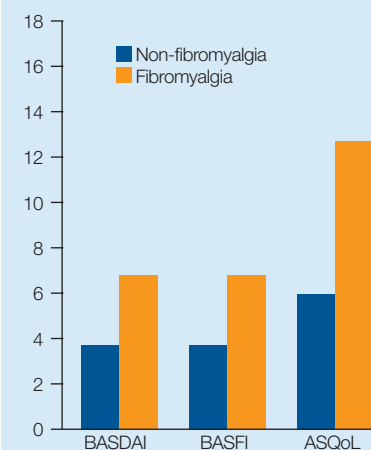
### Fibromyalgia

Fibromyalgia is a condition characterised by widespread body pain and other symptoms. Patients commonly report spinal pain and, as such, there may be considerable overlap with AS. We interrogated the BSRBR-AS data to estimate

1. The proportion of patients with AS who also had fibromyalgia
2. Whether patients with / without fibromyalgia reported similar levels of disease activity, function, and quality of life

Disease activity and function were measured using BASDAI and BASFI (both 0-10 scales, where 10 represents very active disease), and quality of life was measured using the ASQoL questionnaire (0-18, where 18 represents poor quality of life).

We found that approximately 1 in 5 patients on the register met the criteria for fibromyalgia. These patients reported significantly worse disease activity, poorer function, and worse quality of life. Also, they were more likely to receive biologic therapy although blood tests (CRP) were similar to those without fibromyalgia.



It is clear that priority should be given to developing management approaches that would address the significant unmet clinical needs of the 20% of patients with axial spondyloarthritis who also have fibromyalgia.

# Working in partnership: A new project for 2018

Dr Karl Gaffney, Consultant Rheumatologist, Norfolk and Norwich Hospital



NASS has always been cautious about recommending that AS patients visit an osteopath or chiropractor. Dr Karl Gaffney, Consultant Rheumatologist at Norfolk and Norwich University Hospital and Chair of the NASS Medical Advisory Board, explains why it is so important for NASS to work with the Institute of Osteopathy and Royal College of Chiropractors.

## Why osteopaths and chiropractors?

Although AS can have many different symptoms, back pain is usually the most common troublesome symptom. In a 2017 NASS survey, we found that around a quarter of people with AS (24%) had visited a chiropractor, and 17% visited an osteopath prior to diagnosis.

As chiropractors and osteopaths are well known and experienced for treating back pain, it makes sense that someone with back pain may visit one of these professionals in order to obtain relief for their symptoms.

This means osteopaths and chiropractors are ideally placed to recognise the signs and symptoms of AS, and also may have more time to understand the symptoms given that consultations often last for 30 to 60-minutes. Given that there is an 8.5-year delay to diagnosis in the UK, we need all the help we can get!

## What do osteopaths and chiropractors know about AS?

The NASS survey also showed that over half (52%) of AS patients who visited a chiropractor or osteopath before diagnosis were unsure how much the person treating them actually knew about AS. We have been speaking with the Institute of Osteopathy and Royal College of Chiropractors about how much AS education is provided during training and we have been very encouraged! Modules on AS are included in the teaching curriculums for both osteopaths and chiropractors and the societies are keen to encourage continued professional development in this area.

## What do we need to address with this project?

Although AS is included in teaching curriculums, there have been many changes in our approach to diagnosing and managing AS during the past decade. We want to provide a refresher for osteopaths and chiropractors so that we can ensure that everyone is up to date with these developments.

A major issue highlighted by both sets of professionals is that they experience difficulty when trying to refer patients to rheumatology. As no chiropractors and few osteopaths work in an NHS setting, they find that they are unable to access rheumatologists directly and often encounter barriers when undertaking this via GPs. This may be because the importance of making these referrals are misunderstood.

## How will we address these issues?

In early 2018 we are running pilot events in Norwich and Bath. These seminars will include the latest information on diagnosis and treatment as well as new research findings, a detailed discussion on onward referral and, of course, NASS will be there to speak about how the charity supports people with AS, as well as to give the patient perspective.

## Does this mean that NASS is recommending osteopaths and chiropractors to treat AS?

We certainly feel more confident having spoken to the professional bodies that most osteopaths and chiropractors have considerable AS knowledge, having undergone several years of professional training. The main focus of this project therefore will be to provide new information and develop a strategy for how to direct "suspected" AS patients through to rheumatology.

We very much hope that the pilot seminars will inform the project so that we can ensure that this new joint venture is a success. By working together, we really hope that we can help reduce the unacceptable 8.5 year average delay to diagnosis.



I am delighted that the Institute of Osteopathy and Royal College of Chiropractors are partners in this project. We want to ensure that people with AS have timely referral to rheumatology and that any care provided outside of rheumatology is appropriate. This pilot project should help us identify the problems that osteopaths and chiropractors have in making effective referrals which we hope will lead to new ways of working.



# LIVING WITH AS

## My Great British Bake Off Experience

James Hillery  
NASS Member



I have loved the Great British Bake Off ever since the first series. By about the sixth series I wondered if I was good enough to get into the hallowed tent. I applied for the 2016 series but was unsuccessful. I was not quite ready and it showed me I needed to broaden my baking skills. ►





A year later and with a lot more baking skills under my belt, I decided to reapply. I started my application well before the January deadline. I was nervous and kept going back to it, wondering if I would be good enough. I also had a niggle in the back of my mind around my AS and whether it would play ball.

A couple of days before the application deadline, I finally pushed the send button, not realising what a whirlwind year the press of that button would bring.

**While I cannot share the details of application process, each time I got a call back to the next stage, I was amazed and excited.**

During the interview process, I was asked if I had always been an over achiever. It was an interesting question that made me pause for thought. I have always challenged myself but when I read back my past achievements and hobbies on my application form, I can see why the question came up. In my younger years I qualified as a Royal Navy diver in the Royal Navy Reserves. Since then I have completed a number of triathlons, a couple of adventure races, a couple of fun challenges for NASS, the Peak Challenge, a 100k London to Cambridge 24 hour hike, several 5k's, a half marathon and 2 marathons.

It was the training for the London Marathon in 2012 that started the journey to my AS diagnosis. My training schedule called for long runs at the

weekends. I would come back from these absolutely wiped out, more so than I should have been from the run, and with a niggling pain in my right SI joint. The fatigue persisted and got continually worse. Eventually I decide to see my doctor after turning a blind eye to the issue for far too long.

I am fortunate and have a thorough doctor who sent me for a barrage of tests and then to a rheumatologist who also was very thorough and quickly connected my fatigue and lower back pain. After more tests and an MRI, I heard the term AS for the first time.

I was elated and scared. Whilst it may sound odd, I was happy that I did have something wrong with me and it was not it all in my head. I had something to fight, I had a new focus and a hope that I could tame this beast. That fight continues today, it is a long journey. Most days I win, other days Arthur as I call it (as in Arthur-itis), beats me.

In late March I got the call that I would be one of the 12 bakers in the tent. I was elated but once you know you are in the tent you cannot tell a soul apart from immediate family until it is officially announced in the press just before the show airs. 12 innocent bakers become the best liars in the country for a few months!

The day before filming the first episode, all the bakers met up for the first time to have dinner and start to get to know each other. It was both nerve racking and a relief to meet everyone for the first time. There were some familiar faces from the auditions and new faces. Everyone was lovely, welcoming and friendly from the start and we bonded very quickly. At last we were part of a group of people who understood what we had gone through in the preceding months and gave each other support going forwards.

The morning of the first day of filming, I got goose bumps seeing the tips of the tent as we first entered Welford Park. I never thought I would ever actually get

a chance to bake in the tent. Walking down the famous steps to the tent was a great laugh, we were all very nervous and cracking poor baking jokes and puns, giggling like children. That started a tradition of terrible jokes on the way into the tent.

**The one thing you soon realise when you enter the tent is that GBBO is one big happy family, not only the fabulous bakers, judges and presenters but also all of the people behind the scenes. The production and food teams, cameramen, sound guys and runners all put you at your ease and make you feel welcome.**

On the first morning, as we were checking our ingredients for the first bakes, the judges and presenters came in to introduce themselves. From that first meeting I could see the chemistry between Sandy and Noel who were both warm and friendly and I had no doubt the viewing nation would take them to their hearts. Meeting Paul and Prue, who both have an intimidating wealth of knowledge, was scary. I joked on The Extra Slice that in the Royal Naval Reserves I once offered to be a hostage for the SBS to practise rescuing us from a ship taken over by pretend terrorists. That was the scariest thing I had done in my life, until my first bakes had to be judged!

The filming days were long. My AS played ball most of the time. One thing I have been quite religious about is stretching to maintain mobility. The best piece of advice I received was from one of the great physiotherapists at my local NASS exercise class. He told me to visualise waking up on a morning after a frost and seeing a puddle that has a thin layer of ice on it, stamp on the puddle and shatter the ice. If you keep smashing the ice, the puddle will never freeze solid. So think every morning



when you wake up that you need to stretch for 10-15 minutes as that is the equivalent for your back.

I would stretch in the morning before heading to the tent and then stretch in any down time. Also, as I was moving constantly during the day whilst filming, my back held up pretty well. In fact I think the movement, stretching and adrenaline of being in the tent carried me through. Whilst I was filming I kept my condition to myself. I wanted to be judged on my ability not my disability.

There was one morning when I was bending over touching my toes at the back of the tent whilst waiting for the presenters to arrive to announce the challenge. Normally they would come in the front of the tent but on this morning they came in the back way. The first sight they saw when walking in the tent was my bottom in the air, which I am sure put them off their breakfast!

I loved every minute in the tent, I especially liked the technical challenges. We really did not have a clue as to what it would be until we pulled back the tea towel to see the ingredients. I loved the pressure of the unknown and having to rely on your skills and knowledge. Also hoping that you have made something somewhat similar in the past!

My favourite time was the early part of the morning, checking your recipes at your workstation. Sandi would come in at that time and put her arm round me and we would always have a natter. I thought she was absolutely adorable, so nice and genuine and personable. Sandi and Noel really cared about the bakers and spent so much time with us, which was a great help.

There were ups and downs, the judges feedback was direct and fair. I learnt so much from Paul and Prue from my time in the tent and also from the other bakers. I likened the competition to a marathon or triathlon where you are racing the course and yourself. All the bakers would help each other when needed and be there to pick each other up or celebrate in each other's success.

My worst moment was the millionaires shortbread. I knew what I was doing was wrong but I carried on. I poured the hot caramel onto the hot biscuit bake and of course it went soggy. That will always haunt me.

.....  
**My favourite moment was in bread week . Paul absolutely loved my tea cakes and kept popping back to eat a bit more. I did wind him up by calling them the poor cousin to the hot cross bun as I knew how much he likes tea cakes.**  
 .....

We all knew it was a competition and someone had to go each week, but it was still incredibly hard to see a fellow baker leave. That last judging section where one baker wins star baker and one baker does not make it through was the worst part of filming.

I will take a lot away from the experience. Not only 11 fabulous baking friends but a renewed passion for baking and a more adventurous outlook on what to bake. The show pushes you out of your comfort zone and I was baking things I had never heard of, something I thoroughly enjoyed. I now seek out different things to bake rather than stick with what I am comfortable with.

It is a huge honour to get into the show and to get half way through the series was such a privilege it will stay with me the rest of my life. You have the pressure of the environment and everyone has their ups and downs but the camaraderie was really great and friendships have been built. Whenever I try to explain to people how special it is, I say there have been fewer amateur bakers gone into the tent than astronauts into space.

James has a great blog with recipes, including his millionaires shortbread. We love the upside down orange cake recipe! If you do make any of his recipes do send us a photo!

[www.cluckmuckcook.co.uk](http://www.cluckmuckcook.co.uk)



# My AS Champion

David, NASS Member

In 2008 at 31 years old, 8 difficult years after my AS diagnosis, I was the fittest that I had ever been, running; weight lifting; six pack; the lot. Did I feel good, yes I felt amazing.

**My anti TNF was a game changer and I was functioning like a 'normal' human being. I say this because it's easy to feel like the Tin Man from the Wizard of Oz, especially on those dark winter Edinburgh mornings.**

I remember sitting in a soft play centre, having run about mad with my two year old girl Erin and one year old son Thomas, and proudly thinking, "Well this is why you got fit, so that you could have quality time with your children". And then I uttered the words, "Why do these people that complain about their AS not doing something about it, it's not difficult, you just have to put effort into getting fit. They are just being lazy".

As we all know, Karma is a bitch and not only did she laugh at my ridiculous arrogant comment but she put me back to earth with a bang. Twice. First I fell off a 4 foot wall and ripped the tendons in my ankle, putting me in a cast and then I fell off a bike, breaking my elbow.

The fitness training I had been doing was now no longer possible and I rapidly started to fall into unhealthy eating, drinking and no exercise.

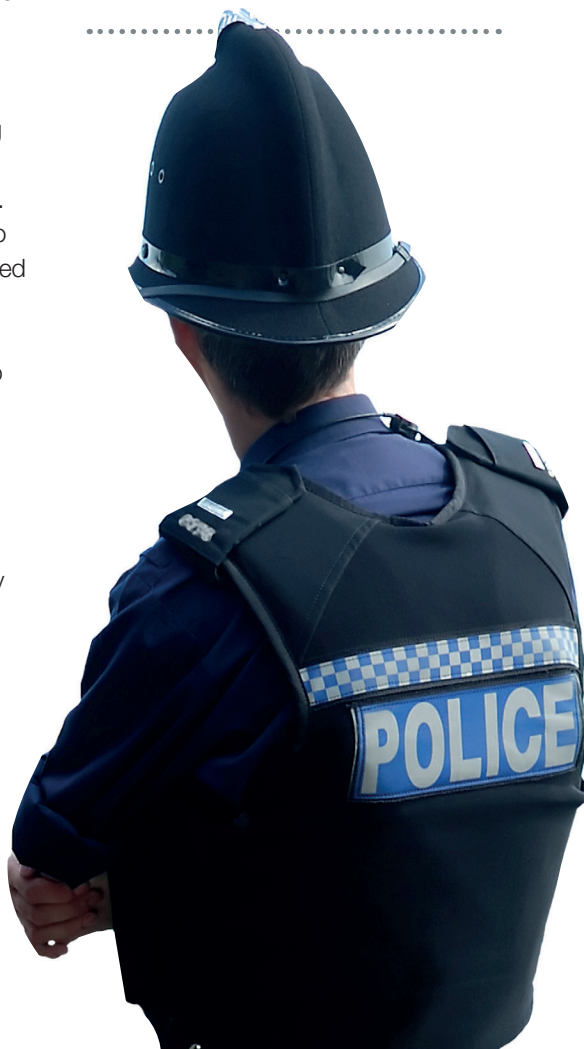
Everything then started to go wrong; my marriage ended, there were unexpected deaths in the family, I was living in shared rented accommodation in near squalid conditions and I was seriously assaulted by a stranger ending up in hospital. A low point in my life is an understatement.

My AS started to give me issues, I couldn't sleep, exercise, sit down for long, walk for long and I had to take time off work. I went through an array of painkillers. I was a zombie and felt that there was no getting out of this downward spiral.

Those strong drugs and Guinness do not mix. In an attempt to feel better I met a few friends and my brother in the pub and had four or five pints, still in pain I went back to the place I was staying and took some pretty strong painkillers. The next morning I woke up wondering where I was and why I wasn't at work. My phone was lifeless having not been plugged in, with no wake-up alarm as a result. Now the problem was that as a police officer not turning up for duty, not answering his phone and known to have had some personal and medical issues.... well, they expected the worst. And to make things worse, having not updated my address details on the computer system, they only 'roughly' knew my latest address and therefore to the no doubt surprise of a nearby resident who had left their house for the day, a door, not my door, was taken off its hinges when officers went crashing through. I of course only found this out when I had enough charge on my phone to call in.

My boss gave me a real hairdryer talking to, I know he was upset as he expected to find me in a worse state than I was, and then he helped me, massively. He got me into the Police treatment centre where I spent two weeks getting physiotherapy and turning around my life again. Without his help, I don't know where I'd be now.

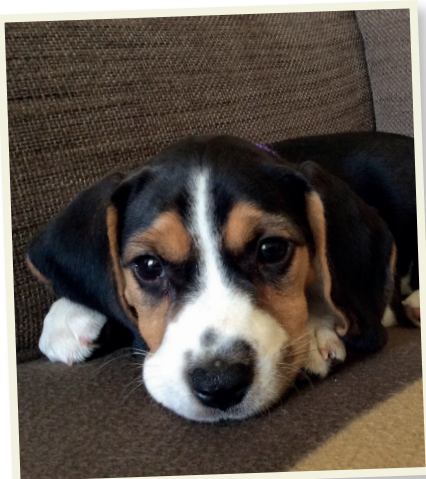
**And then shortly after, I met a very special Portuguese lady called Maria, and it is true what they say that laughter and love are very healing. She took time to learn about the disease and has continued to show me support and love, which I know is difficult given my mood at times. You know you have met someone special when the hard times don't seem quite so bad anymore. She has been my rock.**





My daughter Erin who is now almost 12 years old said to me last week that they were doing a project on resilience and they were to ask someone who has been through a difficult time how they dealt with it. She asked me if she could do it on my life with AS. I felt quite proud that she realised that things aren't easy with a condition like this and that it's about having the resilience to carry on with daily life.

Moving into a new flat with Maria was a big part of things changing for the better for me, getting back on track and some normality in my life. I wasn't a massive animal lover having never had pets as a kid but Maria is a big dog lover and so I thought that we would embark on a new chapter and get a puppy. And so Bella the Beagle came into my life, just as much hard work as a child.



At first I thought, what a nightmare, what have I done? Why would anyone want a smelly dog with all the bacteria floating about also having to take it for walks all the time even in the cold and rain when you can't be bothered. And well that sums it up; having been prone to frequent chest, ear and throat infections due to my lowered immune system, I stopped getting these, in 3 years... not one! And going for

'walkies' all the time, well for AS it's a great thing. And if that isn't enough, when I'm feeling that angry or stressed way when I'm in pain, she lies on my lap and I stroke her fur and it calms me and makes me feel ok. And so am I a dog lover now, yes, they are quite unbelievable creatures.

And so, who is my personal champion? My rheumatologist for providing me with such great care and the medication I need? My friends and colleagues who care enough to go that one step further? Maria, who is patient, loving and understanding? My children who force me to keep active and smiling? Or Bella our dog who has given me greater immunity, less stress and more exercise?

They are all my Champions, helping me in their own unique ways, making me want to be a better, stronger and happier version of me. The me that has AS and knows that I am not alone. The me that can cope with whatever is ahead. The me that isn't so complacent anymore. The me that believes that although there is no cure, this condition has given me an inner strength, resilience as my daughter would say. Supporting my everyday life with a rheumatic disease.

**If I had the opportunity not to have AS then I would, in a heartbeat. However, it has made me appreciate what I have and importantly who I have. It really is the most unpleasant blessing in disguise.**

Without my champions, life would be a very different experience and not for the better and so I am unashamedly grateful to them for what they have done and continue to do for me.



## SPACE TO SHARE HAS MY AS HELPED KEEP ME FIT?

I've been diagnosed with AS for over 30 years. Fortunately it's been quite mild so far. I put a lot of that down to keeping myself very active and fit. I spent some time at local NASS classes 20+ years ago to learn some stretching exercises which I have done morning and night since. I swim and walk a lot as well as cycle and also manage to snowboard in the winter and windsurf in the summer!

I have put a lot of time and effort into staying fit and the AS has always provided that extra bit of motivation to keep things up when otherwise I might have dropped them. Now I'm 57 and still very keen to stay in good shape.

*Richard*



# First steps to... University

Before applying to university and jumping into intensive and fun student life, take time to understand your rights and what services universities should provide for your personal needs. Each university is different but have a look at our short guide on the help you can expect.

## The Equality Act 2010 is the key

Under the Equality Act 2010, universities have a duty to help meet disabled students' needs. You're considered to be disabled under the Equality Act 2010 if you have a physical or mental impairment that is long term (12 months or more) and is having a substantial effect on your daily life.

Under the Equality Act, universities and colleges must make 'reasonable adjustments' so disabled students aren't significantly disadvantaged compared with other students who aren't disabled.

## First things first

Checking how your chosen universities can help. You can ask at open days or look on their website.

When you start your UCAS application form remember to tick the 'disability' box. Many universities will contact you beforehand, so they can put any necessary adjustments in place before you arrive. Even if you choose not to (or forgot...) tick the box, still try to contact your university before arriving.

## Consider applying for Disabled Students' Allowance (DSA)

DSAs are grants to help pay the extra essential costs you may encounter due to your AS. They can pay for a variety of expenses caused by your condition, depending on your needs, that includes: specialist equipment, non-medical helpers or extra travel.

You should apply for DSAs as early as possible and there is no need to wait until your course has been

confirmed and the application process may take quite some time.

## Register with the Disability Team

Next, register with your university's 'Disability Team'. Each university has a slightly different name for their services. Ideally try to register before September, so everything is in place for Freshers Week.

Think about making an appointment with one of the co-ordinators. This way they can verify your disability (don't forget the paperwork from your doctor!) and come up with a plan for you. This is the time and place to communicate what you need. Try to think about it beforehand and come prepared. Remember, some universities might seem less friendly and approachable, but they still need to respect your needs.



## LIVING WITH AS

### Reasonable adjustments you can expect

Your university must offer 'reasonable adjustments'. Even if you're currently managing your AS very well, think it through. Think about your worst days, not the best.

Some difficulties to consider:

- Irregular attendance or lateness (morning stiffness doesn't care what time you should start)
- Periods when you're unable to study or complete assignments on time (flares don't care about your coursework deadlines)
- Concentration and stamina problems (painsomnia and fatigue are nothing new to you).

Adjustments to meet your needs can include:

- Flexibility in attendance (or being late)
- Class and exam arrangements (rest/stretch breaks, adjusted sitting, extra time)
- Assistance in supplying you with handouts and lecture presentations in advance
- Library arrangements (they can deliver materials to you rather than you travelling to campus).

### Deck the halls (of residence)

If you're planning to stay in university accommodation do think about any needs you might have in advance. An en-suite room or a room on the ground floor might be a life saver when your pain and fatigue is really bad. If you are on biologics think about how and where you'll be storing your medication.

### Take time to talk

Do get everything in writing but make time to chat with your department and tutor to make sure they understand your needs.

If you feel your needs aren't being met try to speak with the Academic Advisor, Specialist Advisor, Equality and Diversity Office or any other service that is in place to deal with your query. If you're still not successful you might consider a formal complaint and take it further to external organisations.

Most of the universities provide counsellors that can help you with a range of personal and emotional issues. If you feel like AS is taking a toll on your mental health don't hesitate and contact your university services to schedule an appointment.

**For more articles like this and a chance to share your own experiences visit [ASone.nass.co.uk](http://ASone.nass.co.uk)**



In summer 2017 we launched ASone, a platform aimed at young people with AS. It's a community where young people can share their thoughts, feelings and experiences. ASone covers a range of issues including studying, relationships, managing AS and exercising.

[www.nass.co.uk](http://www.nass.co.uk)

We are very proud to announce that the ASone project is the inaugural winner of the EULAR Young PARE Youth Award.

Of course this award wouldn't have been possible without the generosity of our ASone community of guest bloggers who are willing to share their experiences and stories.

Jakub ([jakub@nass.co.uk](mailto:jakub@nass.co.uk)) would love you to share your stories on ASone. It could be anything from your AS journey, experiences or your way of managing your AS. This is your chance to be heard and touch others.



## SPACE TO SHARE A COMFORTABLE BRA

I've struggled for years to find a comfortable bra. My rib cage feels sore and tender and I need a soft bra that fits well and gives adequate support. I was in Marks and Spencer late last year (probably looking glum!) trying to find a bra when an assistant asked if she could help. She showed me a few post-surgery bras and persuaded me to try them. They are non-wired, so soft and comfortable and give good support but most importantly, they do not 'dig in' anywhere. The only thing that makes them different to 'normal' bras is they have an inner pocket opening for a prosthesis. This is not something that I'm aware of when wearing the bras and isn't visible at all. I thought I would share this information with you should any other women contact you with the same problem.


I wish everyone in the NASS team a very happy 2018 and thank you for all the help and support you have given me and many others over the years.

*Pauline*



# Celebrating SUCCESS

Whether you run, walk, swim, cycle and more – our wonderful supporters go above and beyond for NASS! We rely on our fundraisers to run vital services like our helpline, so a HUGE thanks to each and every one of you for your support!

A photograph of a man and a woman, Kathy and Richard Miller, standing in a vast desert landscape with rolling sand dunes under a clear blue sky. They are both wearing athletic gear, including running shoes, shorts, and hydration packs. The woman is holding a small object, possibly a medal or a small trophy. Behind them is a large, white, vertical flag with the words 'ULTRA ADVENTURE' repeated in a stylized font. In the background, a few white vehicles are parked on the sand. The overall scene conveys a sense of accomplishment and outdoor adventure.

**Kathy and Richard Miller** completed their remarkable year of challenges, raising an incredible £1,391! The duo took on the Isle of Wight Challenge, The Westminster Mile, the Hawkesbury Upton, the Chiltern Challenge, the Saharan Challenge in Morocco and the Winter Walk in London. A simply outstanding effort – thank you both!



## CELEBRATING SUCCESS

**Matthew Anderson** took on mud, dirt, and obstacles in the 10km Wolf Run in support of his Dad, raising £180 for NASS!

**Eirwen Redhead** completed the 5k Big Fun Run in Coventry, and raised £407 – including a generous £200 donation from her employers at Unipart Powertrain Applications. Thank you all!



**Pat Webber** and the **Culm Valley Lace Circle** stitched together £282.50 for NASS! Pat and her friends make Honiton lace to raise money, as Pat's son has AS. She said 'My son was diagnosed when he was 17 years old, and is now 42 years old, married with two children and manages his disease to the best of his ability. He finds surfing beneficial.'

**Lisa Edwards** danced the Cha Cha Cha for NASS and raised £210 at her Strictly Dance event! Thanks to all involved for your support! Lisa said '**I had never heard of AS until a very close family member was diagnosed with it. I have seen first-hand the debilitating effect it can have, but I never cease to be amazed by this person's determination not to be beaten. I am truly thankful for the research and funding that has gone into promoting support for those with AS.**'



**Rob Palmer** (pictured), **Joel Williams** and **Lucie Clarke** ran the Cardiff Half Marathon, raising over £1,280 between them – a brilliant effort!

[www.nass.co.uk](http://www.nass.co.uk)

**David Barnett, Emma Cooper, Robert Keeley, Lorenza Lonardi, Lewis Foreman** and **Alex Vlassopoulos** joined 16,000 others at the Royal Parks Half Marathon. Our super six enjoyed a sunny day, and raised a bumper £3,000 between them!



Lewis' mum **Karen Foreman** wasn't going to let him have all the fun – she also did her first (and only, she insists!) skydive for NASS!

Many of you will know **Laura Richards** from her days at NASS, and will join us in congratulating her for completing the Bristol Half Marathon! Laura also raised a magnificent £212.50 – a brilliant effort!



In September, 14 brave employees from the **Immunology team at UCB** took on the challenge of raising monies for three charities – NASS, BritSpA and Arthritis Ireland – by attempting to cycle 160 miles coast to coast. The ride raised an incredible £6,236.67 for NASS! Thank you to the wonderful team at UCB – your support will provide a copy of our information-packed guidebook to over 3,000 people newly-diagnosed with AS.



AS NEWS Spring 2018 | 25



We also had a stunning seven take on the Great North Run! **Clemency and Phil Wright, Emma Davidson (dressed as a pizza!)** and her dad **Neil (dressed as Scooby Do!!)**, **Daniel List and Katherine Unthank** ran the iconic route alongside nearly 60,000 others. Together, our team raised over £1,600 for NASS. A big, big thanks to you all!



Many thanks to **Jeremy Shaw**, who swam the Coniston Chills swim – a stunning 5.25 mile open water challenge! Jeremy also completed the challenge in 2016, and is keen to continue raising awareness of AS in support of his wife Julie. Great work Jeremy!

**Liz Ross** went Sober for October, which meant she didn't raise a glass for a while, but she raised £220 for NASS! Liz said 'AS is a condition that affects someone close to me. I know first-hand how debilitating it is and the daily struggles it causes for people living with it. Sometimes little known conditions and charities don't receive the same amount of donations as the big ones but the support they give can make the difference to someone's day to day life.'



When NASS Member **Ian Wimpenny** was diagnosed with AS in 2013, he was determined not to let it interfere with his passion for sport. With a combination of exercise and medicine, Ian took the huge step to take on the Barcelona Triathlon in September 2017, raising an incredible £3,000 in the process. Ian said, '**One of the biggest things that I will take away from this experience is that no matter how desperate and negative a situation can feel, with the right mind set and application these can be turned into positives. We should never give up!**'

**If you would like to know how you too can support NASS in memory of a loved one, you can call us on 020 8741 1515, email [Amardeep@nass.co.uk](mailto:Amardeep@nass.co.uk) or visit our website.**



## CELEBRATING SUCCESS



The cheeky chaps at **Sheffield Hallam University Rugby Club** have been at it again! Following their 2016 charity calendar, the guys supported NASS throughout 2017 and raised a wonderful £2,000 – as shown off by a few of the team!



Swim, cycle, and run – fabulous **Fabian Stec** did it all in his Ironman Triathlon, and he raised £940 to boot! Fabian said 'Fortunately NASS are here to help with research and offer support to sufferers at crucial times. Unfortunately they receive no government funding, so any donations will be hugely appreciated and put to amazing use.' Thanks so much Fabian!



**Teona Yardley-Barnes** challenged herself to complete the Oxford Half-Marathon, in support of her husband Ian who was diagnosed with AS 19 years ago. Not only did she do it, she raised a fabulous £560!

**'I am so grateful for the advice NASS gave on their website and to the support and advice on the NASS Facebook page. Raising money for them is the least I can do. Thank you NASS for helping me get my hiking, fun loving and bonkers husband back.'**

An amazing effort by **Chris Dale** saw him finish his first ultra-marathon, the Lakes in a Day! Taking on the challenge in support of his Mum, Chris raised a brilliant £1,710. He said 'Thank you so much to every single person who has contributed - it is hugely appreciated by me, my mum, NASS, and by everyone suffering from AS.'

Trustees **Poppy Hocken** and **Grant Poiner** took the plunge for NASS, completing the 1-mile Swim Serpentine! Poppy raised a fantastic £1,432 in memory of her son Alex, who sadly passed away in November 2016. Grant raised a brilliant £335. Thank you both so much for your ongoing support.



Thank you to **Jessica Posnett** for raising a brilliant £286.25 by taking on the 10k Leeds Abbey Dash!

# MIGHTY Orange mashup!



For her Mighty Orange Mashup, Zoe Bennett cycled the 100-mile Velo Birmingham and raised almost £550! Zoe was diagnosed with AS in June 2017, and said "I decided to raise money for NASS as they have helped me so much in short period of time with something that is life changing." Zoe, we're hugely grateful for your support.



Our friends in the epidemiology group at the University of Aberdeen cooked up some frightfully delicious treats at their Halloween-themed Mighty Orange Mashup! The team laid on a freaky feast in return for donations, raising a spook-tacular £166 for NASS!

Sophie Ibbotson also laid on a freaky feast! With the help of friends and family, Sophie raised a frightfully fab £150 – thank you Sophie!



NASS Trustees Gillian Eames held a fundraiser at Gillian's local pub, The Freelands Tavern, in memory of her mother Doreen. With support from Trustee Jean Morton, the pair organised a brilliant evening involving a raffle, live music and games. Gillian also set herself the bonus challenge of walking 7,000 steps a day. Thank you to the staff and customers who helped to raise over £1,600 for NASS.

## HOLD YOUR OWN MIGHTY ORANGE MASHUP!

Whether it's an afternoon tea with family, a bake sale at work, or a pub quiz with friends, get together, get involved and make a difference to the lives of people with AS.

### How you can get involved

Simple! Visit [www.nass.co.uk](http://www.nass.co.uk) or call us to sign up and we'll send you your FREE fundraising pack, which includes donation boxes, balloons and posters!

### Don't forget your cake toppers!

We've partnered with My Cupcake Toppers to provide these exclusive Mighty Orange Mashup cake toppers – and as a bonus, we'll get 25% from each sale! So whether you're a keen baker or having a dabble, visit [www.mycupcaketoppers.co.uk](http://www.mycupcaketoppers.co.uk) and raise a little extra!

### How your Mighty Orange Mashup will make a difference

Every penny you raise will help to improve the life of someone affected by AS.

**£50** provides expert support from our Helpline to 5 people

**£100** helps 2 people to meet experts at our annual Members' Day

**£250** provides our information-packed Guidebook to 125 people





# MAKING A DIFFERENCE

As we receive no government funding, we rely on our fantastic supporters to continue providing life-changing services, such as our Helpline, for people affected by AS. Here are just a few of our wonderful donors.

## WELCOME TO OUR NEWEST LIFE MEMBERS...

Ms E  
Burns

Mr I  
Sutherland

Mr S  
Hennell

Mr B  
White

Mr R  
Fontana  
-Reval

Ms P  
Blant

**Our Life Members help to ensure that NASS can provide the care that people with AS deserve and need long into the future. If you would like to upgrade to a Life Membership, please call on 020 8741 1515 or visit [www.nass.co.uk](http://www.nass.co.uk).**

When NASS Member **Glenys Morgan** sadly passed away in May 2016, her sister Cherry and her card-making group – The Stampers - wanted to raise money in her memory. For a second year running, they held a charity day, selling beautiful cards, cakes, jewellery and more, raising an amazing £1,030.

Cherry said, 'Glenys would have been delighted that this was done in her memory for NASS - a society which helped her and more recently her niece.'

A very big thank you to Cherry, The Stampers, and Evelyn and Jim Doherty for hosting the event.



### Donations made in memory

We are humbled and thankful to the family and friends who have sent donations in loving memory of:

- Mrs and Mrs R N Healey
- Mr A Norman
- Mrs B Roberts
- Mr R J Sillars
- Mr D Legg
- Mr G J Lynn
- Mr G Thompson
- Mrs E Cribb
- Mr K M Turner
- Mr P Livesey
- Mr R G Hodgson
- Mrs A M Williams
- Mrs D Bugler
- Mrs W P Burnett
- Mrs B Jones
- Mr M Arnold

### Charitable trust donations

NASS is forever grateful to the following Trusts for their continued support of our vital work.

- The Reuben Brothers Foundation
- The Charles Fairweather Charitable Trust
- The Khayami Foundation
- The Sharegift – The Orr Mackintosh Foundation
- The Hamilton Wallace Trust
- The Donald Forrester Trust

## Leaving a lasting legacy of support

We are grateful to the late **Mr G Vincent, Mr R Horsford** and **Mr F Ramshaw**, who each left gifts to NASS in their will. We extend our condolences to their family and friends.

Whilst treatments for AS are improving, it is still an incurable disease - many people will need lifelong support to manage their condition effectively. Leaving a gift to NASS will ensure we can continue to provide vital services like our helpline, exercise branches and range of publications to educate and empower people long into the future. No matter how big or small, every gift makes a huge difference.

If you would like to know more about you too can leave a lasting legacy of support, please call Amardeep on 020 8741 1515.

# NASS NEAR YOU

## NASS branch network wins national award



NASS were delighted to be named the winners in the AbbVie Sustainable Healthcare Patients as Partners Awards. NASS were named winners of the category 'Supporting individuals to take control of their care,' in recognition of the physiotherapy and hydrotherapy sessions NASS branches provide to people with AS across the UK.

We couldn't have achieved this without the hard work and commitment of everyone who volunteers at our branches, including the branch chairs, secretary's, treasures and physiotherapists. Plus, the branch members who give up their time to attend every week which creates a great atmosphere for all in attendance.

Lord Victor Adebawale, Category Judge, said: "The submission for the team at NASS is compelling. The team are providing a vital service to people across the country with a clear focus on both the physical and mental health needs of those they provide support for. The scale and implementation of this project is impressive, and I look forward to seeing the significant impact it has on people's lives going forward."

Dr Dale Webb NASS CEO said: "We're thrilled to be winners in the category of 'Supporting individuals to take control of their care' at the AbbVie Patients as Partners Awards. It's a wonderful way to recognise the brilliant work our volunteer-led branches provide at over 90 locations across the UK, helping on average 1,000 people a week to manage their AS more effectively. Our members tell us that attending their branch has a range of benefits, including reducing pain, increasing flexibility and helping to meet new friends. This wouldn't be possible without our branch volunteers and physiotherapists, so we're hugely grateful."

If you would like to find out where your local award-winning branch is, visit our website and search NASS near you or contact Paul.

## NASS Up North

Barbara Foster from NASS Derby tells us about their wonderful NASS Up North event!

Last October, NASS Derby resurrected the NASS up North event. It was an extremely successful evening, enjoyed by over 100 guests, including members from Nottingham and Sheffield and former CEO Debbie Cook. The brilliant entertainment was provided by singer Ryan Joseph amazing magician Will Gray. Our Branch was very proud to have hosted the event.

We had three members celebrate their 80th birthdays in 2017 and in true NASS Derby style we held an evening of celebration to mark this milestone. We wonder whether the branch and the weekly hydro session are a contributory factor to their wellbeing!

## Glass Act

The Bristol branch recently awarded member Rowena Sutcliffe with a very special award. This was in recognition of her extremely hard work within the branch fundraising, setting up socialising events and organising informative talks about AS. The branch awarded her with a special Bristol blue glass piece displaying the Clifton Suspension Bridge over the Avon Gorge. This is a rare glass which can only be found in Bristol and Somerset. Congratulations to Rowena on her great work from all at NASS.



## Stirling Work

NASS Stirling were recently awarded a very generous local community fund of £1904 from their Co-op. This is a fantastic scheme that all branches across the UK can apply for. To date, the Co-op has donated £20 million to local community projects UK wide. Go online to Co-op website and register your branch too.



L to R, Ruth Teal, Co-Op, Alan Macdonald Chair NASS Stirling, Elaine Robertson Secretary NASS Stirling

## Blackpool Branching Out

NASS Blackpool branched out from their normal exercise sessions and hosted a ping-pong competition organised by Sandra Thompson. Chris Bateson was a very convincing winner remaining unbeaten throughout the competition. Charles Hawkins Blackpool secretary said 'Chris showed AS is no barrier to a variety of sporting pastimes'.





# Agenda

**42nd Annual General Meeting of NASS**  
**Saturday 9 June 2018 at 9.30am - 10.15am. To reconvene at 1pm.**  
**St Mary's University, Twickenham TW1 4SX**

1. Appointment of Chairman of the meeting (Clause R(1))
2. Minutes of the 41st Annual General Meeting held 20 June 2017 (Clause R(4))
3. Report of the Honorary Chairman
4. Elections to the Council of Management (Clause P(5))
  - a. Honorary Chairman (Clause F)
  - b. Honorary Treasurer (Clause F)
  - c. Ordinary members (Clauses G(1&3))
5. Report on the appointment of Co-opted Members of the Council of Management (Clause G (1 & 2))
6. Report and confirmation of the Appointments of President, Vice-presidents and Patrons (Clause P(4))
7. Report of Honorary Treasurer and presentation of the accounts for the year ended 31 December 2017 (Clause P(3))
8. Adoption of the accounts for the year ended 31 December 2017 (Clause P(3))
9. Appointment of Reporting Accountants (Clause P(6))
10. Report of the Chief Executive
11. Any other business
12. Date of next Annual General Meeting Saturday 22 June 2019 (Clause P(1))

Please note that only paid up members of the Society are entitled to vote and to stand for election.

Clause references above relate to the Constitution of the Society adopted at the AGM held 18 November 2000 and amended at the AGM on 17 November 2007 and the AGM on 21 November 2009.

According to the Constitution of Management the Council shall consist of:

- Chairman – Honorary Officer
- Treasurer – Honorary Officer
- No less than 8 (but not more than 12) ordinary members
- No more than 4 co-opted members  
(but the number of co-opted members must not exceed one third of the Council)

Co-opted members are appointed for one year. The Chairman and Treasurer are elected for one year, other members for three years. Retiring members may stand for re-election if eligible.

The Council of Management at the start of this meeting are:

**Honorary Officers:** Chairman: Raj Mahapatra

**Treasurer:** Post vacant

**Ordinary Members:** Eric Eustance; Dr Karl Gaffney; Claire Harris; Ben Hoare; Poppy Hocken;  
Dr Andrew Keat; Monika Mayhew; Ruth Miller; Grant Poiner;  
Dr Raj Sengupta; Roger Stevens, Peter Wheatley-Price

**Co-opted Members:** Nick Clarke; Gillian Eames; Jean Morton; Peter Townsend

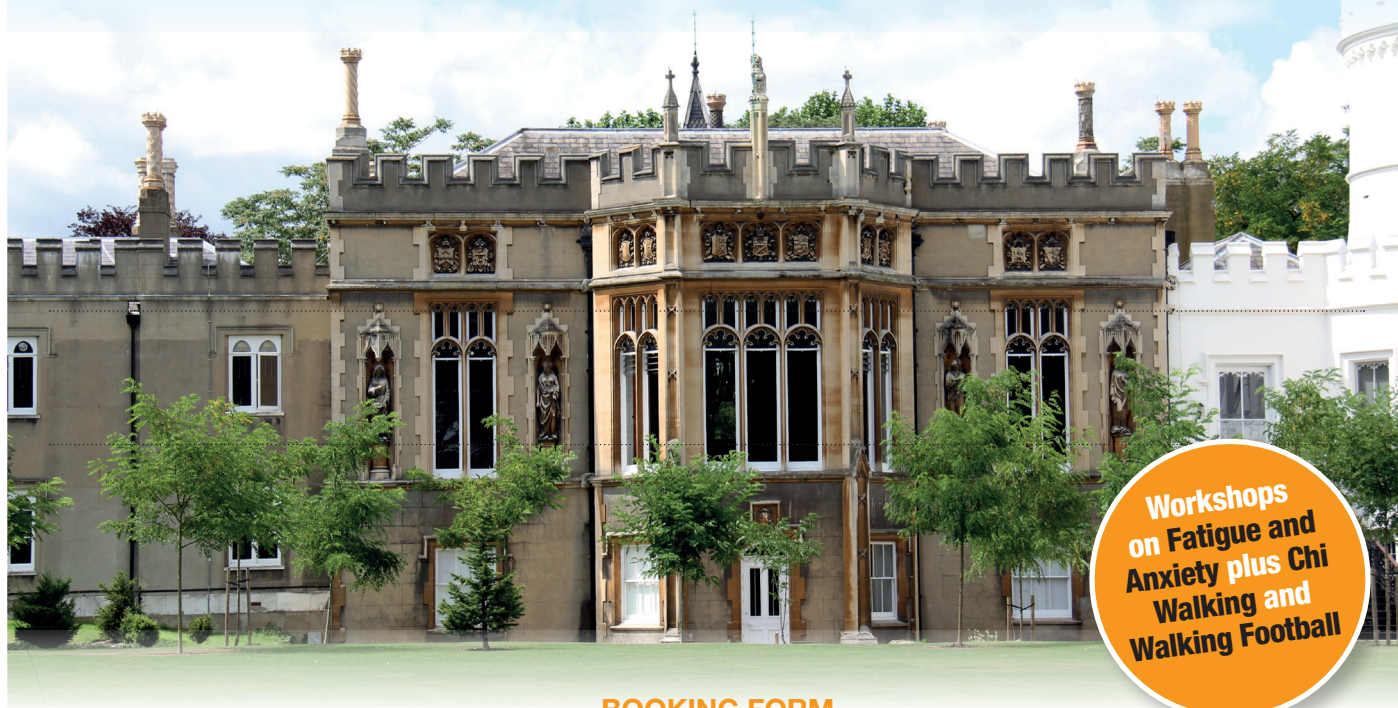
Retiring by rotation at the end of this meeting are Eric Eustance, Ben Hoare and Roger Stevens. All have indicated their willingness to stand for re-election.

Any member who wishes to stand for election to the Council of Management should contact Jill Hamilton or call the NASS office for a nomination form. Please note that the deadline for applications is Friday 18 May 2018



# MEMBERS DAY 2018

Saturday 9th June • St Mary's University • Twickenham



Workshops  
on Fatigue and  
Anxiety plus Chi  
Walking and  
Walking Football

## BOOKING FORM

Member Name

Membership Number

Dietary requirements

Guest Name

Dietary requirements

Does this person have AS?

☐ Yes ☐ No

Access requirements

**Workshop choices** (please choose two workshops from the following 3 options):

☐ Anxiety☐ Fatigue☐ Exploring AS

Address

 Postcode 

Email

Telephone

**Deposit** - £10 per person (please tick)

☐ I have enclosed a cheque ☐ I have paid online ☐ I have paid by telephone ☐ Please keep my deposit as a donation