# Members' MAGAZINE

SPRING 2017

nras
National Rheumatoid Arthritis Society

PLEASE READ & SHARE

# Introducing the NRAScals!

**SUPPORT OUR FUTURE**

A gift in your Will helps NRAS to build a better future for those with RA and JIA
**legacy@nras.org.uk**

**NRAS LOTTERY**

Join the NRAS Lottery
**www.nras.org.uk/nras-lottery**

**GET IN TOUCH**

**www.nras.org.uk**
01628 823 524

# Dear Members

**By Ailsa Bosworth, MBE**

Chief Executive

**2017 has got off to a flying start and you have much to anticipate from NRAS this year! First of all I'd like to thank you all for your support in 2016 which was a successful year for your charity and as a consequence our workload continues to grow, so we really need your support in 2017 to help us fund that continued growth.**

There are so many ways you can help us. Our wonderful fundraising team have produced a new fundraising guide, and 'ideas postcards' to help inspire you to do something, however small, to support us, should you choose to accept the challenge! You can get your pack by post by emailing **fundraising@nras.org.uk**, calling our enquiry line: **0845 458 3969** or download it from the website. Perhaps you might consider doing something in RA Awareness Week which starts this year on June 19th – difficult to imagine it when it's so cold as I write this – but the weather will be lovely and warm then, and you can think about cream teas in the garden, picnics and barbecues! We have a really exciting programme of events to get involved in this year and so can I appeal to hospital rheumatology teams, industry friends and workplace teams to get competitive and consider doing a team event? If you need further inspiration, just call us and speak to one of the fundraising team who will do all they can to support your efforts so that we can carry on helping the 690,000 people in the UK with RA and the 12,000 children and young people living with JIA.

> *I feel I owe a big 'thank you' to NRAS. Finding their website when I was at my lowest was a huge boost for me. They are a lifeline to so many, and they really need your support.*

## Some exciting things you can expect from us this year are:

4 major new publications! The first off the blocks will be our *'Medicines in RA'* booklet which, for the first time, covers all medications used in RA. No more individual leaflets on each medication, but one booklet with everything you want to know about the different medications you need to take for your RA. We plan to launch this at the annual British Society for Rheumatology congress at the end of April.

We are completely re-writing and updating our most popular publication *'Newly Diagnosed'*, which will be re-titled *'New2RA'*. We are also giving a major facelift to *'Managing Well'* for people with existing disease, which will be re-titled *'Living Better with RA'*. Both of these important publications will be available later on in the second half of the year.

And finally, but by no means least, we have started work on the production of a major new booklet on fatigue and its impact. We know that this is a very important issue for people living with RA; in some surveys it ranks first as the most debilitating symptom over pain, and we are very pleased to be working with the Academic Rheumatology Department at King's College, London on this. We anticipate that this will be available later in the year.

We shall be releasing an important video all about biosimilars in the late spring featuring our Chief Medical Advisor, Professor Peter Taylor. I very much hope that this will provide an enjoyable way to learn more about this complex subject. We have been producing information on biosimilars for the last 2 ½ years in preparation for these new original biologic replacements, the first of which - in rheumatology - came to the UK market in 2015. It's important that you know what is happening with biosimilars so that you can have informed discussions with your healthcare team, if and when the time comes for you to move to a biologic disease modifying anti-rheumatic drug.

*(continued on page 4)*

If you are receiving this magazine for the first time and are not yet an NRAS Member, sign up today and receive it on a regular basis.

Simply complete the form inside the enclosed booklet or email **membership@nras.org.uk** to set up your complimentary membership today.

# Members' MAGAZINE

## Contents

To comment on this issue or to submit a story or article for a future issue please email **editor@nras.org.uk**

Editor of this issue;
**Sally Wright**, Head of Marketing and Communications

# Meet the Team

## Making waves down in Brighton

Our new Local Services Supervisors, Karen Keech and Dawn Bamforth, are making progress with our Commissioned Services and New2RA management programmes.

### Dawn on Karen

**Karen Keech**

NRAS Local Services Supervisor

Sussex MSK Central is an interesting place. Not only does the office have a ping-pong table and an official office dog, there's a room called 'The Meadow'; with fake grass on the floor and a mountain mural on the wall, where everyone's welcome to attend three daily yoga sessions.

This is where Karen finds herself since joining NRAS in November. What we know, but they don't, is that Karen spent several years working for the Table Tennis Association. We won't let that slip until after the first office tournament!

Karen has spent most of her life working within sport; whether lecturing on sport business management or working for various sporting bodies, she's well-versed in the importance of fitness and its impact on health.

Since joining NRAS and being based at 'Here', in Brighton she's been managing the disparate needs of Sussex MSK Central, our volunteer facilitators and healthcare professionals. Add to the mix the patients themselves and it's quite a juggling act.

Karen is always positive and upbeat and has been a great sounding board for me as I take on a similar role in the east of the county. It's been a rewarding but often frustrating first few months but don't feel too sorry for her... there's always yoga!

### Karen on Dawn

**Dawn Bamforth**

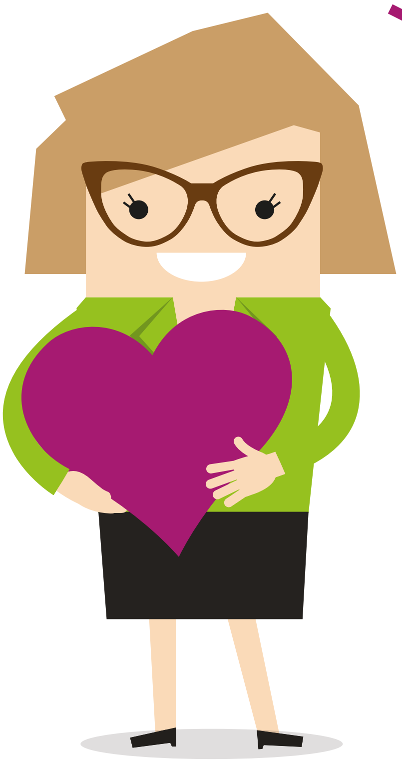
NRAS Local Services Supervisor

Dawn joined NRAS in November and is based at the Sussex MSK Partnership East offices near the station, which is handy when the trains are running! Rooms in the office are all named after old Sussex words, so they have the 'Piggery' for the kitchen and meeting rooms named 'Gurt' (big) and 'Jiggered' (surprised, apparently). There is no table tennis table in the office at the moment but I know Dawn enjoys a challenge so I am sure there will be something soon.

With her wealth of experience working for different charities and completing her degree in London, she has real empathy and understanding for the importance of the role and the benefit for patients. The new contract is challenging and exciting at the same time as Dawn has a blank canvas to work on. Since starting her role she has been trained as a facilitator for NRAS courses, researched and secured course venues, liaised with our volunteer facilitators and healthcare professionals and got to grips with the different data management processes and systems. All this as well as balancing the needs of her family.

Dawn is cheerful and proactive and always thinks of different ways to do things especially if things aren't working. It's been great for me to have someone to bounce ideas around with who knows the things that crop up.

*(Dear Members – continued from page 2)*



Love Your Heart

nras
National Rheumatoid Arthritis Society

On Valentine's day we tweeted about a new online video programme 'coming to a computer near you soon', called 'Love your Heart'. This exciting new programme will be available later this year. It is an engaging, educational platform, where visitors to the site will be able to:

- understand the reasons why RA increases cardiovascular risk
- calculate a QRISK®2 score (a GP recognised prediction algorithm for Cardiovascular Disease)
- learn how to reduce their own individual risk of CVD
- log progress through a series of behavioural goals

It is unique, in that it not only offers important information and education, but it also provides a structure through which people with RA can change their behaviour to improve their individual health outcomes. The data from this programme will also significantly help rheumatologists and GPs, and we anticipate it will become a referral platform when people are diagnosed. This work is a collaboration between NRAS and Dr Holly John, Consultant Rheumatologist, and the wider team at Dudley Group NHS Foundation Trust and I think illustrates what can be achieved when a patient-led charity like NRAS works alongside healthcare professionals and we are hugely excited by its potential.

We look forward to interacting with many of you this year and don't hesitate to get in touch if we can help.

Ailsa

---

**Val Eyre**

NRAS Events Fundraiser

# Celebrating 10 years of 'Val the Fantastic' in our fundraising team

**Over the last ten years Val has supported hundreds of fundraisers who have run, cycled, walked, trekked or jumped for us. Many of our fundraisers are friends to Val returning year after year, which has much to do with the ongoing personal support Val has given them.**

However, Val's contribution does not end there. Her sense of humour, her kindness, her experience and knowledge all go to make her a fantastic and invaluable member of the Fundraising Team.

*'Val was one of the first people I met when I arrived at NRAS and she took me under her wing and showed me the ropes. Her enthusiasm, contagious laugh and dedication are all infectious, which makes her the ideal person to lead our wonderful fundraisers who do amazing things like running marathons, cycling, abseiling, sky diving and so much more. You can always rely on Val being there to calm their nerves before they set off on their challenges as well as there to offer hugs and congratulations when they come staggering over the finishing line! Out in all weathers, Val is nothing less than our own fundraising heroine! I'm sure everyone whom NRAS has supported over the years salutes you Val and thanks you sincerely for the last 10 years, here's to the next 10 years!'* – Clare Jacklin, Director of External Affairs

*'We were delighted to celebrate Val's 10 years of loyal service in February. Her unwavering support for all our fantastic fundraisers, in good weather and bad, has always been evident (and we have the photos to prove it!). Here's to the next 10 years Val!'* – Ailsa Bosworth, CEO

# A warm welcome

## Introducing our newest colleagues and members of the NRAS team

### Ian Hayward – Director of Finance

Ian joined as Finance Director in October, and had an excellent handover from Denise just before she retired.

*'My first impressions are that NRAS is a well-run charity with solid financial backing. It has been a busy first few months with the budget for 2017 to agree and the 2016 year-end. I have two grown up children in their 20's who have left home to pursue their careers. This just leaves my wife and me to look after our energetic dog. Outside of work I swim 10k each week with two swimming clubs to stay fit.'*

### Michelle Vickers – Head of Fundraising

Michelle joins us as Head of Fundraising, with over 16 years' experience of working in the not-for-profit/charity sector in a variety of senior roles. Within these roles, and most recently as CEO of a small independent charity, she has successfully managed the delicate balance between dedication to mission, the need for bold entrepreneurial initiatives, and the application of sound business management.

*'It's always an adventure taking on a challenge and working with a new team. 2017 is an exciting year for NRAS, we have lots of hard work ahead of us and I'm thrilled to be joining the organisation.'*

### Lorraine Price – Executive Assistant

Lorraine joined NRAS at the beginning of November working as Executive Assistant to Ailsa.

*'I have not worked in a 'proper' office for many years. I worked with my husband and 6 workmen for the past 15yrs (24/7), which was difficult to say the least. Mutually we decided that we either murdered each other or found alternative employment. I chose the latter (although I did think about the first option briefly!). I took a short amount of time out before deciding what to do with my life. Having three grown-up children, and with an empty nest, I decided to enter into the big wide world. I had a few interviews, then I was offered the job at NRAS. I am pleased to be part of NRAS and the work they do for people with RA and JIA and I hope to make a contribution to the team in the best way I can.'*

### Dawn Bamforth – Local Services Supervisor

Dawn joined NRAS at the beginning of November and is based in Eastbourne. Working alongside Sussex MSK Partnership East, she is responsible for delivering NRAS' self-management programmes across four CCG areas.

*'My experience is primarily in the voluntary sector, with a five year change of direction into teaching in adult education. I started work in the Direct Marketing departments of three top-ten-by-income national charities but more recently worked for a small county-wide charity supporting local foster carers. My new role is proving challenging but satisfying and though working remotely, it's great to be part of the NRAS team.'*

### Karen Keech – Local Services Supervisor

Since joining NRAS in November as the Local Services Supervisor (Brighton & Central MSK Partnership) Karen is one of many new NRAS staff members.

*'With my background in the education and public sector, and armed with experience of working with the voluntary/community sector I relish the challenge of organising self-management programmes to support patients living with rheumatoid arthritis. It is great to be part of an organisation that is entirely patient focused providing much needed help and support.'*

### Michele Gagie – Finance Assistant

Michele joined NRAS in November to work with Ian, Finance Director. Her background is quite varied, originally in pensions actuarial and then evolving into accounting and finance, particularly financial control and reconciliation.

*'I feel privileged to now be working for such a worthy and supportive charity and look forward to playing my part in the ongoing success of NRAS.' I have three sons and some very creative hobbies such as trompe l'oeil and wire sculpture. I am also an honorary treasurer for a local charity, a part-time mystery shopper and part-time dog boarder and occasionally accompany my other half to Nottingham Forest games.'*


Ian Hayward


Michelle Vickers


Lorraine Price


Dawn Bamforth


Karen Keech


Michele Gagie

# Could you be our next £1,000 winner?

"We spent the cheque many times over in our heads but have decided to put it towards a 14-night cruise from Southampton to the Baltics as we would love to see Russia. Our holidays have had to change because of my mobility and to not only cruise, but to see Russia, is a bucket list holiday. I would urge everybody to join the NRAS lottery as I pay by Direct Debit so no hassle and the money goes towards people who suffer from this awful condition."

*Mrs C Hunter - £1,000 winner*

You too can sign up to play the NRAS Lottery and get the chance to be one of our weekly winners. It costs just £1 per week and you have a 1 in 63 chance of winning a prize from £5 to £25,000! You are allocated a six-digit number, which will remain yours for as long as you play the lottery. Winners have to match 3, 4, 5 or all 6 digits in the correct place in the sequence to win and you can enter as many times as you like. The draw takes place every Saturday and prize cheques are sent out directly to you so there's no need to claim!

The NRAS Lottery is part of Unity Lottery, a specialist organisation which runs lotteries for charitable causes and unlike most other lotteries, gives 50p from every £1 to NRAS.

To play the NRAS Lottery you can either join online at **www.nras.org.uk/lottery** or you can request a leaflet to complete by post on **01628 823524**. You can pay by Direct Debit or by sending a cheque made payable to Unity with your completed form.

By joining our lottery, you will be supporting us and helping us to help you! Sign up today and good luck!

# Prize draw winner!

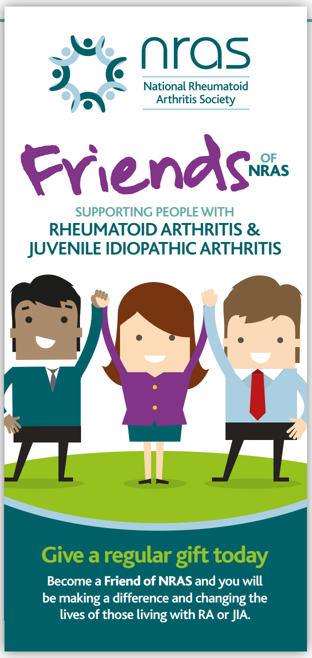
## #BlueMonday may be the saddest day of the year, but for 2017 we're determined to brighten it up!

To do this we decided to give away a gift hamper worth £30 to one lucky person who joined NRAS as a new Member between 16th Jan and 16th Feb (inclusive). We drew the winning name on Friday 17th February and we are delighted that it was successfully delivered to Kate Parker – congratulations! A huge welcome goes to all our new Members who have joined recently.

Please get in touch with the Membership team at **membership@nras.org.uk** if you have any comments or suggestions.

# Friends of NRAS!

## Supporting people with Rheumatoid Arthritis and Juvenile Idiopathic Arthritis



We are often asked by friends, family members and colleagues of those living with RA or JIA, 'is there a way in which they can support them?' One way in which people can help is by setting up a regular gift and becoming a Friend of NRAS. This dedicated group of supporters provide NRAS with a steady and reliable income that gives us the essential confidence we need to maintain our key services, eg our helpline and publications, and commit to new projects. In return, we keep the Friends of NRAS informed, through bi-annual updates, of how their donations are making a difference.

We want to continue to support people living with these conditions and help them to lead as full a life as possible. Regular gifts are invaluable, whatever the size. Direct Debits can be set up online at **www.nras.org.uk/donate-land**, over the phone or email **fundraising@nras.org.uk** to request one of our new leaflets by post.

# New Membership leaflet!

## Become a Member and let us be there for you!

Spring has sprung and we thought it was the perfect time to give our Membership leaflet a bit of a facelift! Members are at the heart of everything we do and we would love to reach even more people living with RA or JIA. If you would like copies of our new leaflet and previous editions of the NRAS Members' Magazine to give to someone you know, or to put in your rheumatology unit/local surgery, please do email **membership@nras.org.uk** and we will happily send them to you.

# We need your innovative ideas!

The NRAS team have been looking at new options for merchandise and we'd like to know what type of items you would like to see us offering and/or you would consider buying yourself! As an added incentive, all suggestions/ ideas we receive will go into a free prize draw and three lucky winners will receive one of our brand-new NRAS badges!

Would you like us to have more:

- Small promotional items eg pens and keyrings
- Bigger items that could also be given as gifts eg diaries, calendars, shopping bags
- Handy gadgets eg easy-grip items
- Fundraising items eg cupcake cases, cake stands or tea-towels for tea-parties

Email **fundraising@nras.org.uk** before 30th April to have your idea entered into our free prize draw. Have a look at the NRAS shop and see what we currently offer **www.nras.org.uk/shop** including wristbands, t-shirts and, of course, our new badges!

## Memorial Tribute Fund

An NRAS Tribute Fund is a special and lasting way to honour the memory of your loved one, whilst helping us do what we do best... supporting those impacted by RA and JIA.

Friends and family from around the world can make donations to the fund on an ongoing basis to help celebrate the life of your loved one, comprising messages, pictures, stories, music, videos and even online candles.

**It's easier than you think to set up a Tribute Fund**

You can do it in 5 easy steps on our website, or you can call the Fundraising Team directly and we will set it for you.

**0845 458 3969**

www.nras.org.uk

# The Art of Cover

By Elena Anastasi-Lee


Vitiligo to hands; left hand only has camouflage applied.

Skin camouflage is not a new concept, it was tried and tested by Sir Archibald McIndoe in his 1942 RAF Patient Support Group – 'The Guinea Pig Club'. His philosophy was that treatment should always be 50% medical and 50% psychological.

Skin camouflage products are designed to mimic and blend with the natural skin colour regardless of skin type or ethnicity. Although skin camouflage products cannot alter the structure of the skin, the immediate visual effect may help you to regain self-esteem, which can do much to improve general health and assist in a return to normal social/sporting activities and employment. For people who have undergone surgery, and are left with scarring, this type of treatment is becoming more popular.

Skin camouflage products differ from corrective beauty aids in that:

- the crèmes are specifically formulated to give light to total covering power, yet only require a thin application
- the camouflage is resistant to water and is smudge proof, which means a return to sporting activities, such as swimming, without the fear of the camouflage washing off
- the camouflage has a potential durability/stability time of between 8 and 16 hours before the need to "touch up" or reapply
- the products contain sun protection properties
- additional sun protection can be applied under and over the camouflage crème
- topical medication can be applied prior to camouflage application
- decorative cosmetics (make-up) can be applied over the set camouflage crème

The products should be removed daily to allow you to inspect your skin and to allow you to apply medication, emollient or sun protection.

A skin camouflage consultation typically lasts about one hour and consists of:

- Face to face skin tone matching service
- Skin Camouflage product application tutorial
- Application, care and maintenance guide sheet
- Personal record (list of products specific to you and information on where to purchase)
- Referral letter for GP (if required) for NHS prescriptions

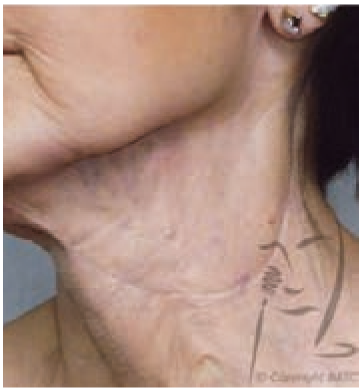
The British Association of Skin Camouflage (BASC) is internationally acknowledged as the leading provider for training professionals in this specialism.

To find your nearest BASC Trained Skin Camouflage Practitioner and for further information please go to **www.skin-camouflage.net**

We would like to do a follow-up article for the summer, so if you live in Norfolk, Suffolk or Lincolnshire and would like to be an RA 'Guinea Pig' for Elena free of charge, then please feel free to contact her directly:

**ella.skincc@gmail.com** or visit her website: **www.ellascc.co.uk**


*Atrophic scarring and vascular malformation*


*With skin camouflage applied*


*Keloid scarring*


*Following camouflage application*

# Rheumatoid Arthritis Awareness Week

## 19-25 June 2017

**RA Awareness Week is an important week in the NRAS calendar. As the name suggests, its aim is to raise awareness and challenge misconceptions and attitudes people may have around rheumatoid arthritis.**

By dedicating a week to raising awareness we aim to broaden perceptions, knowledge and understanding of this disease.

### The theme

2017 will focus on 'Invisible Illness', and what goes on 'Behind the Smile'. People who break their arm or experience an injury are obviously in bad shape but we can see their injury and understand their limitations. But for the millions of people who are living with an invisible illness such as rheumatoid arthritis, explaining what's wrong is another side effect of the condition. Not only do people have to put up with challenging, often painful, and sometimes debilitating conditions every day, but on top of that, they may have to face scepticism from people - friends, family, and co-workers, as well as strangers who don't understand what's wrong.

Throughout the week, we will be focussing on a number of different themes around invisible illness:

| | |
|---|---|
| **Mon** | Invisible Illness; general public perspectives |
| **Tues** | Families and friends: how to support someone with RA |
| **Wed** | GPs and diagnosis: how a GP can encourage people to spot particular signs at home and look for indicators |
| **Thur** | Behind The Smile launch: exploring what it is like to live with RA |
| **Fri** | Managing RA in the workplace - we will look how to manage symptoms that affect work, we will look at different perspectives |
| **Sat** | Intimacy and relationships: advice on relationships when living with long-term conditions |
| **Sun** | Coming Out: the stigma associated with invisible illness. NRAS; we're here for you |

Thank you to everyone who supported us and helped make RAAW 2016 such a success

## How can you get involved?

We have lots of fundraising ideas if this is something you'd like to do. Displaying our posters is a great way to raise awareness or even simply sharing and retweeting posts during the week would be a great help.

You can download a RAAW pack, which includes a fundraising guide, posters, infographics, bumper sticker, pencil and pencil grip. Also included are some smiley lips, which we'd love you to use to take a photo or selfie so you can tweet us and share with friends, perhaps even change your cover image or profile picture?

Another very important way you can support NRAS is by engaging with your local MP. We would like to encourage you to try and arrange a meeting during RAAW to discuss local and national issues as they relate to people living with RA, such as work and prescription charges. You will be able to register for a campaigning pack, which will give you a step by step guide as to how to go about this, at the end of April.

To download or order your RAAW 2017 resource pack please visit **www.nras.org.uk/raaw**
Or call us on **01628 823524**
For media enquiries please contact **media@nras.org.uk**

---

# Filming with Katy Pieris

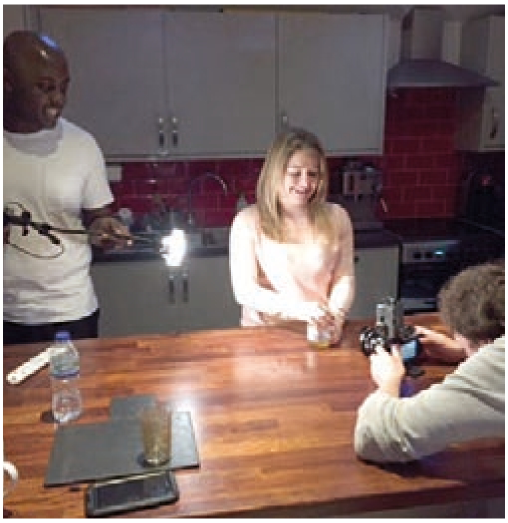
## Coming to a screen near you soon!

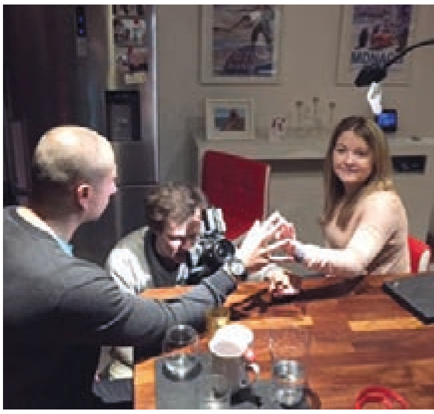
**By Sally Wright**

**On a very cold Saturday in February, I donned my woolly hat and gloves and found myself filming on the netball court (not playing as I usually do, unfortunately). We were filming Katy Pieris, NRAS Member and Croydon group Co-ordinator.**

This promotional NRAS film will be coming to a screen near you shortly, but we thank Katy, her husband Marc and sister Lucie for giving up their Saturday. The filmmakers, My Life Films, are a social enterprise, which means that any money they make from corporate videos goes into making films for people and their families affected by dementia. They capture the memories of people living with dementia before they disappear and record them so that the they can celebrate their lives and maintain their identity.

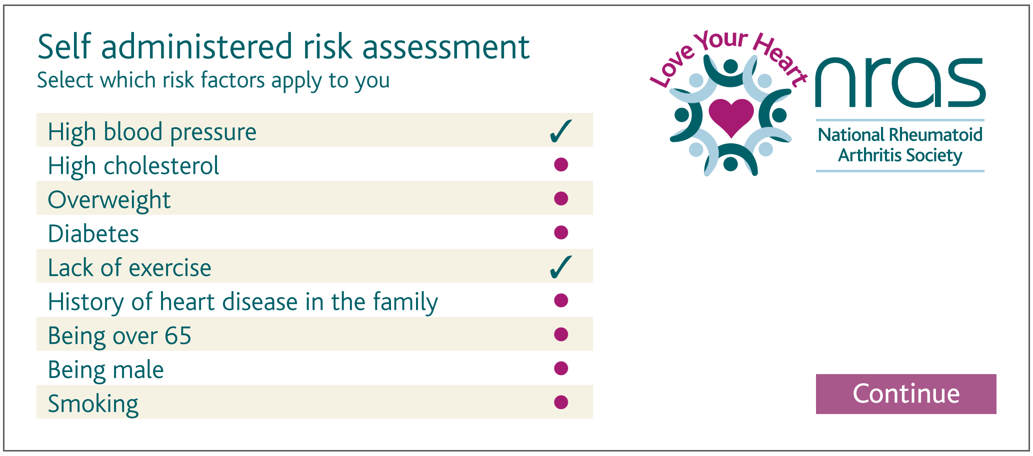
**www.mylifefilms.org**





# Love your Heart Programme

## An interactive, on-line education programme



Self administered risk assessment
Select which risk factors apply to you

High blood pressure ✓
High cholesterol ●
Overweight ●
Diabetes ●
Lack of exercise ✓
History of heart disease in the family ●
Being over 65 ●
Being male ●
Smoking ●

**NRAS has collaborated with Dr Holly John, Consultant Rheumatologist at Dudley General hospital, to provide an interactive online education programme to enable people with rheumatoid arthritis to assess their cardiovascular risk and set personal goals to improve their cardiovascular health.**

> "I found it a valuable and life-changing experience to do this programme"

Rheumatoid arthritis is associated with an increased risk of cardiovascular disease, akin to type 2 diabetes. However, screening for, management of, and education about co-morbidities is not always adequate and as a result, the comorbid risks may be overlooked by the general public, some health professionals, and policymakers alike. Dr John's original pilot as a group format in Dudley achieved promising results. The format however limited the number of people who could access it and NRAS wanted to make it as widely available as possible.

Currently cardiovascular disease is still a relatively misunderstood and invisible disease. Getting to a diagnosis can therefore often be challenging as people don't often recognise the symptoms as a medical emergency. CVD accounts for just over a quarter of deaths in Britain and costs the economy billions in healthcare. We are anticipating that the Love Your Heart programme will have a real impact on helping to reduce this risk in people with RA.

We have created an engaging and interactive online programme to educate people with RA about heart disease, atherosclerosis, diet and lifestyle that will be available later in the year.

Visitors to the site will be able to:

- understand the reasons why RA increases risk of CVD
- calculate a QRISK®2 score (a GP recognised prediction algorithm for CVD)
- learn how to reduce the risk of CVD
- log progress through a series of behavioural goals

Quote from a patient who participated in the face to face programme:

*"Before I did this programme I thought that I was doing pretty well in terms of diet and exercise but it showed me that there was a lot I wasn't aware of, that my knowledge of lifestyle factors wasn't adequate and I needed to do more to help myself. I found it a valuable and life-changing experience to do this programme."*

We are very excited about the launch of this programme as it is an important new resource addressing the major comorbidity which shortens the lives of those with RA. It is unique in that not only does it provide patient education, but it also provides a structure through which patients can change their behaviour. Furthermore, it also illustrates what can be achieved when patient-led charity organisations work alongside healthcare professionals. We are hugely excited by its potential.

NRAS is really excited to be working with Dr John and hope that the Love your Heart programme will help all those with RA to lead a longer and healthier life by addressing those risk factors that are within our own control.

## Margaret Magill and Pat Fernee awarded certificates in Scottish Parliament at The Self Management Awards for

# Supporting Community of the Year

**By Fiona Lovegrove**

Lead Nurse Rheumatology,
Fife Rheumatic Diseases Unit

**For two years, the Fife Rheumatic Diseases Unit (FRDU) has been running Rheumatoid Arthritis Self-Management Programmes (RASMP). This is in conjunction with, and being fully supported by NRAS.**

Four years ago, FRDU were contacted by NRAS, offering the training of Health Care Professionals and Lay Tutors (patients with RA) to enable these Self-Management Programmes to be run. I have been facilitating these along with our two Lay Tutors, Margaret Magill and Pat Fernee.

*Fiona and Pat*

The courses have now been running for two years and each course runs over six weeks, with three hour sessions on the same day each week. A variety of topics are discussed, such as how to self-manage day-to-day, coping better with the impacts of RA, the differences between RA and osteoarthritis, coping with depression and anxiety, goal setting and gaining a greater understanding of RA treatments. The results and impact of these courses have been evaluated by means of participants' questionnaires completed before and after each six week programme, and also six months later. The benefits have been statistically verified and recorded by NRAS.

To date, four courses have been completed and 40 FRDU patients have benefited. Margaret and Pat continue to help run the courses, giving up a lot of their spare time whilst coping with their own RA and its difficulties. They do this with dedication, willingness and a lot of humour added in!

In August 2016, the development officer of the Health and Social Care Alliance Scotland contacted the department and informed us of the Self-Management Awards 2016. These were to be held in the Scottish Parliament at Holyrood in Edinburgh. Both Margaret and Pat, as a team, would be nominated for one of these prestigious awards. The Development Officer was provided with information regarding Margaret and Pat, on the content of the courses and the impact of these on our patients. Photographs were submitted and it was with great delight that I heard that Pat and Margaret were duly shortlisted for an award.

In October 2016, a small group including Pat and 3 Health Care Professionals attended the Scottish Parliament for the award ceremony. Approximately 100 others were in attendance. 12 people or groups of people had been shortlisted for the Self-Management Supporting Community of 2016 Award. Photographs of our two Lay tutors and NRAS groups were projected onto a screen for all to see. It was delightful when Margaret and Pat and our NRAS Self-Management Course came in the top three of all those shortlisted. They were awarded a certificate, in the category of "Supporting Community of the Year" for all self-management groups throughout Scotland. This certificate has now been framed and hangs proudly within the FRDU.

A huge thank you goes to NRAS, and to Pat and Margaret, for their support and dedication to our patients and care professionals.

> "Margaret and Pat continue to help run the courses with dedication, willingness and a lot of humour added in!"

**By Dr Martin Lee**

Consultant Rheumatologist
and Associate Clinical Sub
Dean at Newcastle Hospital

# The importance of sleep management

## and the potential effects of smartphone overuse syndrome (SOS)

**The rapid evolution of smartphones has fundamentally changed how we live and their functionality has had many positive impacts on our lives. We now have access to the internet, social media and a multitude of apps 24 hours a day, 7 days a week. Are there potential downsides however to this technology that could be having a negative impact within our homes and on our lives?**

### Smartphone Overuse Syndrome (SOS)

As a UK rheumatologist, I witness potential negative consequences of smartphone technology almost on a day-to-day basis. Smartphone overuse has the potential to hinder interpersonal relationships within our families and also have a negative effect on our own, and our childrens', sleep patterns, physical and mental health.

I frequently treat people complaining of chronic fatigue, daytime sleepiness, muscle and joint pains and headaches. These symptoms are often accompanied by symptoms of irritable bowel syndrome, low mood and anxiety. These patients often have multiple tender muscle trigger points and would fulfill diagnostic criteria for fibromyalgia. When taking a history from these patients, poor sleep quantity and quality and waking feeling unrefreshed is a recurrent theme. Often patients describe smartphone use in the evenings and at night at a time that could potentially interfere with sleep. This phenomenon appears to be most common in, but not restricted to, young adults.

There are many studies demonstrating that healthy sleep plays a key role in our mental and physical wellbeing. Chronic lack of deep or restorative sleep is a key feature of conditions such as fibromyalgia, which is associated with chronic pain, fatigue, depression and anxiety. Is there any evidence that smartphone overuse, particularly in young adults, could be having a negative impact on our mental and physical health?

*Baby Orla*

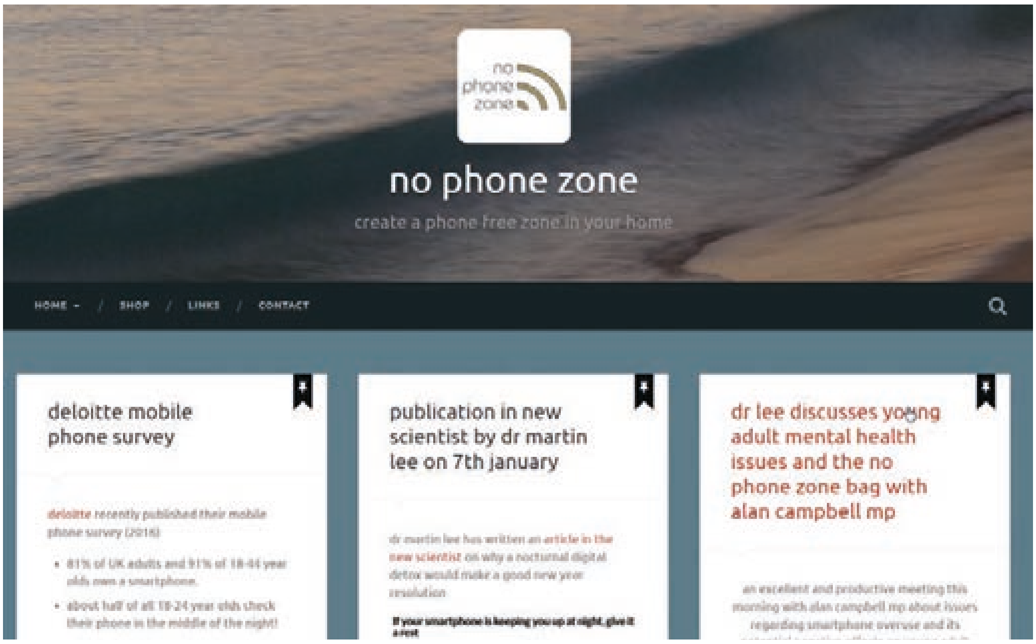
### The importance of fatigue and sleep in inflammatory arthritis

Fatigue and sleep disturbance are key features of chronic inflammatory conditions such as rheumatoid arthritis (RA) and Juvenile Idiopathic Arthritis (JIA). Fatigue is a difficult symptom to treat and often does not respond to disease modifying or biologic therapies. Depression is more common in patients with RA and sleep loss exacerbates fatigue, depression and pain in RA. Therefore fatigue and sleep disturbance are important issues to discuss, assess and address in all patients with RA and JIA.

### Trends in smartphone use

Deloitte recently published its UK mobile consumer survey. This report found that about 80% of adults and about 91% of 18-44 year olds in the UK own a smartphone. Nocturnal smartphone usage is particularly high in the young adult population and about half of all 18-24 year olds check their phone in the middle of the night.

The Headmasters' and Headmistresses' Conference in partnership with Digital Awareness UK recently published a survey of 2,750 pupils aged 11-18, looking into teenage use of mobile devices overnight and the impact this is having on their health and wellbeing. The survey revealed that almost half (45%) of teenagers checked their mobile devices during the night. Of these teenagers, 23% checked their mobile



deloitte mobile phone survey

deloitte recently published their mobile phone survey (2016)

- 81% of UK adults and 91% of 18-44 year olds own a smartphone.
- about half of all 18-24 year olds check their phone in the middle of the night!

publication in new scientist by dr martin lee on 7th january

dr martin lee has written an article in the new scientist on why a nocturnal digital detox would make a good new year resolution

If your smartphone is keeping you up at night, give it a rest

dr lee discusses young adult mental health issues and the no phone zone bag with alan campbell mp

an excellent and productive meeting this morning with alan campbell mp about issues regarding smartphone overuse and its

device more than 10 times per night. Almost all (94%) of these students used social media after going to bed. 68% of students said that using their mobile devices at night affected their schoolwork and a quarter of students said that they felt tired during the day because of how often they used their mobile device at night.

## Smartphone use and sleep

Alongside increased smartphone ownership and use, recent studies suggest a shift towards poorer sleep patterns. These changes include going to bed later, taking longer to fall asleep, poorer sleep quality and excessive daytime sleepiness. There is also a correlation between increased mobile phone use, particularly at bedtime, and shorter sleep duration or increased daytime sleepiness. A number of theories have been proposed about how smartphone use in evenings and at bedtime could potentially have a negative impact on sleep quantity and quality:

- Sleep could potentially simply be displaced by smartphone use at night leaving less time for sleep. This is sometimes referred to as 'sleep stealing'.
- Smartphone use at bedtime could lead to increased mental, emotional or physiological arousal and interfere with time to onset of sleep.
- Light emission from smartphones that use 'blue-range' light may interfere with melatonin secretion (our body's 'sleep hormone') and circadian rhythm (our body's in-built 24-hour clock).
- Smartphones are often left switched on at night and incoming messages, emails, status updates or calls can disturb sleep.

## Smartphone use and health disorders

Alongside evidence of an increase in smartphone ownership and associated sleep disturbance, there is also evidence linking this to mental health disorders. A survey of 362 adolescents published in 2015 found that electronic media use in bed before sleep was related to shorter sleep duration and higher levels of depressive symptoms. Mental and physical wellbeing are intrinsically linked. However, as physicians we struggle to explain this concept to our patients, primarily because our own understanding of this interaction is poor. Conditions such as chronic fatigue syndrome and fibromyalgia syndrome are characterised by poor sleep quality, waking unrefreshed and mood disturbances. Studies looking at relationships between smartphone use, sleep disturbance and physical disorders such as fibromyalgia are currently lacking and it is an area that warrants further research.

## Conclusions

There is overwhelming evidence demonstrating that we are using smartphones more and more and that smartphone use at night could potentially have a negative impact on our sleep and our mental health.

I believe that people (particularly adolescents and young adults) should be educated about the potential effects of smartphone use at night. This could include advice about setting limits on smartphone use at bedtime and night or introducing phone free areas of the home or times of the day. We need to learn how to best run our lives with smartphones as opposed to having our lives run by smartphones.

For further information visit
**www.nophonezone.co.uk**

Smartphone use at night could potentially have a negative impact on our sleep and our mental health

# What causes RA?

## I recently developed rheumatoid arthritis. I am only 42 and nobody in my family has the condition. Why has this happened to me? Have I done anything to bring this on myself?

**Whilst it is not fully understood why an individual develops RA when they do, a lot of the causes and risk factors have been identified.**

**Genetics:** Whilst you may not have anyone in your family with RA or another auto-immune condition, it is possible that you carry genes that make you more susceptible to developing RA. To give you an indication about the significance of the genetic links in identical twins, where one twin has RA, the chances of the other twin developing it is around 15%. When a parent has RA, the chances of their child also developing it are only around 1-3%.

**Environmental:** One of the biggest environmental factors in developing RA is smoking. The chances of developing the condition go up the more heavily you have smoked, the longer you smoked for and (if you have quit smoking) how long ago you gave up. Being a current smoker has also been shown to make symptoms worse and make a good response to medication less likely, so it is a good idea to quit smoking if you have RA or know that it runs in your family. Being overweight has also been associated with a worsening of RA symptoms and has been looked at as a potential risk factor in developing RA.

Hormones are also thought to play an important role in the development of RA. RA affects more women than men under 60, and commonly comes on during periods of hormonal change for women, such as after giving birth or onset of menopause.

So, you might be genetically susceptible to getting RA and this risk might be further increased by hormones and environmental factors. The typical age range for developing RA is between 40-60, so whilst at the lower end of that scale, you also fit with a typical age of diagnosis. The last piece of the puzzle is the 'trigger' and this is arguably the bit that is least understood. Anecdotally, people often talk of their RA coming on after periods of stress or physical or mental trauma, or following an illness, and, as previously mentioned, after giving birth. Some studies have backed up some of these claims, but it is still not clear why that particular event triggered RA at that point in time for that individual (ie if childbirth is the trigger, but this is your second child, why wasn't it triggered after your first child?).

The exact cause of your RA may never be fully understood, and much of it would have been outside of your control. Even if you do have additional environmental risk factors, or feel that something within your control triggered the condition, you should never feel you are to blame. RA is impossible to predict and it probably happened at this time because of a number of factors coming together at once. You may not be able to control the fact that you developed this condition, but by looking after yourself as best you can now, and working with your rheumatology team, you can help to get your RA under the best possible control.

# Applying for Personal Independence Payment (PIP)

## What tips can you give me for filling out the forms and what do I do if I get refused?

**I have recently been sent notification that I need to apply for Personal Independence Payment (PIP). I currently receive Disability Living Allowance (DLA) and I have heard that some people have lost their benefit when changing. I thought that people would be automatically put onto PIP if they were receiving DLA.**

This is something that concerns many people and the transfer from DLA to PIP is not automatic. Although like DLA, PIP is a benefit to help people who have difficulties in carrying out daily activities because of their disability and so incur additional costs because of this, the way in which it is assessed is different to the way in which DLA was assessed.

PIP is a points-based system and it has two parts; a daily living section and a mobility section. When filling in the form, remember to concentrate on the ways in which your condition affects your ability to do things. Rheumatoid arthritis (RA) is a fluctuating condition and many people do not know how to answer the questions as some days they may be able to do some of the activities listed and other days not. In this instance, you should fill in the form by ticking the level which most applies to you 50% of the time. Also, you must be able to perform any activity safely, to a reasonable standard and in a reasonable amount of time. Have you changed the way in which you do things? It is easy to forget that before you had RA, you may have done things in a very different way and also have become accustomed to experiencing some pain when doing these activities. This becomes "normal" for you so think very carefully before answering any questions. Send in any further supporting evidence you may have such as a letter from a healthcare professional. It is a good idea to photocopy this evidence and keep for your own records.

If your application for PIP is unsuccessful initially, don't give up straight away. When you get your decision, you should receive a copy of the report upon which it was based (if not you can ask for it). Look through this to see if there are any mistakes or things that you think are vital to your application that have been left out or misinterpreted. If there are, then the first thing that you can do is ask for a mandatory reconsideration. At this stage point out any inconsistencies in the report.

If the original decision is upheld, then you can go through the appeals process. You must have first asked for the mandatory reconsideration before you can do this. You must appeal within one month of the date on the letter or email telling you the outcome of your reconsideration.

Your appeal will be heard by an independent appeal tribunal. These are informal and are not like courts. A family member or carer can attend the hearing with you and organisations like the Citizens Advice Bureau or DIAL can be contacted to see if they can give you any support and/or provide you with a representative to present your case at the hearing. Currently, there is quite a high success rate for these appeals.

If you would like more information about claiming PIP we have a publication: *'How to Claim Personal Independence Payment'* which can be accessed via the website as a download or ordered as a hard copy (**www.nras.org.uk/publications**). Alternatively, you can ring the helpline on **0800 298 7650** for further information.

# Reducing heart attacks

## Risk of heart attack in rheumatoid arthritis patients almost halved by biologic drugs

**New research shows that biologic drugs, used to treat rheumatoid arthritis, can reduce the risk of heart attacks in people with RA by up to 40%.**

The higher risk of heart attacks in patients with RA is thought to be a consequence of the inflammation caused by the disease. A key goal in the treatment of RA is to reduce this inflammation.

Standard disease modifying drugs (DMARDs) such as methotrexate are used to reduce the activity of the disease and biologic drugs such as the anti-TNFs work by targeting certain proteins in the immune response, thereby reducing inflammation.

The use of biologic drugs in the UK are governed by the NICE guidelines and are restricted to certain patients who fit the criteria set out by NICE. These patients must have a high level of disease activity and it is estimated that about 15% of people with RA receive biologics.

Two groups of people with RA were studied by researchers from the British Society for Rheumatology Biologics Register for Rheumatoid Arthritis (BSRBR-RA) to find out their risk of heart attack and the severity of those attacks. This research was carried out at the Arthritis Research UK Centre for Epidemiology, University of Manchester.

A decrease in risk of almost 40% was noted in patients who received anti-TNF treatment, compared to those who received standard DMARDs only. However, the severity of heart attacks among those who did suffer them was no different between the two groups.

Professor Kimme Hyrich in the University of Manchester's Division of Musculoskeletal & Dermatological Sciences said: *"RA patients already have to endure a debilitating condition, so to have an elevated risk of heart attacks because of their disease is a very worrying complication. In addition to managing risk factors such as high blood pressure and high cholesterol, achieving excellent control of inflammation can also reduce this risk.''*

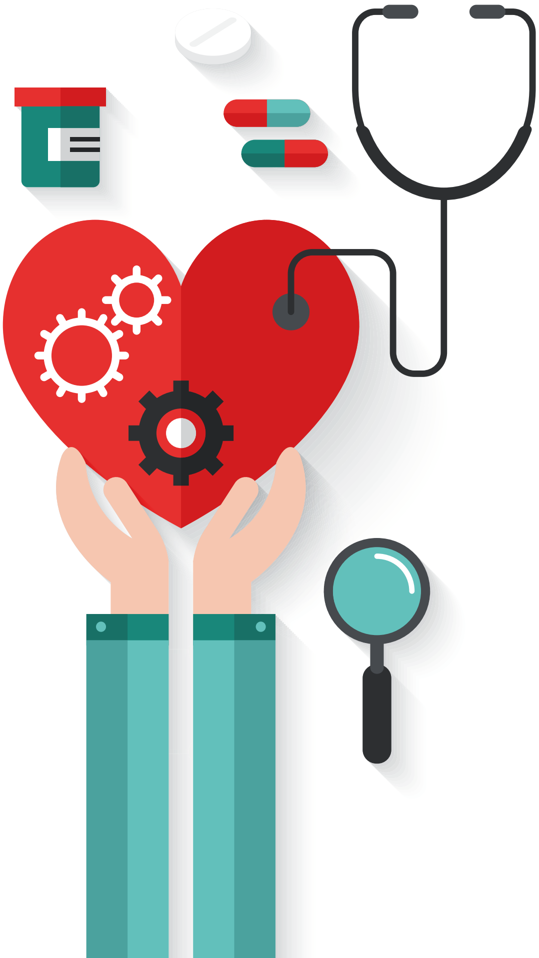
*"Our team has been able to show that this elevated risk can be reduced significantly by using biological drug therapies such as anti-TNFs.*

*The findings and plausible explanations for them could be used to review existing guidelines (for the use of biologics) and in particular, extend the use to patients with moderate levels of disease activity."*

Dr Mike Knapton, associate medical director at the British Heart Foundation (who funded the majority of this research) said: *"This research is interesting, showing a clear association between receiving anti-TNFs and risk of heart attack.*

*"This research will inform future work, as we discover new ways to reduce heart attacks in people living with RA."*

The research is promising, and adds to our understanding of the risks of heart attacks in patients with RA and possible ways to prevent them, though further research will be needed to investigate this.



# Treatment for depression

## Biologic drugs used for autoimmune disease could also help treat depression in the future

**Researchers have provided evidence to show that drugs used to help people with autoimmune diseases may also help people with mental health problems such as depression.**

A study led by Dr Golam Khandaker from the Department of Psychiatry based at the University of Cambridge published the results in the Journal for Molecular Psychiatry.

Inflammation normally occurs as a result of our body defending itself against infections and injury. Our body releases cells known as cytokines (inflammatory proteins) to ward off harmful organisms. Sometimes our inflammatory response does not work correctly and our immune system can start attacking healthy cells instead, and this can then cause autoimmune diseases such as rheumatoid arthritis and Crohn's disease.

Researchers may have made a connection between inflammation and mental health. Dr Khandaker carried out a previous study in 2014, which found that children who had higher inflammatory markers in their blood were more susceptible to depression and psychosis in adulthood.

Dr Khandaker decided to carry out a study to see whether biologic drugs that reduce inflammation in rheumatoid arthritis and other autoimmune diseases could also help the symptoms of depression.

The study was carried out on 5,000 patients with different autoimmune diseases examining how these particular drugs affected this group of patients.

The study found that the biologic drugs were an effective treatment, especially for the people that do not respond well to current antidepressants. A third of patients who are resistant to current antidepressants have evidence of inflammation and may benefit greatly from this type of medication.

Dr Khandaker suggests that we are moving towards an era of 'personalised medicine' as current antidepressants target a particular neuro transmitter in the brain but a third of patients do not respond, so anti-inflammatory drugs may be used in the future for this particular group of patients.

Further clinical trials will need to be carried out before these treatments can be used for depression in clinical practice.

> "It's becoming increasingly clear to us that inflammation plays a role in depression, at least for some individuals, and now our review suggests that it may be possible to treat these individuals using some anti-inflammatory drugs"

# Anti-TNF treatments

## New research reveals why some patients will not respond to anti-TNF treatments

**A new study was carried out in San Francisco focusing on why some people with rheumatoid arthritis do not respond to anti-TNF treatments.**

It was found that a certain protein that drives inflammation may be to blame. Identifying this may help with more personalised medicine in the future and less trial and error prescribing.

The study found that patients who had a higher proportion of an inflammatory protein called type1 interferon beta, compared with another called type 1 interferon alpha, did not respond as well to anti-TNF treatments. They also found certain white blood cells called monocytes, which have a lot of involvement in rheumatoid arthritis, behaved differently in one group from the other.

This gives us an insight into future developments in drug treatments for rheumatoid arthritis. The more that researchers can understand about an individual's personal biology, the more likely it is that they will be able to determine how well someone is likely to respond to a treatment by identifying other markers within the blood.

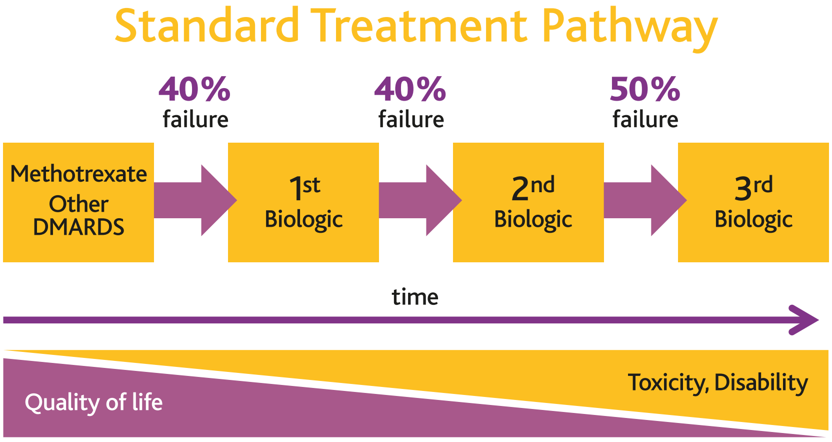
This then should help rheumatologists to find the most effective treatment for the patient as soon after diagnosis as possible. This would in turn reduce uncertainty and stress from the patient's point of view of not knowing if the treatment will work with the current trial and error approach. It would also save the NHS time and money in the long-term on drugs that do not always work for the patient.

# The potential of personalised/stratified medicines

## for rheumatoid arthritis (RA)

By Debbie Maskell, Gaye Hadfield & Zoë Ide

**Just imagine if a blood test and/or a simple biopsy of the tissue in one of your joints could tell your clinician what RA medication would most likely work best for you as an individual. This is the dream of personalised or stratified medicine for rheumatoid arthritis and could transform the way that patients are currently treated.**



Standard Treatment Pathway

Put simply, personalised or stratified medicine as it is also known, means providing the right medicine to the right patient, at the right dose at the right time.

As we know, there have been many advances in the treatment of RA over the last 20 years, including aggressive treatment at the early stages after diagnosis and the introduction of effective new drugs called biologics.

However, the major problem is, we still can't predict who will respond to which treatment: with 40% of patients experiencing no real benefit from each drug that is used, it can take years of trying different drugs before a suitable one is found. It also means exposing patients to the potential side effects of drugs that aren't working for them and often leaves them to cope with the severe symptoms of uncontrolled RA, including unnecessary joint damage. There are also major economic costs to consider with a bill for the NHS approaching £50 million a year - £16-20 million (30-40%) where many savings could be made if patients were treated more effectively.

Currently the standard NICE(National Institute for Health & Clinical Excellence) guideline treatment pathway for RA tells us that patients should be treated with at least two disease modifying anti rheumatic drugs (DMARDs such as methotrexate) first, followed by up to three biologic drugs. Unless an effective treatment is selected early on, as you can see by the diagram, there is a significant risk that patients can be left with increased disability and decreased quality of life.

**MATURA** (**MA**ximising **T**herapeutic **U**tility for **R**heumatoid **A**rthritis) is an international consortium of academics, clinicians and industry partners who are working together to try and make stratified medicine a reality for patients by developing a test that identifies those genes and biomarkers in a patient's biological make up which can predict with quite a high level of accuracy who will respond better to which type of drug. This test would also help us understand if any drugs should be avoided, or used at a lower dose, because of the risk of side effects.

The MATURA team are currently running two specific projects nationally that involve patients in their work to help them achieve this goal.

One is a clinical trial which concentrates on patients who are ready to be treated by a biological drug and is currently taking place in 15 hospitals. It is called **STRAP** (**S**tratification of Biologic **T**herapies for **RA** by **P**athobiology) and is investigating whether the most effective choice of drug may be guided by the examination of the tissue in a swollen joint (synovial tissue) and whether particular immune cells (B cells) in the tissue can predict a response to treatment.

In parallel, blood samples are being collected in over 45 hospitals through the **BRAGGSS** (**B**iologics in **RA** **G**enetics & **G**enomics **S**tudy **S**yndicate) study to test whether changes in genes, antibodies, inflammatory markers, cells or other factors can be used to predict future response to treatments.

The MATURA consortium have set up, with the help of NRAS, a nationwide group of patients with different experiences and backgrounds who are at different points on their journey with RA. As part of their role they help the project understand more about the treatment pathway from a patient's perspective and the frustrations often involved. They also make sure that the investigators are asking the right questions and concentrating on the right areas in the research undertaken. The group is called MPAG (MATURA Patient Advisory Group).

## Some personal statements from patients about what Stratified Medicine could mean for them…

"Having tried two biologics with no results before finding one that works for me, I am all too keenly aware of the years of uncertainty that could possibly have been avoided while I waited hopefully for each medicine to start working."

Hannah Maltby

"If stratified medicine had been available when I was growing up with juvenile idiopathic arthritis, it might have meant that I would have needed fewer medicines on a 'trial and error' basis, before finding one that worked well for me."

Simon Stones

"I am really looking forward to the day a biopsy and/or blood investigation helps me and my consultant choose the best treatment for my RA rather than 'Professor pathway NICE' and 'Dr High hurdle DAS' who really aren't very good at all for me."

Zoe Ide

"Stratified medicine could increase the chance of successful treatment sooner for RA patients than I experienced myself, hopefully eliminating the painful wait for the right treatment."

Caroline Wallis

"If the stress and anxiety associated with failed RA treatment could be reduced with a targeted solution, my quality of life would have improved significantly."

Chris Wills

We hope this article has stimulated your interest in stratified medicines and has highlighted the potential of this approach to revolutionise future care for RA patients. If you are interested in being part of the patient advisory group, you can contact one of the project managers to find out more details on this or any aspect of the studies:

**Manchester:** Deborah Maskell
deborah.maskell@manchester.ac.uk | Tel: 0161 275 5046

**London:** Gaye Hadfield
g.hadfield@qmul.ac.uk | Tel: 020 7882 2904

MATURA
MAximising Therapeutic Utility for Rheumatoid Arthritis

For more information about these research studies and to find out which hospitals are taking part please visit:

for STRAP: **www.matura-mrc.whri.qmul.ac.uk/**

for BRAGGS: **http://research.bmh.manchester.ac.uk/Musculoskeletal/research/CfGG/pharmacogenetics/braggss/**

If you are interested in participating please discuss this with your rheumatologist.

**By Sally Wright**

Head of Marcoms

**Shivam Arora**

Web and Social Media

# Life is short, so do what makes you happy

## Sally Wright, Head of Marcoms and Shivam Arora, Web and Social Media, interview Matt Iseman

**Matt Iseman is the celebrity host of American Ninja Warrior, Clean House, Hallmark's Home and Family, and is the 2016 winner of the American version of Celebrity Apprentice. He is also a stand-up comedian, and has appeared in sit-coms and Transformers 2...all this and he has Rheumatoid Arthritis. A simple email to Matt some months ago resulted in him kindly telling his story.**

**SW So, tell us a little about your story Matt?**

**MI** Well my symptoms started about a year and half before I was diagnosed. I was an MD at the time, my dad's an MD and some of my friends are also doctors but despite having all that information it still took me 18 months to get a diagnosis. During which time, my body really fell apart. I gained about 45-50lbs; the pain in my hands, feet, neck, my whole body plus all the fatigue that was going on meant I stopped working out. It impacted me so much physically and emotionally, that for me, when I was told I had arthritis, it was a relief; people find that hard to believe. Even as a doctor and someone who has studied RA, when you look it all up on the internet, you of course automatically look at the 'worst case'.

I didn't know anyone with RA, or who talked about RA, and I wanted to know what it was like living with the disease. That's why I started working with the Arthritis Foundation and advocacy groups because I didn't want people to feel that when they look up RA they always see the worst case. I wanted people to have different stories to read, be able to tell my story so people saw that for me, when I started responding to treatment, the pain started to go away, I felt a lot better. The problem with RA, is that you don't often hear about the ones doing well. This disease doesn't need to define who you are. So, that's been my motivating factor in sharing my story.

**SW We tend to have a lot of problems in getting people to 'come out' and talk about RA, especially celebrities like yourself. Why do you think that is?**

**MI** I don't know... having been a doctor and realising that disease doesn't know any prejudice, to think people may think differently about me, well that doesn't even enter my mind. If you're selling the illusion of being an action star then how much more bad ass am I, doing what I'm doing talking about RA? I also understand why people may not be comfortable, I don't want people to look or think of me differently. I want people to realise that just because you have RA, your life doesn't have to be limited, it'll be different, just not limited.

**SW At the time of your diagnosis, what support was there for you?**

**MI** My family were in Colorado and I'm in Hollywood, so my support system was stand-up comedy. That's what I used to cope with the disease day to day. As I felt my body deteriorating, what really kept me going was getting on stage, telling jokes, making people laugh, being around others who would make me laugh and that was the thing that emotionally helped me deal with it. RA is the hardest thing I've ever been through, so once I was diagnosed, my family were great. But it's really helped to find and talk to like-minded people.

**SA Can I ask what sort of treatment you're taking at the minute?**

**MI** Sure. I'm on an immune system modifier, Remicade, methotrexate, which I've been on since the start, and fortunately responded well to. I was diagnosed Christmas 2002 at my dad's in Colorado, one of his friends (doctor) diagnosed me. They looked at my x-rays and said that I was having some pretty aggressive erosive changes, so they started me on methotrexate straight away.

**SW One of our Members has asked if your methotrexate causes you brain fog?**

MI I don't know if I can blame the methotrexate for that! I've done stand-up where I'm entertaining a room for an hour, so mentally I feel sharper than ever. I haven't experienced 'brain fog', but hey, talk to my friends or family, they may tell you differently! What's great is that we're living in an amazing time. I was diagnosed in 2002 and the treatment I'm on was approved in 1998. These biologics really were the silver bullet for RA, they really advanced treatment, and I think, what a fortunate time for me to get a disease when these treatments are out. It's such a promising time for us and advocacy groups like NRAS, raising money, raising awareness. There are more options out there and more to come.

**SA Your job is so unique, has it posed any challenges? I know you used to work out at Gold's gym and you still look fit, have you had to make any compromises that way?**

MI Yeah, because of the changes in my feet I couldn't jog, play basketball, do high impact sports, actually I've just had surgery and I'm in a boot right now. So, I went from lifting weights, jogging etc, to pilates and yoga. I still work out, you can still do something and I think if you're battling something like this, activity becomes more important. Finding whatever it is you can do; be it standing in a pool and moving your arms to whatever, I truly believe that the more active you are the better you'll be able to combat your disease.

**SA How do you manage the flare ups and fatigue that can strike without warning?**

MI Well you need to take care of yourself first. Know when you can't do something, take time, don't punish yourself, say NO to things. The more active I keep my body, the better I feel - good sleep, rest and hydration are important, but find things that energise you. Be that physical fitness or hobbies. When I feel run down and fatigued, finding something that energises me – a nap, a great song, a show, something that makes me laugh is great. It's ok to place yourself first. It's ok to ask for help from your kids or family. Finding people that have felt the same way helps too.

**SW So what advice would you give to kids living with RA or JIA, or what advice would you give your younger self?**

MI Never let this disease define you, you may feel it's placing limitations on your life, but try things, try and do things you think you can't do. You may be surprised at what you can accomplish. Go seize life, let this diagnosis be a wake-up call as to how precious life is and to not focus on what you can't do but what you can do.

**SW Is there anything that keeps you up at night? Is there anything that stresses you?**

MI As I get older you start to think about family. Both my parents have health problems and that's when you realise the fragility of life. I'm about to turn 46, I want to make sure I step back every now and again and see what I'm doing. That's what keeps me up, making sure I'm not missing these great moments or I'm not getting caught up in my own struggles or issues.

**SA Have you got a life motto or mantra?**

MI When I left medicine and decided to try stand-up, I told my Dad (who's a Professor at the University). To follow in his footsteps and then go off and do something else - I was terrified to disappoint him, to feel I'd let him down. And do you know what he said? He said, 'Life is short, do what makes you happy!' That gave me permission to pursue the things that made me happy. Make sure you find that thing that lights the passion.

> "Make sure you find that thing that lights the passion"

**SW So we know it's your birthday in a few days, what will you be doing?**

MI One of the guys I'm on the show with Chael Sonnen is a UFC fighter, he has a fight so we're going to his fight and then just eat cake and just be with my girlfriend!

You can read the full interview here (with extra 'off-the-cuff' questions)
**www.nras.org.uk/stories**

# Anne makes marathon magic

*Anne O'Neill*

**Sunday 28th August was a poignant day for Anne O'Neill, a long-time supporter of NRAS and dedicated fundraiser.**

This was the second time that Anne would line up on the starting line to take part in the Longford Marathon. Anne was taking part in her second full marathon in the home town of her late Mother, Kathleen, who had suffered with RA for over 25 years. Anne had seen first-hand her mum struggle on a daily basis and her mobility get progressively worse over the years. Anne had wanted to do something to remember her mum and her sister at the same time who had lived with Epilepsy.

Anne ran her first full Marathon in Longford in 2014, followed by a half marathon on the same course in 2015. In 2016 Anne ran her final full Marathon on this very special course as she too has arthritis and is waiting for a knee replacement. Determined as ever, knowing this was the last time she would challenge herself to the gruelling 26.2 miles, she cycled some of the more remote sections of the course. Anne completed the course on a very hot day, in a fantastic 3 hours 5 mins and 31 seconds running over the finishing line to receive her medal with great pride. Anne split her fundraising between two charities and NRAS was delighted to benefit from a fantastic £462 in 2016. In total Anne has raised over £4,500 for NRAS and we are honoured she has supported us over the past few years.

---

# Could NRAS be your next Charity of the year?

*Wellington Prep School*

**NRAS has been fortunate to receive great support from businesses and social clubs in the past, this provides us with a fantastic opportunity to raise awareness of RA, JIA and NRAS locally.**

*Orsett Golf Club*

Last year NRAS Charity of the Year supporters raised over £22,000 which is incredible, so our thanks on behalf of all those we support living with RA and JIA goes to them all. We're always looking for new partnerships and want to make your year the best yet. If your sports club, business, or community group are interested please get in touch today by emailing brianna@nras.org.uk or call 01628 823 524 and speak to the fundraising team.

Some of the highlights from last year are:

## Wellington Prep School

Wellington Prep School, who chose us as Charity of the year in 2016, raised an amazing £2,000 which is fantastic! Year 7 pupil Papatya Kaya, whose mother Tracey Kaya is a teacher at the school and lives with Rheumatoid Arthritis, drove the initiative at her school to raise this incredible sum.

## Orsett Golf Club

Thanks to a new Captaincy, Orsett Golf Club chose to support us as their charity of the year - Rheumatoid Arthritis was very close to Sue's heart due to her mother-in-law suffering greatly. Over the year, Sue and the club raised an amazing £5,630!!!

# Super supermarkets

## Super supermarket schemes ....more than just a "token" gesture!

**Supermarkets give millions of pounds each year in support of local causes and charities. With RA Awareness Week running from June 19th to the 25th NRAS would like all our supporters and Members to try to help us get nominated for as many instore charity schemes around the UK in your local supermarket as possible.**

To get nominated for a month, or during RA Awareness Week, is the goal we are aiming for – but we need your help! It really is a numbers game so the more people we get submitting nominations or voting with tokens the better our chance of getting selected. Not only do we want to benefit from funds but we want to raise the profile of our charity and what we all do including all our NRAS groups out in the community.

Most of the well- known supermarkets, including Waitrose, Asda and Tesco, all run the token schemes now and you can either nominate a charity online, or if you prefer, pick up a form from their customer service desk and complete. It really is as simple as that.

Sainsbury's run a slightly different scheme called the 'Local Charity Scheme'. Every May, customers and colleagues get the chance to nominate their favourite charity; once selected this charity is then the store's local charity and is supported by fundraising and volunteering for the coming 12 months. This can be done in store or online but it has to be done during the month of MAY.

Even some of the smaller chains like Nisa or Costcutter now run charitable giving schemes – 'Making a Difference Locally' and this is aimed to help independently run stores add value in their communities. This works by money being raised from the sale of specific products and then the store owner can nominate their own charity to benefit from the funds. Over 2,000 stores participate in this scheme nationwide – all display the 'Making a Difference Locally' logo, so if this is your regular local shop, do speak to the staff and share your knowledge of NRAS to see if you can encourage them to make a donation to us.

We can help you with relevant information that you might need about NRAS when completing any of the nomination forms. So please contact us in fundraising if you require any advice or guidance.


*Bronwen receiving the Waitrose cheque*

# Dealt a good hand

## Playing your cards right for NRAS

**William Hill, Master of The Chartered Surveyors Livery Company in London, dealt NRAS a good hand after being impressed by our first ever evening of playing cards in 2015 and decided that he would like to hold his own event and raise funds for NRAS.**

Some of our fundraising team went along on the evening, Val and Bronwen made sure the 100 guests knew how to play the game and our Head of Fundraising Michelle, along with Brianna, joined in and played a few rounds of Swedish Pursuit. Michelle accepted a cheque for £2,000 presented by William on behalf of the Chartered Surveyors.

A huge thanks to all those who helped to make the evening such a success.

# Gum disease and RA

## Common bacterium that causes gum infections may trigger RA

**A study at Johns Hopkins Hospital has found new evidence that a bacterium known to cause chronic inflammatory gum infections also triggers the inflammatory 'autoimmune' response seen in conditions such as rheumatoid arthritis. These new findings could have important implications in the treatment and prevention of RA.**

The common denominator identified in gum disease and in many people with RA is a bacterium called Aggregatibacter Actinomycetemcomitans.

A clinical association between gum disease and RA has been observed since the early 1900s and over time, investigators have suspected that a common factor may trigger both diseases. An infection with this bacterium appears to induce the production of citrullinated proteins, which are suspected to activate the immune system.

Citrullination happens naturally in everyone as a way to regulate the function of proteins. This process becomes disrupted in people who have RA resulting in an abnormal amount of citrullinated proteins. This leads to the creation of antibodies to these proteins leading to the attack on a person's own tissues, causing inflammation.

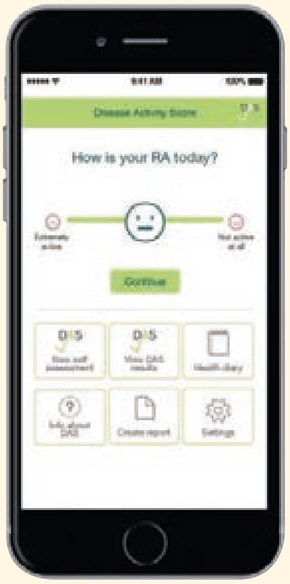
For this study, a team of experts in periodontal (gum) microbiology/disease and RA began to search for a common link to both diseases. The study showed that a process previously observed in the joints of patients with RA was similar to one occurring in the gums of patients with periodontal disease.

As part of the study, the team developed a test to detect antibodies against the bacterium in blood. Of the 196 patients with RA tested, almost half had evidence of infection with this bacterium. This was similar to data for people with gum disease but in the group of healthy people, only 11% had a positive test.

Felipe Andrade, Senior Study Investigator and Associate Professor of Medicine at the Johns Hopkins University School of Medicine, cautioned that more than 50% of the study participants with RA showed no evidence of infection with the bacterium, which may indicate that other bacteria in the gut, lung or elsewhere could be using a similar mechanism to cause the citrullination of proteins and that more research needs to be done and suggests that: "If we know more about the evolution of both combined (bacterium and disease), perhaps we could prevent [the disease] rather than just intervene."

## Download the NRAS DAS App

**www.nras.org.uk/publications/know-your-das**



# DAS study reveals...

## Smoking and being overweight affect RA symptoms over time

**A recent study in Canada has shown that being a current smoker or being overweight or obese negatively affects RA symptoms over time. The study used the 'disease activity score' (DAS) as a means of measuring the severity of disease activity in over 1,000 patients over a three year period.**

The study found that the average rate of improvement in patients' disease activity was greater in males versus females, healthy weight versus overweight and non-smokers versus current smokers. Interestingly, people who had smoked previously but were no longer smokers also benefited from a greater improvement in disease activity over time, demonstrating the importance of trying to quit smoking for people with a diagnosis of RA.

This large-scale study adds to the large body of evidence for the importance of making life-style changes, particularly with regards to weight and smoking for people with RA.

# NRAS Groups' update

## Winter months don't deter the External Affairs team from taking to the roads of Britain!

**Kim and Gill started November by travelling to Stoke-on-Trent to launch a new Group. This Group launch was instigated by NRAS Volunteer Trina Rule who felt, since taking early retirement, that she would like to help other people with RA in the local area. With the help of June Brammar, Rheumatology Project Manager at the Haywood Hospital, the event took place on 8th November.**

The severe weather conditions did not deter people from coming along and we were very pleased with the number of attendees. Trina did a comical, yet sincere talk about her RA journey, which was followed by a presentation by Professor Hassell. A lively Q&A followed with the panel of experts including Professor Hassell, Carol Graham, OT and Gill Levey, Podiatrist.

The new Group already have their first meeting booked for 30th March and we wish them every success with this and ongoing meetings.

The following day Kim and Gill drove to Southend-on-Sea to host an information evening as a new Group Coordinator has taken over the reins of the existing Group. A thank you presentation by Professor Dasgupta was made to Thelma Renton who ran the Group successfully for many years and has now handed on the baton to Claire Chandler, the new group leader. Claire has lots of new ideas and enthusiasm and we wish her luck in her new role.

*Southend-on-Sea information evening*

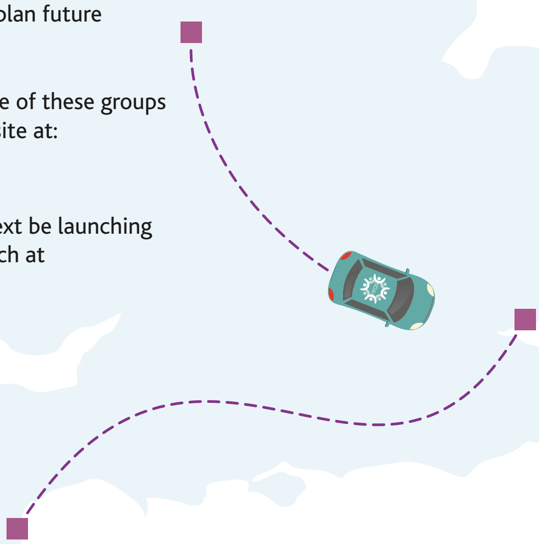
Claire did a heartfelt presentation about her life to date with RA, and then Professor Dasgupta presented on the exciting research taking place at Southend University Hospital regarding stratified medicine. Next was a lively Q&A session with Professor Dasgupta joined by his colleagues Madeline Whitlock and Annie Barton, both Clinical Nurse Specialists; Dr Billy Fashanu, Consultant Physiotherapist and Martin Sheppard, Biologics Lead Pharmacist. With over 100 people there not everyone got to ask their questions but we have great confidence that the Group will continue to flourish and meetings have already been booked for the whole of 2017.

In the same week the rheumatology team from Torbay Hospital hosted an inflammatory arthritis information day which was attended by Clare, NRAS Director of External Affairs. This event was extremely well attended and there was great interest following Clare's presentation in setting up an NRAS Group in the area. Kim and Gill have since then met with a Group of willing Volunteers in February who are all keen to plan future meetings in the Torbay area.

More information about all three of these groups can be found on the NRAS website at:

**www.nras.org.uk/groups**

The External Affairs team will next be launching a Group in Tayside on 22nd March at Ninewells Hospital in Dundee – more details about this Group in the summer magazine.




Teresa Jewell


Maggie Johnston

## SPOTLIGHT ON THE

# Mid Somerset NRAS Group

**All the NRAS Groups are doing amazing work to support people with RA in their areas. The Mid Somerset Group was established back in March 2011 and has gone from strength to strength ever since....so what's their secret to success? We decided to share with you here the views of those involved in running a Group and attending the Group by asking them a series of questions.**

We asked both Teresa Jewell, Rheumatology Nurse Specialist, Musgrove Park Hospital, Taunton and Maggie Johnston who is one of the Group Coordinators why they became involved in helping to set up a Patient Group for RA.

**TJ** Both Dr Laversuch, Consultant Rheumatologist and my predecessor, Lorraine Cooke aspired to have a local Group. Following appointment to my role, I became involved in helping to set up the Group. The Group gives our patients an opportunity to network with other patients and carers and gain additional knowledge about managing their RA.

**MJ** At the time the Mid-Somerset branch of NRAS was launched, I was at a crossroads in my life; I had developed lung disease connected to my RA and had recently been medically retired from my job as a result of this condition. I was keen to find some new directions and interests, so volunteering to be a coordinator of this new group was an ideal starting place for me to move forward.

The Group gives positive impact to the department and is also a voice to express back to the rheumatology team any local concerns. I enjoy seeing the group thriving and successful. Less input is required from me now that the group is established with a dedicated coordinating team. I still however, dedicate some time to giving professional input at meetings, plan sessions and attend coordinator social events.

We went on to ask Maggie what her role as one of the coordinating team entailed and what it meant to her?

**MJ** My role in the MSRG (Mid Somerset Rheumatoid Group) is to liaise with the speakers, and write introduction and thank you letters to guest speakers. I am responsible for publicising the meetings in the local press and radio stations and, along with the rest of the Coordinators, help with fundraising and promoting awareness and education around RA. I enjoy working as part of our team, we cooperate really well together with a lot of humour and have become good friends. All of us have RA, or have a partner with the disease, so really 'get' what it is like, making us able to help and support each other through the ups and downs of living with RA. Being part of this Group has given me more confidence. I have been interviewed on the radio about NRAS and the work of our group several times (the thought of this would have terrified me previously.) I have learned so much about rheumatoid arthritis through the presentations given by the various guest speakers on different aspects of RA, so now I am asked to speak about RA as an 'expert patient' at study days and training sessions for health professionals. I have met so many wonderful and inspiring people through NRAS and this would never have happened if I hadn't become an NRAS Volunteer.

When asked what their most memorable moments were in running the NRAS Groups, both Teresa and Maggie had similar responses - both got to visit the Houses of Parliament!

**TJ** My most memorable moment was being notified by NRAS that the Group Coordinators had nominated me for an NRAS Healthcare Champion award in 2013, and attending alongside them to collect my award from Theresa May.

**MJ** Attending the NRAS reception in the House of Commons, celebrating the developments in RA and NRAS Volunteers. Walking through that historic building and seeing several well-known MPs walking past felt quite surreal, I hadn't realised that the interior was so beautiful and ornate. Sitting on the terrace, with NRAS coordinators from all around the UK and my Mid-Somerset friends is a memory I will always treasure.

To get fuller picture we also wanted to find out from an attendee of the Group what attending the Group means to them.

> "The group gives our patients an opportunity to network with other patients and carers and gain additional knowledge about managing their RA"

We asked Philip White who regularly attends the Group what prompted him to go along the first time?

**PW** I was sent information about the formation of the Group and just thought that it seemed to be a worthwhile thing to do. I'm not normally one for joining such things, but it appeared to offer some useful advice and news. The reason I keep going is the Group Coordinators do a great job of finding speakers who cover a variety of subjects. They are always willing to take suggestions for different subjects when planning future talks. It doesn't matter if a speaker is invited back, because there is always some new development, research, or treatment to tell us about. Aside from the social aspect, I find it encouraging to know that a lot of work is being done in the field of rheumatology to improve the lives of people with RA. Another message that has come through is to encourage us to take an active role in the management of our own condition.

We went on to ask Philip about encouraging others to attend an NRAS Group.

**PW** When attending appointments, I don't often see anybody else whom I know, so I find it good to be part of a little 'community'. It's also good to meet with some of the professionals outside of the hospital environment - it seems to make it a little more personal. I think some of the speakers have been really informative and a couple of people have even completed marathons or other events because NRAS means something to them.

Hopefully this has given you a flavour from three different standpoints what NRAS Groups are all about, not only for those involved in running the meetings, but also for those attending.


*Philip White*

# Who's afraid of the Big Bad Wolf?

## Goodies and Baddies combined to raise much needed funds for two Berkshire based charities in January.

**The Wokingham based community pantomime staged by Corpus Christi Catholic Church pantomime group was delighted to hand over more than two thousand pounds to the nominated charities, Crossroads Care Wokingham and NRAS.**

Crossroads Care Wokingham provides extended breaks to carers to allow them some precious 'Me time' to reduce their stresses and improve their well-being, above all, to have a life beyond caring. **www.wokinghamcrossroads.org**.

A key reason NRAS was selected as one of the nominated charities this year may have been something to do with the fact that our very own thespian Clare (Director of External Affairs) was treading the boards as the pantomime Dame, Dolly Mixture! The things NRAS staff get up to in their free time for the charity is nothing if not amusing! NRAS Head of Fundraising, Michelle Vickers was presented with a whopping great big cheque for £1,050 by some of the characters from the Babes in the Wood cast.


*He's behind you, Michelle!*

# Sshh...

## How Frankie managed a vow of silence for NRAS

> "She knew it would be a challenge because she is quite a chatterbox"

**A natural chatterbox took a difficult vow of silence to help raise money for two charities, one being NRAS.**

Talkative Frankie Saunders managed to utter no words between 8.30am and 6.30pm on Friday 13th January.

It was a struggle as the extremely chatty eleven-year-old had to use a whiteboard to converse with teachers at Northwick Manor Primary School and learned hand signals to communicate with her best friend.

Mum Donna, who has RA and is NRAS Group Co-ordinator for our Worcester Group, said the challenge was all Frankie's idea; she has managed to raise an amazing £246.41.

"She knew it would be a challenge because she is quite a chatterbox: she had wanted to do something for ages because over the years she has helped me organise events for NRAS. My mum and I both have RA – it is well known in our house and NRAS is a cause very close to our hearts.''

A huge well done and thank you to Frankie.

---

# Wedding Favours

## We are very pleased to announce that we have designed a beautiful NRAS lapel badge fit for the occasion

It is a thoughtful way to give a donation to NRAS and to offer your guests a small token of appreciation. We provide the badges and an attractive place card for each guest. All we ask is a £1 minimum donation per badge and card.

To place an order please email us on **fundraising@nras.org.uk** or call us on **0845 458 3969**

# Be purpilicious!

## …and #WearPurpleforJIA – Friday 9th June 2017

**JIA-at-NRAS are delighted to be chosen again for the second year running, to be supported by the #WearPurpleforJIA initiative.**

The idea of promoting Wear Purple was borne from an idea by two mums. Lynette Haselip from Northampton, whose daughter Farah has JIA, started the campaign; she shared her reasons behind the idea:

*"Wear purple for juvenile arthritis started after my daughter Farah was diagnosed with arthritis aged 2 years old. It took 5 months for a diagnosis. Once diagnosed I realised there was no support, no awareness and no recognition for children with arthritis. Then #WearPurpleforJIA was born – a day when people can be silly, have fun whilst raising much needed awareness around JIA. Before Farah was diagnosed, I had no idea children could suffer with arthritis. So by wearing purple and spreading the word, I hope more people will be aware. The Wear Purple team is myself, Lynette, a JIA mum and my friend Rachael, who sees first-hand how awareness and understanding of JIA is paramount. So please join me in spreading the word and have lots of fun."*

Lynette and Rachael are manning the campaign from their homes as well as juggling busy family lives, and NRAS are delighted to be supporting them as their chosen charity. Purple t-shirts, hoodies, wristbands and bags can be ordered via Lynette and Rachael by visiting their dedicated Facebook page at **https://www.facebook.com/Wearpurpleforjia-1437272986589319/?fref=ts**

NRAS have created a #WearPurpleforJIA fundraising pack and also hope that as well as wearing purple, schools and workplaces will get baking some truly purpilicious cakes to sell on the day! We want you to get involved, so to sign up for a fundraising pack, visit our JIA website at **www.nras.org.uk/wear-purple-for-jia-2017**

*Farah*

*Lilliah and cakes*

**Run for NRAS**

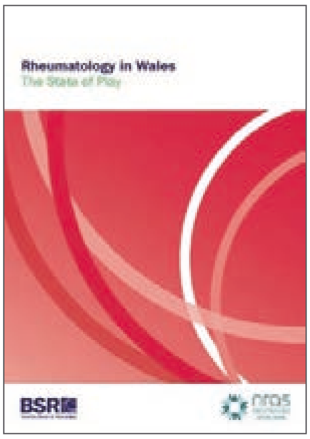
**We have lots of guaranteed places in runs! Grab your spot for 2017 – sign up at www.nras.org.uk/runs**

**NRAS is Changing Minds, Changing Services, Changing Lives for People with RA and JIA**

nras National Rheumatoid Arthritis Society

# Rheumatology in Wales

## NRAS report shows a lack of NHS resources in Wales is delaying RA treatment and diagnosis



By Conn O'Neill

**In December, we launched a joint report with the British Society for Rheumatology (BSR): Rheumatology in Wales: The State of Play. This report, conducted in Spring 2016, draws on in-depth interviews with clinicians working across Wales and information gathered in a survey of NRAS Members and supporters living with RA.**

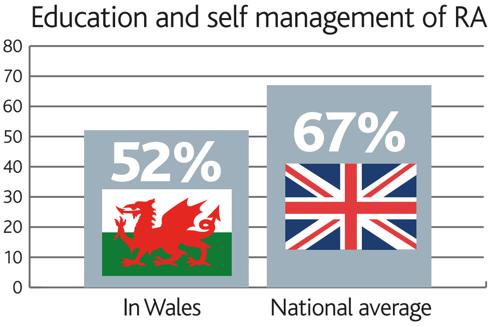
The number of patients seen by Welsh rheumatology departments is increasing, referrals are up 66% on 2012 levels, but resources for treatment aren't keeping up with the demand. There are estimated to be 25,000 people now living with RA in Wales. New patients are waiting longer for their rheumatology appointment and existing patients are struggling to secure follow-ups and self-management advice.

The report finds that the experience as a new patient in Wales is mixed:

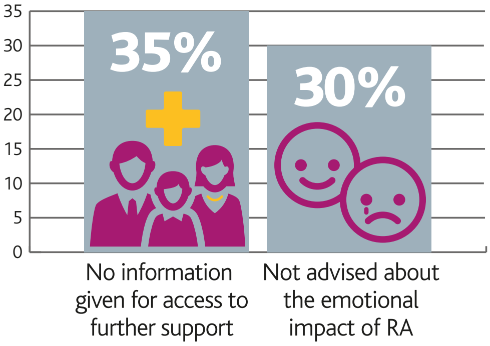
- The number of patients receiving a rheumatology appointment within 6 weeks of GP referral has declined over the last year to just 39% as of June 2016. Only 22% of patients in Wales with RA in 2016 were being seen within three weeks, compared to the English and Welsh average of 37%
- Wales has the lowest number of Early Inflammatory Arthritis (EIA) Clinics anywhere in the UK, compounding the service delays
- Wales is the best performing region of the UK for GP referrals within 3 days of first presentation, 46% compared to the UK average of 20%

RA patients already within the system also face problems, for example:

- Four in ten patients reported that intervals between appointments were too long to keep their condition under control, and a third found it difficult or very difficult to get an appointment with their consultant
- Only 52% of patients in Wales received education and self-management for RA within one month of diagnosis compared to a national average of 67%



- 35% of NRAS' survey respondents stated they were not given information on services or organisations who could give them further support, and 30% indicated nobody had spoken to them about the emotional impact of their condition



Early diagnosis, treatment and management of inflammatory arthritis conditions is crucial to avoiding long-term damage and disability.

Rich Flowerdew, an NRAS Ambassador in Wales, said, "*These results are worrying and show that NHS Wales and Local Health Boards need to support rheumatology services to meet quality standards for the treatment of RA. It is abundantly clear that patients are not being seen enough within the 12-week window of opportunity of diagnosis. If patients are seen within this window, their longer-term outcomes are better.*"

Our NRAS Ambassadors in Wales, supported by the Policy & Public Affairs team at the NRAS office in Maidenhead, will be presenting this report to politicians and other key decision makers as we seek to improve services for everyone with RA and JIA in Wales. We are currently seeking to expand our volunteer Ambassador team: you can find out more by emailing **campaigns@nras.org.uk**

Four in ten patients

reported that intervals between appointments were too long to keep their condition under control

One third of patients

found it difficult or very difficult to get an appointment with their consultant

## NRAS becomes co-chair of

# The Prescription Charges Coalition

**By Conn O'Neill**

Policy & Public Affairs Officer

**People of working age, living with a long-term condition, are unfairly impacted by an out of date medical exemption criteria, which requires them to pay for all of their life saving medication.**

The prescription charge has once again risen from £8.40 to £8.60, but the pre-payment certificate has been frozen at £29.10 for 3 months (equivalent to £116.40 pa) or £104.00 annually. People with long term conditions are required to pay for each individual item. Over the years, many NRAS Members and others with RA or JIA report that these costs are a most unwelcome burden when living with a condition they did not wish upon themselves.

Some medical conditions are exempt from the charge, they are on the 'medical exemption list', drawn up IN 1968, nearly fifty years ago, and revised only once to add Cancer in 2009. The then Labour government had commissioned an independent review into prescription charges which recommended that all long-term conditions should be added to the exemption list. Labour committed to fully enacting these recommendations if they won the 2010 election but the incoming Coalition government shelved the plans. As a member of the Prescriptions Charges Coalition, NRAS has campaigned for over a decade for people with RA, JIA and all other long-term conditions to be given free prescriptions, we are delighted to have now joined Parkinson's UK and Crohn's & Colitis UK as co-chairs of the Coalition at a pivotal time.

There are glaring omissions from this list, which highlights how much has changed since the list was created. For example, cystic fibrosis is missing because in 1968 someone living with the condition was very unlikely to live past the age of 16, so would be exempt for their lifetime. Many other conditions are not listed because there were no treatments that a charge could be levied for in 1968, so it was not considered necessary to exempt them.

I remember the shock of my grandmother when, aged 7 or 8, I told her that my history homework was to interview her about the 1960s. That was when I first listened to the Beatles, including their 1968 chart toppers Hey Jude and Lady Madonna. Little did I know then that 1968 was also the last time the government comprehensively reviewed the list of who would get free prescriptions in England!

In the run-up to the fiftieth anniversary of the medical exemption list in summer 2018, we will be conducting research, writing reports and furiously lobbying government for change. Watch this space.

*Nostalgia may be okay in fashion and music but surely it's time to move on and review this outdated decision?*

> Yet again, prescription charges are rising to £8.60

prescription
charges
coalition

# Improving Lives: The Work, Health and Disability Green Paper

## What does it mean for people with RA and Adult JIA?

'Improving Lives: The Work, Health and Disability Green Paper': What does it mean for people with RA and Adult JIA?

You may be aware that a few weeks ago, the government launched a 'green paper' on the topic of work and health. This is a top issue for people with rheumatoid arthritis (RA) or adult juvenile idiopathic arthritis (JIA). The National Rheumatoid Arthritis Society would like to help you feed in your views to the major government consultation. Read more to find out about the process, the contents of this green

**Mark, from our fundraising team, who has lived with JIA since he was 8 years old, interviewed our Policy & Public Affairs Manager, Conn, about the recent 'green paper'.**

**Mark To start off with, what exactly is a Green Paper?**

**Conn** A Green Paper is a report from government with very early stage proposals and ideas on a topic, it is intended to provoke discussion. The government wants to get the views of MPs, relevant organisations and the public. At the end of the consultation process, the government may decide to produce a 'White Paper' which, when presented to parliament, begins the process of creating or altering laws. New laws are not the only way the government can make a difference, and so a white paper is not always the obvious next step.

**Mark What is this Green Paper about?**

**Conn** 'Improving Lives: The Work, Health and Disability Green Paper' was published at the end of October 2016 and the consultation ran until mid-February. This was a report on the state of play for people with disabilities and long-term health conditions, who are either in work, or want to be. The overarching question for the consultation that NRAS and others offered answers to was: What will it take to transform the employment prospects of disabled people and people with long-term health conditions?

**Mark Why now?**

**Conn** One of the commitments in the Conservative party manifesto for the 2015 general election was to 'halve the disability employment gap'. At present there are fewer than 5 in 10 disabled people in employment compared with 8 in 10 non-disabled people and at the current progress, it will take 200 years to halve the gap. This isn't about making people who are unable to work 'get on their bike', it's finding ways to support people who are disabled or living with a long-term health condition, who are both able and wanting to work, to do so.

What will it take to transform the employment prospects of disabled people and people with long-term health conditions?

Our response to the consultation emphasises the need to recognise that after a very lengthy period out of work or in the case of RA and JIA, after many years of uncontrolled disease, it may not be possible to return to work and support should be available accordingly.

**Mark How was NRAS involved in the creation of the Green Paper?**

**Conn** NRAS and many others involved in healthcare have long argued that a joined-up approach whereby work is understood to be a health outcome is the only way forward. We argued this when we last met with our patron, the Prime Minister, to discuss the topic of work and health. She subsequently facilitated our invitation to join the government's expert advisory group on work and health which helped inform the drafting of the green paper.

We were delighted that the first case study in the report looked at the experiences of an NRAS Member, Susannah Everington. Ensuring decision makers think of RA and adult JIA when considering the impact of long-term health conditions on work is key for everyone who lives with this invisible, and poorly understood disease.

**Mark What did NRAS tell the government in our formal response to the Green Paper?**

**Conn** We told the government:

- That there had to be recognition that some people could not work and deserved continuing financial support
- The DWP should categorically not go ahead with the £30 a week cut to the Employment & Support Allowance for people in the work related activity group from 1st April, as this is completely contradictory to the aims of this Green Paper
- We welcome the move towards recognising work as a health outcome, but cautioned against this being used as a tool to measure the effectiveness of GPs or hospitals
- That anyone involved in assessing for or delivering support should have readily available, condition specific information that has been produced in collaboration with patient organisations
- That there needs to be education of employers, those who provide support and the wider public, on the nature of and specific challenges of living with inflammatory arthritis, which differs from osteoarthritis
- Everyone needs to better recognise the high probability of concurrent mental health problems when you live with a physical long-term condition like RA or JIA, and that this may not necessarily be formally diagnosed
- Employers should be offering flexibility as a norm to all employees and this could then be utilised by someone with a health condition or by someone who had a young child without feeling they were asking for special treatment. Flexibility here does not just refer to working hours but also to attitudes around sick/disability pay and absence policies
- There should be recognition that the Personal Independence Payment (PIP) and Disability Living Allowance (DLA), especially the mobility component, supports many people to get to and from and to stay in work. There should also be a move towards sharing of data from assessments for these benefits and the Employment & Support Allowance (ESA) to reduce the stresses of the assessment process
- We want to keep working with them to help bring about a shift in public opinion so that working with a health condition becomes far easier than it has been so far for people with RA and JIA

**Mark What are the next steps?**

**Conn** We will continue to be active members of the expert advisory group on work and health and so have a place at the top table whilst discussions take place on how the government will interpret the responses to the consultation.

This is an ongoing, long-term project for the government, and we will continue to feed in fresh evidence about how people with RA and JIA are experiencing the work place. We will be running a major survey on work, health and RA/JIA in partnership with the University of Manchester, which is due to go live in the next few weeks. Please do take the time to respond to this in-depth survey, which will allow us to produce a report that has the potential to be incredibly influential on government policy.

We are also looking at the resurrection of our Workwise events, which will provide the opportunity for 'speed-dating' style meetings between people with RA, employers and others who can help with workplace challenges, across the UK.

> "That there needs to be education of employers, those who provide support and the wider public, on the nature of and specific challenges of living with inflammatory arthritis"

Transport Accessibility

Taxi drivers can lose their licence and face a fine of up to £1,000 if they fail to transport wheelchair users

Department for Transport

# Accessible transport news

## You know what they say, you wait ages for the bus, and then they all come at once!

**It has been a busy few months with lots of positive developments with regard to accessible transport for people with limited mobility.**

### Taxi and private hire drivers will from 6th April 2017, be obliged by law to:

- transport wheelchair users in their wheelchair
- provide passengers in wheelchairs with appropriate assistance
- charge wheelchair users the same as non-wheelchair users

This change to the law comes about as part of provisions being enacted from the Equality Act. Drivers face hefty fines, and risk having their licence suspended if they discriminate against wheelchair users when driving a vehicle that can accommodate the chair. If a driver has a legitimate medical reason that prevents them assisting a wheelchair user, they may apply for an exemption from this requirement. See more at: **www.gov.uk/government/news/law-change-demands-equal-treatment-for-disabled-taxi-users**

### UberWAV launches in London zones 1-4

If you're a wheelchair user in London and a fan of Uber, there's more good news. By selecting the UberWav option in the Uber app when you request a car, your driver will arrive in a wheelchair accessible vehicle. More details on the company website: **https://newsroom.uber.com/uk/ldnwav**

### Supreme Court win on priority of wheelchair users on public transport

NRAS Member, Baroness Sal Brinton, a long term campaigner for the rights of disabled people on public transport, joined other activists at the Supreme Court on 18th January to see Doug Paulley's historic win. The verdict confirmed the priority of wheelchair users for the wheelchair space on buses.

Bus drivers now have the right to ask a passenger occupying the wheelchair area to move and if they unreasonably refuse to do so, they have the right to ask them to leave the bus. Sal summarised this sensibly nuanced part of the judgement: "this means, for example, that a mum with a crying baby would probably not be asked to leave the bus but the man who refused to allow me on the bus even though there was space for both his buggy and me would have been required to move.'' The judges made clear that legislation was required to make this happen, and so Sal will be tabling amendments in the House of Lords to the Bus Services Bill – watch this space!

*Sal Brinton outside court*

### TfL launches 'Please offer me a seat' badge

Transport for London has launched a new badge on a similar theme to their popular 'Baby on Board' badge.

TfL recognise that many travellers have hidden conditions and struggle to get a seat when they need one. Following a successful trial in autumn 2016, which included several people with RA, 72% of users reported their journey as being easier and 86% said they were more comfortable asking for a seat. The badge will be launched more widely in Spring 2017, sign up for accessibility updates from TfL here: **https://tfl.gov.uk/forms/12424.aspx**

We're on the right track towards more accessible transport options for people with RA and other health conditions, NRAS will continue applying pressure to ensure these projects do not run out of steam!

# Scottish Ambassadors

**By Sheila MacLeod**

**Over the winter months, Scottish Ambassadors have continued to be involved in a number of different projects and settings working with other groups to further the interests of people in Scotland affected by RA. These include contribution to the Scottish government's public health strategy, discussions on integration of health and social care and on-going work to establish a set of metrics to improve the quality of management of established disease.**

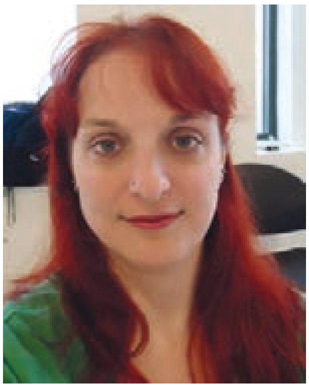
As the pace of our programme picks up in the spring we very much look forward to firming up on our plans for the year: central to these will be promoting the findings and recommendations of the NRAS *'Who Cares?'* report on the health and perceived social care needs of people with RA living in Scotland, and pressing forward with an improvement in services for those with established disease.

We look forward also to the first meeting (1st March) of the newly re-constituted Cross-Party Group on Arthritis and Musculoskeletal Conditions which promises to be well-supported, vigorous and enthusiastic with an excellent programme of work ahead of it.

2017 has already seen the recruitment of several new Ambassadors to our ranks and some other keen supporters joining our wider Campaigns Network to support political events in Scotland. We look forward to meeting together and planning ways to work together in this year and next in due course.

# The Bridge Over The River

## An excerpt from Liz's story



**By Liz Morgan**

**It probably wouldn't surprise you to know, but developing rheumatoid arthritis and being diagnosed with RA was not on my bucket list. I don't remember what outcome I expected from my first consultation, I think I was expecting to be told that the pains in my wrists were just a result of too much typing at work and be happily discharged. One reassured patient-box ticked. Funny how life doesn't go quite according to plan!**

The disease first manifested itself with weakness in my hands and pains in my fingers, especially the middle finger of my right hand. I would wake up with one or more of my fingers curled up and had varying degrees of pain in straightening them up again. Even now, I'm cautious about curling up certain fingers for fear of not being able to uncurl them again. Appropriately enough, a straight and extended middle finger is a pretty good summary of how I feel about RA!

In my mid-20s, I was diagnosed with Meniers' Disease, which has left me with reduced hearing in my left ear. There is something that feels very 'individual' about being deaf and arthritic in my mid-30s. Sure, by the time my peers are in their 70s and 80s they too will probably be deaf and/or arthritic. Whilst they'll be getting used to nodding along, not quite being able to hear what's going on, or not quite having the grip to open jars, I'll be an old hand at it all, having 30 years' head start on them. For once in my life, I can be a trend setter!

I tried to explain this to my consultant, I only got as far as saying that I didn't expect to be deaf and arthritic by the age of 35 at which point he looked at me with apparent incredulity and said "you're not arthritic". It did seem somewhat churlish to ask why I was seeing him, if I wasn't arthritic. As far as I was, and am, concerned, I had the diagnosis of arthritis and had been experiencing pain and stiffness therefore, in lay person's terms I was arthritic! His response stung me, not because I claim to be an

> "A diagnosis of RA not only indicates a change in you, but also changes the way you relate to the world around you"

outstanding wit, more that I felt my consultant did not understand self-deprecating humour was a coping mechanism. Maybe by clinical definitions, I wasn't arthritic, but if trying to make a joke about it helped me come to terms with something I found rather overwhelming and scary, is there any harm in that?

At one of my first appointments, I was given an ultrasound of both wrists, and was told that I was lucky to have this as a means of diagnosis, as it wasn't something commonly used. So soon after being given what is a life altering diagnosis, the word 'lucky' wasn't really what I wanted to hear.

I found RA to be a very lonely place. Whilst there are a lot of shared experiences I have with my girlfriends, RA isn't one of them. Then there's the routine of having RA – blood tests, eye tests, GP appointments, hospital appointments, trips to the pharmacy to collect drugs, remembering to actually take the drugs, back to the hospital. For the most part, I can block out the fact I have arthritis and pretend that everything's normal, but the routine of illness always reminds me that's not the case. This is why I am never at my happiest when visiting the hospital. I remember one particular consultation – during a stressful period my doctor commented that I seemed very low, which, to be fair, I was. I just didn't see benefit in going into meltdown during the appointment, I saved that for ten minutes later in the ladies' loos! More importantly, after previously being told that I'm not arthritic, I didn't really feel encouraged to open up and share my thoughts with him.

Please understand that we patients can be scared or confused or just plain shy and may well not give you, the consultant/nurse, all the information you need. I admit that this is something I am not good at. Had my consultant not simply commented that I seemed low, but had in fact asked the direct questions – 'is there anything on your mind particularly' or 'are you feeling especially tearful or finding it difficult to cope', the consultation may have had a very different outcome.

I don't feel angry that I got RA... I do feel angry that my hospital appointments to date haven't given an appropriate space to express what it means to me to have arthritis. Time for clinical appointments is limited, and rheumatologists are not trained counsellors. For me, the diagnosis was a form of grief, but a kind of grief which doesn't follow a linear process. As it were, I have emotional flare ups, as well as physical.

For me, the bottom-line is that I am never not going to have arthritis. I may achieve this mythical 'burning out' that one nurse mentioned, but the worry of a flare-up or other complications will always be there. A diagnosis of RA not only indicates a change in you, but also changes the way you relate to the world around you.

You can read Liz's unabridged story at
**www.nras.org.uk/stories**

# Biologic treatments

## Monitoring the long-term safety of biologic treatments in children and young people with JIA

**By Katy Mowbray**
Studies Coordinator
and
**Kimme Hyrich**
Professor of Epidemiology at the University of Manchester

**Biologic treatments such as Enbrel and Humira have been available for a number of years and can be prescribed to treat children and young people with Juvenile Idiopathic Arthritis (JIA). Two research studies based at The University of Manchester, called "biologic registers", have been monitoring the long-term safety of these treatments.**

The longest-running register is called the BSPAR Enbrel study (BSPAR-En), which was set up in 2004 and monitors patients starting treatment with Enbrel, alongside a comparison group of patients receiving methotrexate. The second register – Biologics for Children with Rheumatic Diseases (BCRD) – was set up in 2010 and monitors patients starting therapy with any other biologic or biosimilar therapy. The two studies run in parallel, but are separate due to the way that they are funded. Collectively, they have registered over 2,500 patients to date.

Both registers recruit patients within six months of starting their new therapy, and detailed follow-up information is collected via the hospital notes at six months, twelve months and then annually for at least five years. The information collected is inputted into a secure online database and includes details of any changes to therapy, any new illnesses or side effects that are experienced, and information on how well the drugs are controlling the JIA. This collection of safety data is separate from the Medicines and Healthcare Products Regulatory Agency's 'Yellow card' system, whereby you (or your health professional) can also report any suspected side effects from medication via an online report system, accessed here: **https://yellowcard.mhra.gov.uk/**

The data is then analysed by researchers to see if any patterns can be seen in the types of side effects being experienced. The data can also be used to understand why some children might not respond as well to these medications. Any findings are fed back to the rheumatology community through conferences and journal articles, and updates are provided to participants and parents via a study newsletter.

So far, the researchers have found that Enbrel reduces disease activity to a minimal state in almost half of the children with JIA. Those patients who seemed to respond to treatment better were those who started Enbrel at a younger age, had been diagnosed more recently and in those who were not taking steroid medicine. However, these associations were not very strong, so whilst this finding may teach us a bit about Enbrel, we are not advising people to avoid using Enbrel based on these characteristics alone.

Regarding side effects, the researchers found that children receiving Enbrel were more likely to report infections compared to children receiving methotrexate. However, the risk of developing an infection that required hospitalisation is not increased, which is good news. Research into the benefits and side effects of Enbrel and other biologic drugs continues.

These studies are important because they look at "real-world" data on the use of biologic and biosimilar therapy in the long-term. If you have any questions about the biologics registers for JIA please contact Mrs Katy Mowbray, the BCRD study coordinator (katy.mowbray@manchester.ac.uk) or Dr Emily Sutton, the BSPAR-En study coordinator (Emily.sutton@manchester.ac.uk). The studies are still open for recruitment of children newly starting these therapies for their JIA. Further information about joining the study can be obtained from your rheumatology consultant or nurse.

> "The data can also be used to understand why some children might not respond as well to these medications"

By Aran Chauhan

# Living with JIA

**I don't really remember a time when I didn't have arthritis. It's always been a part of my life.**

My very first childhood memory was waking up in a hospital bed, confused about where I was and what was happening to me. I now know that I had just had my first procedure on my knees. I had just turned three. Most of my early memories are of hospital visits, blood tests and injections. I was being examined by a doctor every other week, or at least that's how it felt. But most of all I remember the pain in my knees. Not wanting to walk because it just hurt too much and taking ages to get up in the mornings because my knees were so stiff and cranky. I used to get tired a lot. Not your 'no sleep' kind of tired, but the kind of tired that leaves you completely wiped out and unable to do anything. I didn't really understand what was wrong with me at the time. All I knew was that my knees were poorly.

*The Santa Run*

There were lots of ups and downs along the way trying to find the right medication that worked for me, but once we did, things improved quickly. Nowadays, my arthritis is very well controlled. Most afternoons you will find me tearing up the rugby pitch or playing football. I love sport and understand that being active is a really important part of keeping my joints healthy. I have never let my JIA stop me from doing the things I enjoy. Of course, some days are harder than others, but I refuse to let it get the better of me.

The more I have learnt about the disease, the more I realise that I am lucky. I know that there are other children whose arthritis is not as well controlled as mine. It is for this reason that raising awareness and funds for JIA is so important to me. I have had amazing support from my school, Lambrook, and together, we raised a huge amount of money for a children's arthritis charity through various fundraising events. I have also been raising money myself through activities which have challenged me physically, such as the 5k colour run, a stair climb to the top of the Eiffel Tower and most recently, a 5k Santa fun run.

Having JIA has taught me that strength comes from the inside and learning to cope with this disease has given me a determination and drive to help others that I might not have otherwise had.

My wish is that one day there will be a cure for arthritis. Until then, I will keep doing what I can to continue raising awareness for the disease that affects so many of us.

# This girl can

## Getting the best out of life with RA

**By Sara Warren**

**I am 38 years old and I have had RA for over 5 years. I remember the day it started in October 2011; I went for a run and the next day the ball of my foot was hurting. It didn't improve and I remember thinking that I surely can't have hurt my foot from a run.**

Over the following weeks my other foot started to hurt and by January 2012 my hands were swollen and stiff. I couldn't bend my thumbs at all. It progressed quite quickly and by the Summer of 2012 I couldn't really use my hands at all, I couldn't lift my arms and I struggled to walk as my feet were so painful.

I didn't have to wait for a referral to rheumatology since I was already under their care having had reactive arthritis in my knees several years earlier after contracting mumps. I managed to get an appointment with the rheumatologist early in 2012 and initially I was diagnosed with fibromyalgia and prescribed pregabalin for three months and then gabapentin for three months. Neither of them worked. Throughout this time my husband was so supportive, he helped me as much as possible and since I was unable to do anything in the house, he would do all the chores.

I was still in work although I was struggling. I am a maths teacher in a secondary school, quite a demanding job which was making me very tired. My head teacher and colleagues couldn't have been more supportive. My colleagues would carry things for me and help me any way they could. Even the pupils would help out; I couldn't take a lid off a pen for example. In July of 2012 my husband came to an appointment with me as I was getting progressively worse and in constant pain. The rheumatologist decided to do MRI scans. I spent over two hours having 8 scans on my hands and feet. A few days later a rheumatology nurse called and said I needed to start methotrexate immediately and my new diagnosis was RA. The MTX made my shoulders and neck better but my hands and feet were still very sore and swollen.

In July 2013 I was asked if I would participate in a clinical trial. I agreed as there was no placebo, I would either be given cimzia or humira. The trial was to see if cimzia worked more quickly so I would definitely be given one of the anti-TNF drugs. I didn't know which drug I was on for 3 months but I started to feel improvement after the first month of being on the drug. I was actually being given cimzia and I was part of the trial for 2 years. To me it was like a miracle drug, my DAS when I started the trial was 7.5 and at the end of the study was under 0.5. I have continued to take the cimzia and have now been taking it for nearly 4 years. I decided to do things that I couldn't have done before. I joined a rowing club locally and have competed in races in the Northwest. I have always loved water and I really enjoyed learning this new sport and making new friends. I also now have a dog and go on long walks every weekend. I live in the Wirral so we often drive to North Wales to go walking – although my dog's maximum is about 6 miles! I enjoy doing things now 'because I can'. On a recent holiday my husband and I went canyoning and on segways and we go out cycling often (with the dog in her trailer). We also enjoy canoeing in the summer.

I don't have any worry about telling people about my condition; I often find they don't understand about autoimmune conditions and if they are interested then I am happy to explain. My family, husband and my colleagues have all been so supportive, I feel very lucky to have had so many people willing to help.

> "I decided to do things that I couldn't have done before"

# My name is Jayney Goddard

## An excerpt from Jayney's brilliant Edgar Stene competition essay

By Jayney Goddard

**My name is Jayney Goddard, I live in Hastings, a tiny town on England's South Coast – our claim to fame is that we were invaded by the Normans in 1066 – we have long memories and not much has happened there since.**

*Knees pulled up tight, 'derrière' tucked under, core engaged and arms, neck, shoulders and head loose – looking elegant and above all, effortless. I looked into the full-length mirror and all was in perfect alignment. My body, that I had honed over the years, was looking right – for once. Ballerinas are their own worst critics.*

*The piano struck a chord and on the first count, I began my initial plié of the day, knees bending softly - easing into the rhythm of the ballet class, the exercises beginning gently, and becoming more intense as muscles, tendons and joints all loosened and began, one by one to join the dance.*

*Today was different though, I noticed that my Achilles tendons were stiff. I instantly dismissed this niggling discomfort – ballet dancers are quite used to living with aches and pains – we just 'get on with it'. As I warmed up, the pain subsided and I made a mental note to get it checked out anyway. Of course, I forgot and it wasn't until a few days later, when the morning pain just kept coming back that I went to the doctor. She told me that it was 'only tendonitis' and to be anticipated at my age – a 30-year-old ballerina is positively geriatric anyway and really should expect problems. It was not deemed worth investigating, in spite of the fact that I have a strong history of auto-immune disease on both sides of my family.*

Jayney continues to take us through her challenging experience and rollercoaster journey of living with RA; from the very worst case scenario – right through to full, lasting and sustainable remission. Her story is one of personal victory, told with passion, humour and from the heart.

You can read the whole story here
**www.nras.org.uk/stories**

# The sun will always shine again

**By Karina Gunn**

**I was always a sporty child, I played rugby from the age of 8 and cycled long distance time trials with my dad from the age of 10. This was until my third year of high school when I tripped in a pot hole and dislocated my hip.**

The doctors rushed me into hospital and pinned my hip, but I've never been the same since that day. It was a few weeks after my surgery, I was walking to school on my crutches and couldn't understand why my hands were so hot and swollen. I went back to the doctor, saw many specialists, and 3 months later at the age of 14 I was diagnosed with having JIA. I was in agony all the time, struggled to do basic tasks, and was exhausted. Being in school, confined to a wheelchair and depressed; I never thought I'd ever be able to live a 'normal' life again. I did most of my school work from a hospital bed and even missed my first set of exams due to an extended hospital stay. Finishing school, I was completely deflated; all the medications I'd try either made me sick, didn't work or caused me to gain weight.

From the age of 16 to 18 I was getting treatment at least once a month in hospital. I was ready to give up on life, I was depressed, in complete agony and suffering with chronic fatigue. It wasn't until I was 17 when I was preparing for my first hip replacement that they found a medication that started to work. I got out of hospital the day before my 18th birthday and immediately felt brand new. I went to college and got my BA Hons, which I never thought would be possible. After getting my degree, I moved back in with my parents as my other hip was failing, and at the age of 24, I had my second full hip replacement. Now I am 25 years old, living 300 miles away from my family in Glasgow, about to start a full-time job in care. Whilst JIA has been the hardest thing I've ever had to deal with, I know that I would not be as strong and determined a person if not for all that I've been through. JIA has taught me to never give up and that no matter how awful I might feel the sun will always shine again.

JIA at NRAS

JUVENILE IDIOPATHIC ARTHRITIS

# Events Diary

| | |
|---|---|
| Date TBC | **Oxfordshire local family fun day**. If you are supported by the Nuffield Orthopaedic Hospital and have a child aged 12 to 16 years, please join us for a bush craft cooking extravaganza experience, meet the experts, and have lots of outdoor fun. Please register to come along with the whole family and meet other families. |
| 2nd-4th June<br>Full details TBC | **Residential weekend in Wales**. This is open to all families supported by the rheumatology team in Cardiff hospital. Registration is on a first come first served basis and will be open in April. |
| July<br>Date TBC | **Family Fun Day Thames Valley**. This event is open to every family nationally living with JIA. Registration will open in June. |
| July 15th | **Family Fun day in Ilkley, West Yorkshire**. Following the success of last year's event, we have re-booked Nell Bank. This event is open to every family nationally living with JIA. Registration will open in June. |

All events are free programmes – to register, please visit **www.jia.org.uk/events**

*Designed and printed by Michael Burbridge Limited – michaelburbridge.com*

*Our thanks go to AbbVie for the distribution of this magazine.*

nras
National Rheumatoid
Arthritis Society

JIA at NRAS
JUVENILE IDIOPATHIC ARTHRITIS

Helpline: **0800 298 7650**
General: **01628 823 524**
e: **helpline@nras.org.uk**
w: **www.nras.org.uk**

Ground Floor
4 Switchback Office Park
Gardner Road
Maidenhead Berkshire
SL6 7RJ

/nationalrheumatoidarthritissociety
/jiaatnras

@NRAS_UK
@JIA_NRAS

NRAS_UK

healthunlocked.com/NRAS
healthunlocked.com/JIA

MBL 26326-4