

# Members'

# MAGAZINE

WINTER 2017



**nras**  
National Rheumatoid  
Arthritis Society



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A gift in your Will helps NRAS to build a better future for those with RA and JIA  
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By Ailsa Bosworth, MBE

Chief Executive

I wish you all a peaceful Christmas and best wishes for 2018 from the team here

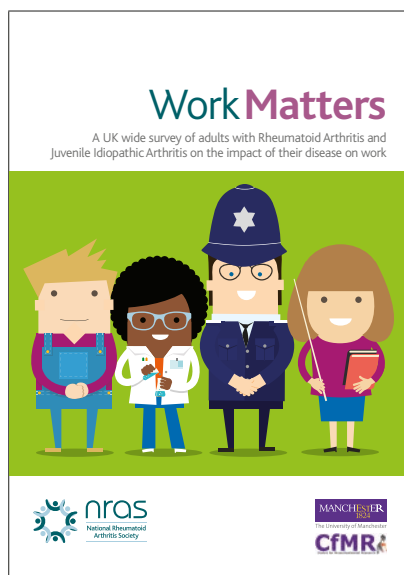
If you are receiving this magazine for the first time and are not yet an NRAS Member, sign up today and receive it on a regular basis.

Simply contact [membership@nras.org.uk](mailto:membership@nras.org.uk) to find out more about joining.

# Dear Members

The year is rushing past far too fast as usual and I can't believe we're in October already. I have been avoiding going into any large stores because I'm not yet ready to come face to face with Christmas decorations! However, by the time our magazine lands on your doorstep, I suspect I will have been forced to acknowledge that Christmas is but a few weeks away!

World Arthritis Day, October 12th, which is an important date in the calendar for all charities representing people with Musculoskeletal Disease, fell within an incredibly busy week with a number of things going on. A key event for us was the launch in parliament on 11th October of our new report 'Work Matters'. We were delighted that Penny Mordaunt MP, Minister of State for Disabled People, Health and Work took the time to come and speak at our launch. See Page 38 for news of the launch.



We are grateful to more than 1,500 people with RA and adult Juvenile Idiopathic Arthritis (working and who had stopped working), for taking part in this important survey.

We carried out this survey in 2017, 10 years on from our 'I want to work' survey carried out in 2007. We wanted to see if anything had changed from 2007, and so we included some questions in the 2017 survey which had been in the previous survey as well as adding in others, we also incorporated 3 validated instruments to gain comparative data to that which already exists for these particular questionnaires.

Sadly, nothing much seems to have changed, although in 2017 the majority of the respondents; 63.3%, were in paid employment and 7.61% were self-employed

which is higher than in the 2007 survey when 54.8% of the participants were in employment. This may reflect a greater number of people whose disease is better controlled as a result of modern therapeutic approaches maximising disease activity control and use of biologics (if disease cannot be controlled), but may also include people who have applied for help under government policies such as the Access to Work scheme, enabling them to remain working. This policy was highlighted in NRAS booklets for employees and employers, developed in response to the survey from 10 years ago and have been widely used by people with RA and rheumatology health professionals.

In the foreword, Professor Karen Walker-Bone BM, FRCP, PhD, Hon FFOM, Director, Arthritis Research UK/MRC Centre for Musculoskeletal Health and Work, quoted words from Dame Professor Carol Black who has, since 2006, been instrumental in working with successive governments to provide vital research into the link between work and health.

"Work is central to human existence and the motive force for all economies. For individuals, it provides structure and meaning and is good for people's health and wellbeing, as well as their financial health and prosperity. Moreover, work benefits families and is socially inclusive."

In other news during the week of World Arthritis Day you may have seen the new version of Behind the Smile film on our social media platforms or the "Angry Hand" film or perhaps you attended the fantastic information event for Members in Swindon that week. Remember you can keep tweeting and liking the awareness films to keep spreading the word.

"Don't delay, Connect today!"

With best wishes to all of you.

*Ailsa*



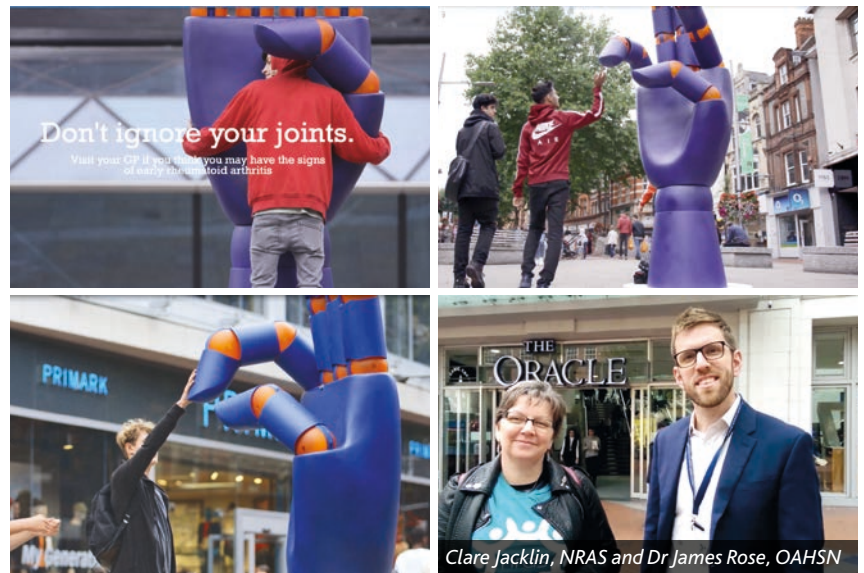
# Members' MAGAZINE

## Contents

- 2 Dear Members
- 3 Angry Hand | Methotrexate Animation
- 4 NRAS Pen Pals
- 5 Your NRAS Needs You | Mash Partnership
- 6 EULAR Edgar Stene Prize
- 7 NRAS comes to Durham | Rheum for You Swindon
- 8 Membership Survey 2017 Results
- 10 How Accessible Is Your Home?
- 12 Don't Delay Connect Today
- 13 Listening Books
- 14 Introducing the Medicines Experts
- 15 Help for Methotrexate Issues
- 16 Men with RA study
- 18 Abseil-Relay in the Name of NRAS | Waitrose Community Matters
- 19 Trusts and Foundations | Charity of the Year
- 20 Arthritis and Pregnancy
- 22 Ask the Helpline
- 23 RCN Rheumatology Nursing Workshop 2018
- 24 Self-Management Services
- 25 Arthritis Drug and Pregnancy Study | Two New Molecules Found
- 26 Workers At Risk Of Developing RA
- 27 Anti-Rheumatic Drug Management for Hip and Knee Surgery Patients
- 28 New and Effective Oral Combination Treatment for RA | NRAS Runners Do Us Proud Again!
- 29 External Affairs Update
- 30 New2RA and Living Better with RA
- 31 Ask the Helpline
- 32 NRAS' Peer to Peer Telephone Service
- 33 The Greatest Gift You Can Give Someone
- 34 Community Fundraisers
- 36 Scottish Campaigns Network
- 37 Updates from Policy and Public Affairs
- 38 Work Matters
- 39 My Story: How My Rheumatoid Arthritis Has Adapted to Cope with Me
- 40 JIA: Hi, I'm Isabel
- 41 Residential weekend for children and young people with JIA and their families
- 42 Update: Wear Purple for JIA

To comment on this issue or to submit a story or article for a future issue please email [editor@nras.org.uk](mailto:editor@nras.org.uk)

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



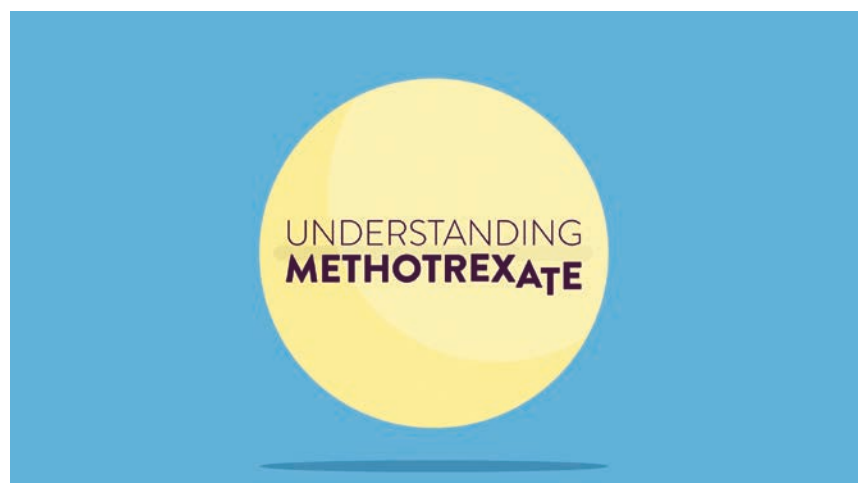
Clare Jacklin, NRAS and Dr James Rose, OAHSN

# Angry Hand

## visits Reading, Oxford and London

NRAS recently embarked on a joint collaboration with the Oxford Academic Health Science Network (OAHSN) supported by Sandoz Pharmaceuticals to raise public awareness of RA. The clear, important message was 'Don't ignore what your joints are trying to tell you'. The giant 12ft animatronic hand with glowing knuckle joints interacted with the public via a hidden speaker, operated in real time by a comedian on the other end, which the public were unaware of with amusing results!

We hope to be taking the Angry Hand out and about next year during RA Awareness Week, so watch out to see if it will appear somewhere near you. NRAS would like to sincerely thank the OAHSN for 'handing' over the hand to us for our future use!



## Becoming animated about methotrexate!

NRAS is delighted to have worked with MEDAC pharmaceuticals to develop a friendly, informative animated film to answer the most frequently asked questions about methotrexate. Take a look at [www.nras.org.uk/methotrexate](http://www.nras.org.uk/methotrexate).

It tells you all you need to know about how methotrexate works, its benefits and its possible side effects. We guarantee you'll like it!



# NRAS Pen Pals!

In the summer edition of the NRAS magazine we wrote about setting up a pen pal service. We're delighted that 3 NRAS Members have responded with their adverts, which you can find below

If you would like to respond to any of the adverts, please send your letter c/o Emma Sanders, NRAS, Ground Floor, 4 Switchback Office Park, Gardner Road, Maidenhead, Berkshire SL3 7RJ and we will collate any responses and forward them on to the writers below. Remember to include the address you wish them to respond to!

If you have an advert for a future edition, please also send them to the address above, email [membership@nras.org.uk](mailto:membership@nras.org.uk) or call Emma on 01628 823524.

## Jane 91184

Small livestock farmer in rural Devon, looking for pen friends male or female, any age, anywhere. My interests range from cattle to politics (anything really). We all have interesting lives and there is nothing quite like putting pen to paper, a mug of tea on the kitchen table, a cat by your side on a dark windy night, and the radio on quietly in the background. Hope to hear from you soon.

## Bev 15080

My name is Bev and I'm 68 years old and was diagnosed with RA in 2009. I live in a very beautiful, rural part of North Wales and I love writing and receiving proper letters! My hobbies are quite varied - I sew and knit, I enjoy gardening and walking my Border terrier (although not as far as he would like sometimes!). I will reply to any and all letters, and have no reservations regarding gender or age, so please put pen to paper and contact me the old-fashioned way!

## Lynda 12465

Hello! Witty, gregarious female in my 50's, North West area - seeks single male pen pals to correspond with. Age 50 to 65. My hobbies are voluntary work, dining out, music, gardening, TV, theatre/cinema. I also enjoy technology and the internet. I have had RA since childhood but maintain an active life and feel disability is no barrier to leading a successful and fulfilling life. Let's hope all your letters to me keep the postman busy.

Raise **FREE** funds for us when shopping online for...

# Christmas Gifts

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# Your NRAS needs you!

A large part of our role here at NRAS is to raise awareness and challenge public misconceptions around RA and JIA. Other than social media, events and the website, one of the other routes to the big bad world out there is through the media. Yes, love them or loathe them, we often get calls from press officers asking for a 'case study' and when I ask, 'when do you need someone?' the answer, more often than not, is yesterday! The bald patch, where I've torn my hair out is now starting to show!

We are lucky to have received some extraordinary stories from some extraordinary people and we are so very grateful to be able to share these and

raise awareness, but also to shine a light on RA and provide some inspiration for others. What we do struggle to find, however, are younger people, especially those in the 18-30 year old age group, to share their experiences and encourage other young people to share theirs. RA is more often associated with 'older people', so, we want to challenge those views and misconceptions. So, if you are aged between 18-30, we would love to hear from you and potentially get a feature in a national or consumer magazine.

Please mail us at [media@nras.org.uk](mailto:media@nras.org.uk) if you are interested in telling your story.

*Thank you*



## Mash Partnership

We have been working with NRAS for almost a year now, to help raise awareness of rheumatoid arthritis and juvenile idiopathic arthritis and to help tackle common misconceptions about both conditions. This cause has been very close to our hearts from the beginning of our journey together and we're proud to actively make a difference for those living with the disease and educate those who are completely unaware that arthritis doesn't just mean 80 and old!

In addition to generating exposure for RA on a national scale, with features being published in HuffPost and interviews with BBC Radio and ITV News - we've also supported NRAS on a regional level. NRAS' Community Groups are a vital factor in making patients' lives easier and making these accessible and known to a larger audience is an important part of our work.

We've been able to promote some exciting NRAS projects in 2017 – from initiatives such as Wear Purple for JIA and RA Awareness Week, up to hosting our own press event in central London in July, where we held an immersive experience for journalists to have a better understanding of what life with RA is like. In order to do this, we asked journalists to try on pharmaceutical gloves, which simulated the impact of RA on your hands, and challenged them to complete simple daily tasks, such as buttering toast or doing up buttons. The feedback we received was overwhelming: people were genuinely amazed and hadn't before given thought to the condition.

We had some incredible people sharing their RA story and journey attend the event too and we're grateful for each and every one of them. Journalists frequently ask us for real life stories to share with their readers. So, everyone who chooses to open up about such a difficult topic with us, in their own way, helping to increase awareness about RA and JIA.

We're looking forward to continuing our joint mission to raise awareness and challenge misconceptions for NRAS. If you do find yourself in the 18-30 age bracket and think you can help us to maximise the impact of our media work and share your story with others, please do get in touch.

Please mail us at [media@nras.org.uk](mailto:media@nras.org.uk)

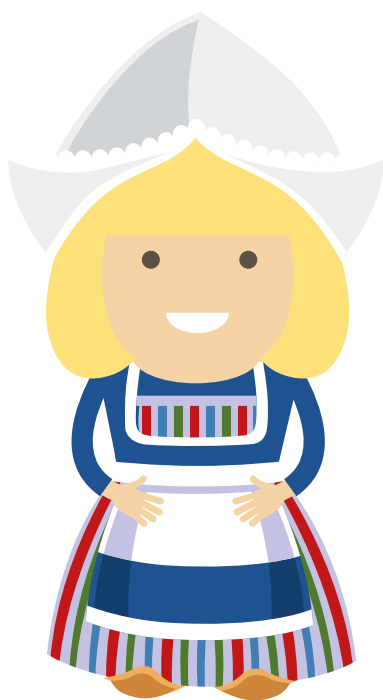
Thank you.



By Stu Campbell-Carran

Managing Partner, Mash PR





## EULAR Edgar Stene Prize open for entries!

The Edgar Stene Prize 2018 competition is open to people 18 years and over who are living with a Rheumatic and Musculoskeletal (RMD) disease. The 2018 prize will be awarded to the winning essay on the topic:

For many people with RMDs it can be a long journey to receive the right diagnosis and appropriate treatment for their condition. The competition invites entrants to write about their personal experiences. If you have an RMD this can be sometimes challenging enough. EULAR would like to hear from you, who your personal champion is, and why. It can be a family member, spouse, a friend, Healthcare Professional or even a family pet who gives you comfort and support. This is a great opportunity to celebrate all those who are around us every day and thank them for the unconditional love and support which often goes unnoticed.

Please submit all completed essays to Emma at [emma@nras.org.uk](mailto:emma@nras.org.uk) or by post by midday on Wednesday 20th December 2017. Each entry should not exceed two A4 pages. Full competition rules and further details can be found on the EULAR website: [www.eular.org](http://www.eular.org)



Each national jury will nominate the best entry from their country and a EULAR jury will select the 2018 overall Stene Prize winner by 15th March 2018. The Stene Prize winner will be awarded a prize of €1,000, travel to Amsterdam, hotel accommodation for up to 4 nights and an invitation to the EULAR Congress Dinner. The runner up will be awarded €700 and third place awarded €300.

*Good Luck!*

“My personal champion – supporting my everyday life with a rheumatic and musculoskeletal disease (RMD)”

# NRAS comes to Durham!

Our first Rheum for You conference of 2018 will be in Durham on Friday 23rd March. We're delighted to be welcoming our NRAS Medical Advisor, Dr Martin Lee, to the event as our key speaker. Dr Lee has been a fantastic supporter of NRAS over the past few years and many of you will remember his epic kayak around the UK which raised over £30,000! Dr Lee is Consultant Rheumatologist at the Freeman Hospital in Newcastle as well as being Honorary Senior Clinical Lecturer and Associate Clinical Sub Dean.

The event is open to all Members and a guest free of charge but numbers are limited so please register your place by emailing [membership@nras.org.uk](mailto:membership@nras.org.uk) or call Emma on 01628 823524.

We look forward to seeing you there!

Rheum for You heads north in March. Book your places NOW!



The Durham Centre inside



Rheum for You

# Rheum for you Swindon

NRAS was delighted to welcome many new and old friends to the latest Rheum for You conference in Swindon last month.

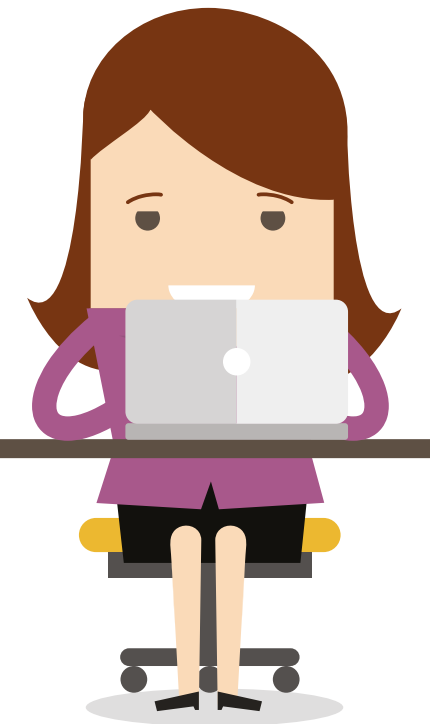
As well as the NRAS team giving the audience a sneak peek at new promotional videos and upcoming activity, we were also joined by some excellent speakers from Great Western Hospital including Suzannah Pegler, Lead Research Practitioner speaking about the latest RA research, Dr Sara Carty, Consultant Rheumatologist presenting on comorbidities associated with RA, and Dr Ahmed Azeem, Consultant Rheumatologist, who talked about

the latest RA medicines. The day was rounded off by Barry Davis from Citizens Advice, who shared the history of the organisation and explained what extra support and help they can provide.

The event was greatly enjoyed by those who attended and we were lucky enough to have beautiful weather to enjoy the views of the grounds whilst socialising over lunch!

Top image: Rheum for You Swindon  
Bottom image: Sally, Brianna and Emma from NRAS





# Membership Survey 2017

## Our first annual satisfaction survey results

In the NRAS summer magazine and August e-newsletters we put a link to our first annual satisfaction survey. Whilst we were a little disappointed with the number who responded to the survey, we were delighted that those who did, seemed positive towards Membership, the benefits we provide and the work that NRAS does. We will repeat the survey again next year and aim to allow more time for postal responses to encourage as many of you to respond as possible. A summary of some of the key results and suggestions can be found below. Any thoughts/ideas about Membership or the work of your society are always welcome, please email [membership@nras.org.uk](mailto:membership@nras.org.uk)

We asked our Members to rate their Membership benefits on a scale of 1 to 5, with 5 being the most valuable. For the majority, being the first to hear about new research opportunities and our NRAS magazine were jointly rated as the most valuable, with our monthly e-newsletters coming in third. One Member said, **"I find it comforting to know that there is always research going on, and how NRAS keeps everyone informed."**

A couple of you talked about not having conferences in your area. We appreciate that the conferences aren't always close to where our Members live but in the 4 years we have been running them, we constantly move them around to try and reach as many as possible. So, if we haven't come your way yet, we hopefully will be soon!

We always aim to let Members know about their local Group meetings when they sign up and we will continue to do so going forward. If you would like to receive email reminders about Groups and are not already signed up to email, do contact us at [membership@nras.org.uk](mailto:membership@nras.org.uk) and we will arrange this for you. There is currently only one Group that meets in the Northern Ireland area but we have had several Members in the area express an interest in extending our Ambassador programme to the region. If this is something you would like to get involved in, please email Matthew, our Policy & Public Affairs Manager, at [matthew@nras.org.uk](mailto:matthew@nras.org.uk)

We're pleased that most responders felt we were providing all the benefits/services that are needed but many of you also had some great ideas for future magazine articles. One Member asked to see **"more space in the magazine on the side effects of drugs."** The current magazine edition features an article on the effect of methotrexate on oral health and we will work on

similar articles for future editions. Don't forget you can find out more about side effects in our medicines booklet, published earlier this year.

A few of you wanted to see more healthy diet articles. Dr James Galloway wrote a fantastic article for our Spring 2016 magazine, which you can find by logging into the Members' area or in the diet section of our website [www.nras.org.uk/diet](http://www.nras.org.uk/diet) If you want more information, do contact the Helpline.

Other Members felt very positive about the fact the magazine **"doesn't feature any adverts or sponsored articles."**

Many of you had some great general suggestions and comments; we haven't been able to respond to all of them here but please be assured they will be taken into consideration:

*"More information on: How to explain your condition to your children, ways to manage changes in family life as result and helping children cope with their own emotions about their parent's condition"*

We completely agree! Whilst we have looked into this ourselves through our Family Matters survey back in 2012 and, more recently, our Emotions, Relationships and Sexuality booklet, this is definitely something we'd like to explore more fully in the future.

*"More up to date research about new drugs and an update of some stuff on the web site which is a bit old"*

Our lovely Volunteer Nicky, who is a retired rheumatology nurse, is currently reviewing all our online articles to ensure we have the most up to date information and, although it isn't an easy task, she is making great progress! In the meantime, don't forget our Medicines in Rheumatoid Arthritis booklet features all the latest medications, including biosimilars and JAK-Inhibitors, currently available and our Helpline team are always available to speak to anyone with any questions or concerns.

*"Can you educate rheumatologists to take foot pain and issues more seriously? They seem reluctant to even look at feet or arrange for helpful footwear"*

*"I think your helpline and info on the website are invaluable, I would not have coped as well without NRAS because you are filling gaps left by lack of time/resources/information in the NHS"*

*"A marvellous organisation which I have found very helpful. Having been diagnosed with RA in later life I was somewhat shell shocked and it was/is great to know you are there"*





*"The fact there was a helpline was invaluable to me, even though I was very reluctant to use it, as never experienced anything like this before"*

*"Although everything is online these days, I still appreciate the Members magazine, and I know there is always someone I can speak to on the telephone"*

*"I have had some great correspondence and help from Bronwen Cranfield from community fundraising when I have taken part in fundraising activities"*

Something like 90% of people with RA experience pain and problems with their feet and footwear is a huge issue for many. If you're struggling with feet/foot pain, do ask your rheumatologist to refer you to a specialist podiatrist, they can help with feet and helpful footwear. Our NRAS Medical Advisor, Dr Robert Field, also worked with us to create our Foot Health section - [www.nras.org.uk/foot-health](http://www.nras.org.uk/foot-health) which features videos from Healthcare Professionals and patients plus information on footwear, adaptations and much more!

*"You could do with explanations of acronyms like EULAR for instance"*

Great idea! Our Helpline team have a list of common abbreviations and we'll start putting them in new Member packs going forward, but do get in touch if you would like to receive a copy. The JIA glossary is quite helpful too and you can find it on [www.jia.org.uk/glossary](http://www.jia.org.uk/glossary)

To finish, we're delighted that over 91% of you are planning to renew your Membership in the future. If you're someone who isn't and you're happy to share your reason(s) we'd like to know why so we can aim to retain even more Members next year.





By Lesley Gibbs

# How accessible is your home?



Two Victorian houses: on the left, steps up to the raised ground floor and down to the basement. On the right, three steps into the house

This process can take a long time, so patience is needed!

I have had rheumatoid arthritis since 1982, first treated with aspirin, and now with anti-TNF drugs with methotrexate. I have had 2 knee replacements, fusion of C1/C2 vertebrae and many operations on my feet. I trained as an architect and have worked in housing all through my career. Mostly this has been social housing for housing associations, and accessible homes. My current work is focused on inclusive design.

- The prevalence of disability rises with age. Around 6% of children have a disability, compared to 16% of working age adults and 45% of adults over state pension age
- 1 in 5 people with a disability who require adaptations to their home believe that their accommodation is not suitable (Government Official Statistics)

## How accessible is your home?

Most of the homes in this country were not built to be accessible by anyone who uses a walking aid or a wheelchair. If you think of Victorian housing, it always has at least one step up to the front door, or a semi-basement with a flight of steps up to the raised ground floor. Often there are steps within the ground floor, narrow corridors, and a bathroom upstairs. With purpose-built flats the situation is better as everything is usually at one level. But if the flat is above the ground floor, there is no way of getting to it unless a lift is provided, and that's not always the case.

## Why don't people build accessible homes?

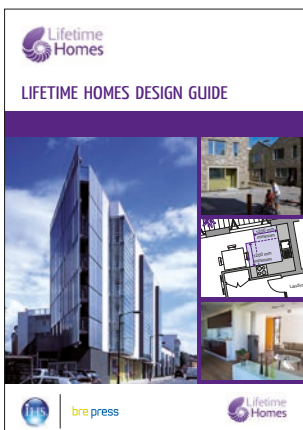
Well, some of them do! Habinteg Housing Association is an example. They have 40 years of experience in housing and disability; they campaign for good quality appropriate housing for all and develop standards for the design of accessible homes.

Habinteg developed the concept of Lifetime Homes in 1991 with the Joseph Rowntree Foundation. The intention was to design homes to meet people's changing needs over time. So, your home would still be suitable for your needs if you broke a leg, had a hip replacement or otherwise became less mobile for a short period, or had visitors who use a walking frame or wheelchair, or if you became frailer with ageing or a deteriorating condition.

- There are 11 million people in Great Britain with a limiting long-term condition, impairment or disability
- The most commonly-reported impairments are those that affect mobility, lifting or carrying

The principles of Lifetime Homes include:

- A level entrance without any steps



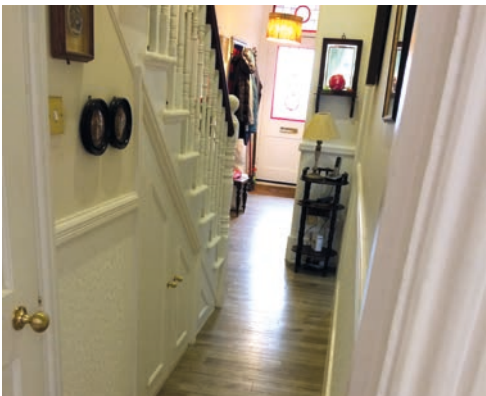
Habinteg's Lifetime Homes Design Guide



A new ramp rises from the pavement up to the front door to eliminate steps



15mm (3/4 inch) for easy access by a wheelchair



A level floor in the corridor with no steps makes it easy for everyone to use



Lever taps on all sinks and basins are much easier to use than knobs

- No changes of level at the entrance
- A living space at entrance level
- A toilet at entrance level
- A bathroom which can be adapted for a wheelchair-user
- Walls strong enough for grab rails to be fitted
- Space for a stair-lift or through floor lift in 2-storey homes
- Wider doorways

## What is the government doing about accessible homes?

From 2013, the government has required all new homes to have a basic accessibility level - level access to the front door, downstairs toilet, no level changes at entry level, switches and sockets at a reachable height on the entry level, minimum corridor widths and space to open doors.

Today, in 2017, the building regulations describe three levels of accessibility for new homes;

- basic level
- an enhanced level (similar to the full Lifetime Homes standard)
- highest level, which is wheelchair adaptable/ accessible standard

The planners can demand a percentage of each type in every new development. In London, 10% of all new homes are required to be built to wheelchair-accessible space standard.

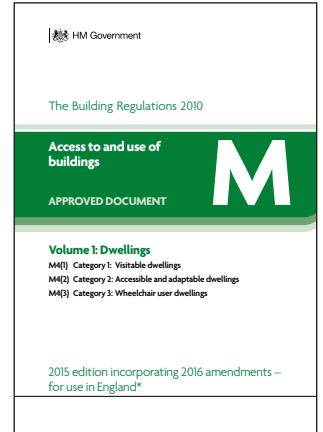
## What about existing homes?

In 2016 there were 28.1 million homes in UK, and the majority of these are not accessible. So, what can be done to make them suitable for our needs?

There is a range of aids and adaptations which can be undertaken, from the simple fitting of grab rails to installing a ramp to the front door, changing a bath to a shower, installing a downstairs toilet or fitting a stair-lift or through floor lift in 2-storey homes.

To pay for any adaptations, you can apply for a Disabled Facilities Grant (DFG) from your local council. The DFG is now part of the Better Care Fund, and it is means tested.

The process for applying for a DFG is to approach your local council, who will arrange an initial assessment of your needs by a Community Occupational Therapist (OT). The OT will then refer you to the Home Improvement Agency who will visit and make an assessment of cost, agree how much you will need to pay (if anything), arrange for plans to be drawn up and arrange quotes. You can use your own architect and builder if you prefer.



A level access shower can be easier to use than a bath. Note the flip-down seat on the wall.



Deep kitchen drawers are more useful than cupboards because it's easier to access the contents

**Acknowledgements:**  
Thank you to Tricia Rusling for allowing me to take photos of her home adaptations.



# Don't Delay Connect Today

12th October marked World Arthritis Day which is a global initiative bringing people together to raise awareness of issues affecting people with rheumatic and musculoskeletal diseases (RMDs)

The theme for 2017 is 'Don't Delay, Connect Today' and is a Europe-wide and locally-implemented campaign that calls on people, including healthcare professionals, physicians, the public and policy makers to connect today for earlier diagnosis of RMDs and timely access to evidence-based treatment. The overall goal is to highlight RMDs as major diseases and a public health concern of pandemic proportions; whilst emphasising that early diagnosis and timely access to treatment can prevent further damage and burden on the individual as well as to society.

To help break down the barriers that delay early diagnosis, the integrated campaign activity connects everyone working in RMDs, from medical doctors and healthcare associations to patient groups.

The objectives of the 'Don't Delay, Connect Today' campaign are:

- To highlight the importance of early diagnosis of RMDs and timely access to evidence-based treatment in order to prevent further damage and burden on individuals and society
- To break down the barriers that delay early diagnosis. People often do not go to their doctor or Healthcare Professional as soon as symptoms appear because society does not place sufficient value on joint care
- To help Healthcare Professionals, via educational activities, to identify and treat diseases as early and appropriately as possible to avoid further damage (aligned with the School of Rheumatology)
- To highlight the EULAR Recommendations on early diagnosis and timely evidence-based treatment of RMDs
- To foster support for patients, so that they understand their individual needs for optimal diagnosis and management of RMDs

EULAR (European League Against Rheumatism) have produced a film to highlight the importance of early diagnosis. It features Kate, Aran and Simon who all talk openly about the importance of talking to your doctor or healthcare professional.

We have also worked with Lilly to combine the 'Behind The Smile' films with a direct message to people and Healthcare Professionals - 'Don't Delay Connect Today'.

You can view both films by visiting [www.nras.org.uk/worldarthritisday](http://www.nras.org.uk/worldarthritisday)



# Listening Books

Wonderful audiobooks for those who struggle with printed books

Whether it's discovering a new classic for the first time or relaxing with an old favourite, reading can have a huge impact on our lives and our wellbeing. But if you struggle to read or hold a book due to the pain or fatigue caused by rheumatoid arthritis you may find yourself missing out. Listening Books can help!

We are a national charity providing a postal and online audiobook library service to people with an illness, disability, learning difficulty or mental health issue that makes it difficult or impossible to read text, hold a book, or turn its pages. We are passionate about making books accessible and know that audiobooks can have many benefits, offering all the comfort, relaxation and enjoyment that reading can provide. As one Listening Books member explains, "I am housebound and stuck in bed a lot. Listening Books has made a huge difference to my quality of life. I can escape to a different world when I listen to a book."

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We have a number of fantastic FREE memberships available for people who would like to become a member but would find our membership fee a barrier to joining (usually £20 – £45 per year). If you, or someone you know, would benefit from a free membership, please get in touch!



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## Christmas Gift NRAS Membership

**If you're struggling to find the perfect gift for a loved one then why not give the gift that lasts all year?**

If you have a family member or friend who lives with rheumatoid arthritis, why not consider buying them the gift of NRAS Membership? For just £25 for the whole year, they will receive all the benefits of Membership plus a gift card which has space for a personal message from you. We can arrange for it to be sent directly to the recipient or we can send it to you so you can gift it to them yourself.

If you, yourself, have RA and are being pestered by family and friends to give them some ideas of what you'd like for Christmas, why not suggest they buy you the gift of NRAS Membership. NRAS Membership is a thoughtful and unique gift that will not only benefit you but thousands of others like you as well. There are only so many scarves and bath cubes one needs in one's life after all!

If you are interested in Gift Membership then please call Emma on 01628 823524 or visit [www.nras.org.uk/gift-membership](http://www.nras.org.uk/gift-membership) to print off the Gift Membership form at home.



**nras**  
National Rheumatoid  
Arthritis Society

As you will come to understand, after reading Stewart Glaspole's article below, Pharmacists are increasingly, and rightly in our view, becoming a more recognised member of the multi-disciplinary team in the treatment of long-term conditions such as RA. NRAS has been working to raise awareness of the value of local Community Pharmacists in being able to carry out Medicines Use Reviews, particularly for people with RA who may have other co-morbid conditions such as diabetes, heart disease or depression for example,

and therefore be taking multiple medications. We were, therefore, very pleased to discover earlier this year that there was a new professional body, Rheumatology Pharmacists UK (RPUK), who are a growing professional group embedded within multi-disciplinary teams in rheumatology departments. The complexity of treatment options involved in an RA patient's care is growing with the advent of switching from originator biologics to their biosimilars and the introduction of the new small molecule drugs (JAK

inhibitors) and so we welcome the opportunity to collaborate with RPUK. I have been invited to speak at their conference in November where I will have the opportunity to represent the patient voice in this increasingly complex landscape.

#### Ailsa Bosworth

For more information on drugs used in RA, please see the NRAS booklet 'Medicines in RA' [www.nras.org.uk/publications/medicines-in-rheumatoid-arthritis](http://www.nras.org.uk/publications/medicines-in-rheumatoid-arthritis)



#### By Stewart Glaspole

FFRPS MRPharmS FHEA, Specialist Interface Pharmacist, Brighton and Hove CCG and Senior Lecturer in Clinical Pharmacy, University of Brighton

# Introducing the Medicines Experts

**Over the past 20 years, the treatment of rheumatoid arthritis has been revolutionised by the development of new medicines. Whilst this undoubtedly provides a significant patient benefit, these medicines are not without their problems. Careful management of how they are used, especially when a patient is on other medicines or has other problems, is important to reduce the waste of NHS resources, and to improve the benefit these medicines can offer.**

Many hospitals now have pharmacists in the rheumatology department whose specific job it is to help patients with their medicines. In this article we look to see what rheumatology pharmacists do and how they can improve the patient journey.

## Pharmacist training

To be a pharmacist you need to study for at least 5 years to qualify. However many hospital pharmacists continue studying whilst they are first qualified to develop more advanced knowledge and skills. A typical rheumatology pharmacist would probably have studied for between 7-10 years and have at least 2 years of experience looking after rheumatology patients. A pharmacist can also legally prescribe any medicine for their patients if they have attained the independent prescribing qualification. This means a pharmacist can make any necessary changes to prescriptions without taking time from medical doctors and nurses.

## Rheumatology Pharmacists UK

As the number of rheumatology pharmacists has started to increase in our hospitals, a new professional group has been developed to represent its members. Rheumatology Pharmacists UK (RPUK) is aiming to support rheumatology pharmacists in practice so they can help patients as much as possible. RPUK has also developed links with NRAS and the Chair of RPUK, Dr Stewart Glaspole, a pharmacist with a special interest in rheumatology, recently commented about his hopes for their relationship:

"I'm thrilled that we can work with such a well-respected organisation as NRAS. Pharmacists can be an invaluable tool in helping patients understand their medicines, to get the most from them. We are committed to putting patients at the heart of what we do and are excited for the future."

## What pharmacists do

Not every rheumatology department has a dedicated pharmacist, and not every department works in the same way, but usually the rheumatology pharmacist is the medicines expert of the team and any complex queries relating to medicines are passed to them. This allows consultant rheumatologists and nurse specialists to devote more time to other aspects of patient care. Decisions around selecting the best medicine for a patient are often taken as a group in a multi-disciplinary team meeting, where the pharmacist is a key member. This group decision making can often help to prevent future problems by making sure the right medicine is used for the right patient, at the right time.



#### Hilary McKee

Consultant Pharmacist

## Putting patients at the heart of decision making

One area where pharmacists can benefit patients is in helping them arrive at appropriate decisions concerning their medicines. Pharmacists are trained in discussing the complex data produced by manufacturers, and translating this to enable patients to make decisions that are right for them. This is becoming increasingly important with the widespread adoption of biosimilar medicines within the NHS. This, together with the development and introduction of new medicines, means that patients should have the opportunity to discuss their medicine related options with an expert before their treatment choices are decided. Dr Glaspole clarifies the pharmacist's role in this key activity:

"We know from experience that when patients understand the risks and benefits of the medicines offered to them, and those choices are discussed in a way that involves them, the benefit of the selected medicine is greater. RPUK feel that a pharmacist is an ideal Healthcare Professional to fulfil this role."

## The Antrim example of good practice

Hilary McKee is a Consultant Pharmacist at Antrim hospital and is the clinical lead for RPUK. Hilary has devoted a large proportion of her

professional career to looking after rheumatology patients and was instrumental in driving forward the leadership of the pharmacist group. As well as sitting on several expert groups, her clinical activities are an excellent example of what a rheumatology pharmacist does. As Hilary is an independent prescriber, she can manage a patient's medicines without diverting other Healthcare Professionals away from their primary role. Taking a holistic approach is important, and here is where Hilary demonstrates how she directly benefits patients. Having a wider view and considering often forgotten areas like cardiovascular disease, diabetes and depression, together with expert knowledge relating to the medicines in these fields, means that Hilary can make a real difference to how patients feel.

## How to speak to a pharmacist

All hospitals have pharmacists, but not all have a dedicated rheumatology pharmacist. NRAS holds a list of rheumatology departments that have a RPUK pharmacist. If patients have any concerns about their medicines, they should speak to their doctor, nurse or a pharmacist, or call the NRAS helpline to see if there is a RPUK pharmacist near to them.



# Help for Methotrexate Issues

In 2015, I began taking methotrexate and unfortunately had some quite severe side effects until my body got used to it. The most unbearable side effect was the mouth ulcers. When I asked my consultant he took a photo of my tongue as if I was some sort of freak and said there was nothing he could suggest; he just shrugged his shoulders! Reducing the dosage of methotrexate helped for a while but then the ulcers came back with a vengeance!

I decided to take matters into my own hands and began to search the net. There I came across the National Rheumatoid Arthritis Society (NRAS) and rang the Helpline. I spoke to Beverley who was wonderful, very sympathetic and listened to my woes. She suggested I look at the Oral Health section on NRAS' website.

She talked me through where to find the section as I was so upset and could not think straight. Beverley also introduced me to HealthUnlocked – a social network for health.

I typed in 'methotrexate + mouth ulcers' on HealthUnlocked and was able to see solutions that other people living with RA had tried. I wrote down approximately 20 suggestions. Then I went to my local pharmacist and showed him my list. He said the best solution was to gargle with saline (salt + water) 4 or 5 times a day. Within 48 hours the mouth ulcers began to subside and I could eat again! What I found worked best for me was just holding the warm water in my mouth for 1 minute, 5 times a day.

Within 2 weeks the ulcers had completely gone!

The most effective strategy I found was using the saline solution for 2 to 3 days – 48 hours after taking my methotrexate. 4 months later the mouth ulcers gave up the fight. I had won! I'd beaten those pesky mouth ulcers without compromising the control over my RA.

[www.nras.org.uk/oral-health](http://www.nras.org.uk/oral-health)  
<http://healthunlocked.com/nras>



I joined NRAS as a Member, and life is good again!

Jason Lewis

By Dr Caroline Flurey

Senior Lecturer in Public Health at University of West England, Bristol [visual of Caroline]

"When my boy turns around and says to me, 'Why can't you come and play football with me Dad?', that really, really hurts."

# Men with RA study

Rheumatoid arthritis affects more women than men; around 70% of patients being female. It is, therefore, not surprising that, to date, the majority of RA research has focused on women. However, with a growing body of research concentrating on the importance of men's health, and a recent European report claiming that men need their own health strategy, it is fair to say that giving a voice to men with RA is long overdue.

Women with RA report more pain and disability than men with RA, but we don't know why this is. It could be due to physiological differences between the genders; it could be because men and women perceive their experience of pain differently; but it could also be because the measures that we use in rheumatoid arthritis have been developed in standard clinical populations (70% female) and therefore, are more sensitive to the way women report their disability. Nevertheless, it is unlikely that disease severity alone contributes to this difference.

A comprehensive literature review found that there was no agreement on whether gender affects ability to cope with RA. Despite these differences, prior to our own research only 2 small interview studies had ever focussed solely on men with RA.

We conducted focus groups with 22 men with RA to understand their experiences of the condition, and how they cope with it. We followed this with a study using Q-methodology, (Q Methodology is a research method used in psychology and in social sciences to study people's "subjectivity" -that is, their viewpoint) which involved a group of 30 men. Finally, we sent a postal survey to men across England (293 men responded) to assess how widespread experiences and coping styles are, and to understand men's support preferences.

## How do men experience and cope with RA?

We found that men experience challenges to their masculinity, which can be due to having to adjust to a reduction in strength and the ability to do things previously taken for granted. For men with manual jobs this meant no longer being able to work in the same way they used to. The men in our focus groups explained that this reduction in strength could leave them in a position of having to ask for help, which they felt is "not a very macho thing" to do. This was particularly difficult when they had to ask

for help from people who had previously been physically 'weaker' than them, such as their wives.

Men also had to deal with challenges to their masculine identity; they commented on not being able to do the 'man's tasks' within the home. For men who had stopped working due to their RA, the loss of their role as the breadwinner was particularly difficult to accept. Some men felt their roles as father or grandfather were challenged, unable to play physical games with their children or grandchildren: "I can put up with everything else, but when my boy turns around and says to me, 'Why can't you come and play football with me Dad?', that really, really hurts."

Many of the men talked about "just getting on with it" as a way of coping with their RA, and they discussed the need to pace, plan, and keep active. Similar to findings with other conditions, men with RA were hungry for information about their condition, and were keen to find out about current and upcoming research. In an attempt to get on with their lives despite their RA, many of the men would push themselves to their limits, such as continuing working in a manual job for as long as possible. Some of the men also reported using exercise as a way to vent frustration and anger, which would exacerbate symptoms. They reported withdrawing socially; for some, this was to deal with the emotional aspects of the disease, for others it was because they no longer felt able to participate in sports or social drinking.

Appropriate exercise is recommended for managing the symptoms of RA but contact sports or extreme workouts can exacerbate symptoms.

These coping methods support the idea that men try to behave according to (British and American) ideals of stoicism and emotional self-sufficiency. Many of the men explained that their wives and adult children were their biggest form of support. However, the majority claimed their friends were not supportive, and they felt they couldn't or shouldn't talk to them about their condition. These men reported being willing to talk to their rheumatology team if directly asked about their emotional well-being, but wouldn't offer this information unprompted. Thus, rather than asking questions that may not illicit a full response (eg 'how are you doing?'), Healthcare Professionals should be encouraged to explicitly ask men about psychological and emotional issues. There is value in taking an indirect approach, such as talking about 'safe issues' like work or family to encourage men to talk about issues that matter to them, rather than using words such as 'feelings'.





## Are men struggling to cope with their RA?

Some men are able to accept and adapt to RA, by finding different ways to do the things they find difficult after the diagnosis, or finding activities to replace those they've lost, this allows them to retain a certain amount of independence and control over their condition. Proactively adapting to their condition allows them to feel they are taking control, and thus conforms to Westernised ideals of masculinity. However, we found that a second group of men are fighting the impact of RA by pushing themselves to their limits and being reluctant to ask for help. This may be because some men see ill health as a threat to their identity, and confronting health concerns contradicts masculine ideals of being self-reliant and resilient.

Our survey study revealed that at least 43% of men with RA experience poor psychological outcomes (eg depression, anxiety, poorer overall mental well-being, and greater levels of patient-perceived stress), and these men also report using less effective coping strategies, thus finding it difficult to accept their condition. They also reported worse disease activity, but we do not know the cause of this relationship: it is possible that these men have worse psychological outcomes and poorer coping due to their worse disease activity; however, there is evidence within rheumatology research that symptoms of depression and anxiety are associated with poorer health outcomes and reduced treatment response. Furthermore, as these men were predominantly on aggressive medications already, it is important to consider other ways of supporting them.

## How can we support men with rheumatoid arthritis?

With a cultural shift towards gender equality, and the passing of the Equality Act in 2010, it is time to stop blaming men for their lack of engagement with the healthcare system. We need to start looking closer to home, and provide healthcare services that men want to engage with.

A comprehensive literature review of the acceptability of different types of support for men with long-term conditions found that men need support interventions to have a purpose, be structured, and provide opportunities to gather new information.

This supports the theory that while women prefer face-to-face conversations, many men find this too personal and instead benefit from 'covert intimacy', which tends to take the form of shoulder-to-shoulder conversations, while engaging in shared activities.

Interestingly, the men valued the opportunity to talk to each other in the focus groups, and it was often the first time they had met another

man with the same condition. However, when offered a similar group as part of their care, they emphasised that they were attending the focus groups to help with the research project rather than to help themselves.

## What next?

Our next project is focussing on men with other rheumatic diseases, with the aim of designing a self-management intervention for men with all rheumatic diseases.

*Any man living with RA (or an associated condition) will recognise himself in this research. Aside from being physically disabling, having to try and cope with a chronic, incurable and degenerative disease also destabilises all culturally-held norms about gender identity, and makes it virtually impossible for you to behave in the way that you have been taught to all your life. It is particularly tragic that men who are unable to accept this, attempt to persevere regardless to the further detriment of their health.'*

Philip Aherne, NRAS Member

43% is a significant proportion of male patients who are in need of appropriately targeted self-management support



**Rheum2Talk** workshops for all those working in rheumatology are the ideal way to find out how to build this approach into your clinical practice – if you are a healthcare professional and would like more information on the workshops and/or would like to register for the next one on December 5th 2017, please email [clare@nras.org.uk](mailto:clare@nras.org.uk)

# Abseil-Relay in the name of NRAS



One day, NRAS Volunteer Teresa Shakespeare-Smith, along with her Rheumatology Specialist Nurse, Sharon Pearson, came up with the crazy idea of putting together a team of people who would take part in an abseil/run/cycle ride or walk at the Olympic Park in Stratford, all on one day! They planned and prepared, and finally on 16th September they completed their mammoth challenge - it had been arranged for June but Sharon hurt her ankle so was unable to walk very well, let alone abseil!

First to go were Sharon and Dr Ellis, and nurses Angela and Louise (from the East and North Herts NHS Trust's Rheumatology Department), who completed their 262ft free-fall abseil from the ArcelorMittal Orbit in the Park. They said the

worst part was stepping off the platform, but the views were fabulous. As they reached the ground they were buzzing with adrenaline and had huge smiles on their faces! They then handed the baton over to runners, cyclists and walkers who completed between 5 and 15km each. Relatives including the team's children, aged between 7 and 15, also took part in the challenge and the adrenaline-fuelled abseilers even went on to cycle the course after completing their descent!

Teresa said, "It was a lovely family event, with children, partners and parents all joining in! The whole day had a lovely feel to it, we were very lucky with the weather; it was dry all day!" The team left the park tired, but very happy and more than a little relieved!

The team were raising money for the rheumatology department at the hospital, with £3,000 coming to NRAS. Great challenge, well done and thank you to everyone who took part.

Fancy taking on an abseil yourself? Visit our website at [www.nras.org.uk/adrenaline-rush-2017](http://www.nras.org.uk/adrenaline-rush-2017)



# A 'Token' of our appreciation!

The National Rheumatoid Arthritis Society was chosen by Waitrose in Maidenhead for their Green Tokens Scheme in August 2017.

We were nominated by residents in the local area for the scheme, which works by customers placing a token in the Community Matters box at their local Waitrose branch. Since its launch in 2008, the scheme has donated £14 million to local charities chosen by the public.

We were informed at the beginning of September that we had won the collection in Maidenhead and received a magnificent £500!

You can apply for NRAS to be in your local Waitrose by collecting an application form, which can be found on the side of the Community Matters box. To find out more contact the



fundraising team on [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk) or call us on **01628 823524**.

Other stores such as Tesco, Sainsbury's and Asda operate in a similar way. To find out more, pop in to your local store and speak to a member of their customer service team.



# Trusts and Foundations

Grants awarded by charitable trusts and foundations are crucial for NRAS to be able to carry out its work – they form 30% of the total income of the charity. For the last 10 years, this income has been secured by a Trusts and Grants team, with the support of former NRAS Trustee, Mark Liddell and Peter Steel. Mark and Peter have done an amazing job, but they will now take well deserved retirement and hand over completely to a new team.

We would like to give huge thanks to Mark and Peter for their fantastic support over many years and wish them well for the future. We would also like to thank the numerous appeal patrons who have been instrumental in helping to open doors to some of the trusts and foundations that have so generously supported us.

Joining the fundraising team in Maidenhead are Laura Dominguez Pastor and Dawn Waterman,

who will be leading on securing grants from trusts and foundations going forward. When NRAS first started working with grant giving bodies, the importance of building strong relationships was key. Mark and Peter have supported this activity very successfully and have helped to build some excellent links and establish some loyal trust supporters.

Dawn and Laura will continue to develop these relationships, and any support from NRAS Members and supporters in helping to make links between NRAS and trusts and foundations would be most welcome. If you are a Trustee of a grant-making trust or foundation, or know people who might be, and would be willing to introduce NRAS to them, we would be delighted to hear from you.

Many thanks.

Tel: **01628 823524 Ext 569**

**dawnw@nras.org.uk | laura@nras.org.uk**



Dawn and Laura

# Charity of the Year

In May 2017, we were contacted by Lauren How who is the mother of Molly How. Molly was diagnosed with JIA at just 15 months old. Lauren saw one of our posters in the Nuffield hospital, Oxford, advertising our Wear Purple for JIA event, which took place in June 2017. She wanted to get involved and help raise funds for JIA at NRAS and has now taken us on as her Charity of the Year. Lauren has made it her mission to raise funds and, more importantly, awareness about JIA.



Lauren works for The Red Lion Pub in Little Missenden and on Saturday 26th August, Lauren held a Charity Family Fun day in aid of JIA-at-NRAS. The day included lots of different activities such as a dog show, face painting, a tombola and a bouncy castle. Families came together to support NRAS by raising funds and awareness. The total amount raised on this day alone was £854!

Lauren said, *"We feel very proud to be raising money for such a great charity and it also gives Molly a chance to meet other children like herself."*

Could we be your next Charity of the Year? If so please give us a call on **01628 823524** or email Gill Weedon – **gill@nras.org.uk**





By Dr. Martin Lee

MB.BCh.BSc(Hons).  
FRCP(Rheum).PgDipClinEd.  
FHEA.MAcadMED

Consultant Rheumatologist,  
Honorary Senior Clinical  
Lecturer & Associate Clinical  
Sub Dean

Newcastle-Upon-Tyne  
NHS Foundation Trust &  
Newcastle University



# Arthritis and Pregnancy

Rheumatoid arthritis is more common in females and often presents at an age when people are considering starting families

The management of rheumatoid arthritis before, during and after pregnancy is an important topic and one that is often discussed in clinics. Managing rheumatoid arthritis in pregnancy can be complex for several reasons:

- Rheumatoid arthritis disease activity and some of the medications used to control disease activity have the potential to affect fertility and foetal development
- Pregnancy has the potential to affect rheumatoid arthritis disease activity

Ideally people with rheumatoid arthritis considering pregnancy should be managed in a specialist unit with combined input from both the rheumatology and obstetric teams. Active inflammatory disease is associated with adverse pregnancy outcomes and an overarching principle in maternal medicine is that maintaining health in the mother plays a key role in both fertility and a positive pregnancy outcome. Prescribing in pregnancy is complicated by a lack of clinical trial data and knowledge that has the potential to lead to patient misinformation or withdrawal of appropriate medication. Fortunately, there have been recent guidelines published by both the British Society for Rheumatology (BSR) and the European League Against Rheumatism (EULAR).

## Non-Steroidal Anti-Inflammatory Drugs (NSAIDs):

NSAIDs are commonly co-prescribed with Disease Modifying Anti-Rheumatic Drugs (DMARDs) in rheumatoid arthritis to treat inflammatory symptoms. Current data suggests that NSAIDs are safe to use in the first and second trimester of pregnancy but should be avoided in the third trimester to avoid premature closure of the ductus arteriosus (a blood vessel connecting two main arteries) in the infant. There is some data suggesting that NSAIDs' use may reduce fertility in women trying to conceive. There is limited data on selective COX-2 inhibitor anti-inflammatory drugs (such as celecoxib or etoricoxib) so these should be avoided during pregnancy.

## Prednisolone:

Prednisolone is compatible with each trimester of pregnancy and with breast-feeding and is sometimes used to control disease activity in pregnancy if other DMARD medication needs to be withdrawn. Therefore, prednisolone can be continued at the lowest effective dose throughout pregnancy although this should be discussed with the obstetric team. There is some data suggesting that prednisolone doses >7.5mg/day may reduce fertility in women trying to conceive but higher doses may be required to control disease activity which is vital to ensure a positive pregnancy outcome.

## Hydroxychloroquine:

Current data suggests that hydroxychloroquine is safe to continue throughout pregnancy and is compatible with breast-feeding.

## Sulfasalazine:

Current data suggests that sulfasalazine is safe to continue throughout pregnancy (at doses up to 2g/day) with folate supplementation. Sulfasalazine is also compatible with breast-feeding in a healthy, full-term infant.

## Methotrexate:

Current evidence indicates that methotrexate use in females in pregnancy is associated with an increased rate of congenital malformations. Therefore, it is usually recommended that methotrexate is stopped 3 months ahead of planned conception. Although methotrexate only appears in breast milk in small amounts, it is usually recommended that methotrexate be avoided in breast-feeding mothers. Based on limited evidence, low-dose methotrexate may be compatible with paternal exposure.

## Leflunomide:

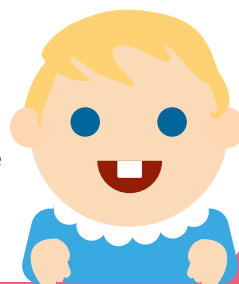
There is very little evidence surrounding leflunomide exposure in pregnancy in humans. Currently, leflunomide is not recommended in women planning pregnancy and a washout using cholestyramine and measurement of drug levels is recommended prior to conception. Data with regards to breast-feeding whilst on, as well as paternal exposure to, leflunomide is lacking.

### Anti-TNF Biologic Therapies:

There has been some controversy in recent years about the safety of anti-TNF use during pregnancy. There is now registry data available about the use of some anti-TNF therapies in the perinatal period. Adalimumab, certolizumab, etanercept and infliximab are not considered teratogenic (cause birth defects) and are all considered safe for use in the first trimester. If possible, it is recommended that adalimumab, etanercept and infliximab should be stopped in the second or third trimester due to placental transfer of these drugs and the theoretical risk of immunosuppression in the new-born child (although the placental transfer of etanercept is much lower than that of adalimumab and infliximab). However, any potential harmful affects on stopping these drugs to maternal health and subsequent foetal health must be considered. The structure of certolizumab is different from other anti-TNF biologic medications (it lacks a part of the antibody termed an 'Fc' portion) and therefore there is minimal transfer across the placenta. It is therefore considered safe to continue throughout pregnancy. Certolizumab is also bound (pegylated) to a large protein and does not cross into breast-milk. If any anti-TNF therapy is continued throughout pregnancy then live vaccines should be avoided for the first 7 months of the baby's life. Anti-TNF therapies are felt to be safe whilst breast-feeding although there is limited data available.

### Other Biologic Therapies:

There is limited or no data available for other biologic therapies used for the treatment of rheumatoid arthritis (such as abatacept, rituximab and tocilizumab). Rituximab has not been shown to be teratogenic and only second or third trimester exposure is associated with neonatal B cell depletion. Overall, due the limited data available, it is currently felt that these biologic therapies should be replaced before conception and should only be used in pregnancy when no other pregnancy-compatible drug can effectively control disease activity in the mother.



Katy Pieris

"There is a lot to consider before embarking on the journey to conceiving and when you have RA there is more to think about. The advice & research into safe medication is forever changing and it is therefore important as a patient to ensure you listen to the advice of the medical teams whilst doing your own research"

Katy Pieris, NRAS Member and Croydon Group Co-ordinator

Drug compatibility in pregnancy and breast-feeding for medications commonly used to treat rheumatoid arthritis disease activity					
	Peri-conception	Compatible with 1 <sup>st</sup> trimester	Compatible with 2 <sup>nd</sup> /3 <sup>rd</sup> trimester	Compatible with breastfeeding	Compatible with paternal exposure
<b>NSAIDs</b> (excluding COX-2 inhibitors)	Yes	Yes	Stop by week 32	Yes	Yes
<b>Corticosteroids</b> (prednisolone & methylprednisolone)	Yes	Yes	Yes	Yes	Yes
<b>Hydroxychloroquine</b>	Yes	Yes	Yes	Yes	Yes (limited data)
<b>Sulphasalazine</b> (with folic acid)	Yes	Yes	Yes	Yes	Yes (although low sperm count has been reported)
<b>Methotrexate</b>	Stop at least 3/12 in advance	No	No	No	Yes (limited data)
<b>Leflunomide</b>	No (requires cholestyramine washout)	No	No	No data	Yes (limited data)
<b>Anti-TNF biologics</b> (adalimumab, certolizumab, etanercept, infliximab)	Yes	Yes	Stop by 3 <sup>rd</sup> trimester (certolizumab is considered safe throughout pregnancy)	Yes	Yes
<b>Rituximab</b>	Aim to stop 6/12 in advance	No	No	No data	Yes (limited data)

*This table is adapted from BSR guidelines. It should be noted that there is limited data available for some of the medications and all patients should consult their rheumatologist and/or obstetrician for further information.*

# Dear Helpline



I have recently been feeling pins and needles in my hands and feet along with some numbness and occasionally some shooting pain along my arms and legs. My doctor tells me that I am experiencing peripheral neuropathy. Could you explain more about it to me?

Peripheral neuropathy occurs most typically when nerves in the hands, feet and arms are damaged. Symptoms vary according to the type of peripheral neuropathy and may develop quickly or slowly.

The main symptoms of this condition include;

- Numbness and tingling (pins and needles) in the hands or feet
- Burning, stabbing or shooting pain in affected areas
- Muscle weakness
- Loss of balance

There are many health conditions that can cause peripheral neuropathy and included in them are auto-immune conditions such as rheumatoid arthritis, lupus and Sjogren's disease. It's important to see your GP if you experience the early symptoms of peripheral neuropathy. They will ask about your symptoms and may arrange some tests to help identify the underlying cause. You may be referred to hospital to see a neurologist (a specialist in conditions affecting the nervous system).

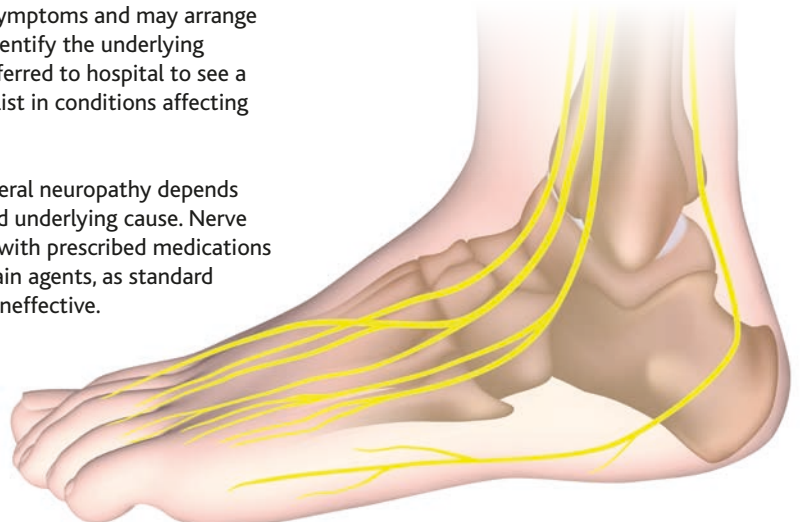
Treatment for peripheral neuropathy depends on the symptoms and underlying cause. Nerve pain may be treated with prescribed medications called neuropathic pain agents, as standard painkillers are often ineffective.

As peripheral neuropathy can be quite troublesome and

not respond fully to medication, some people try complementary therapies and medicines to help such as acupuncture and herbal remedies. Whilst some people find these helpful, they may not help everyone and as always, you should check with your GP or pharmacist before taking any complementary medicine to ensure that it is not going to interact with any of your prescribed medicine.

You can find out more about peripheral neuropathy on the NHS website:

[www.nhs.uk/conditions/peripheral-neuropathy/pages/introduction.aspx](http://www.nhs.uk/conditions/peripheral-neuropathy/pages/introduction.aspx)





# RCN Rheumatology Nursing workshop 2018

## 'Rheum with a view'



To book your place, call:  
02920 546460

Friday 12 January 2018

RCN Headquarters, 20 Cavendish Square, London W1G 0RN

Workshop just  
£50 + VAT

### What is this event?

This workshop is based on the results of a forum survey which asked you to identify issues relating to the management of rheumatological disease, interventions, treatment and support.

The aim is to address these issue as well as developing the unmet need of clinical leadership skills and personal and professional resilience. This event will enable specialist nurses to continue to deliver excellent care, follow best practice and inspire colleagues despite continued NHS barriers and difficulties.

This is critical to enable robust analysis of roles and responsibilities while specialist nursing banding is being reviewed on a national scale.



#### I'm a specialist rheumatology Nurse, is this event aimed at me?

Yes, this event is aimed at you as well as nurses who have an interest in rheumatology.

#### Why should I attend?

Rheumatology development days that are specifically targeted towards specialist nursing are hard to come by.

### Workshop timings

Registration from	10.30-11am
Workshop	11am – 3pm

By attending this event you will have the rare opportunity to:

- **hear** from expert speakers on the current issues
- **understand** the vital role that nurses play in the assessment, support and management of rheumatological disease
- **share** experiences and expertise in a safe environment
- **build** skills and experience.

### What topics will be covered?

- patient fatigue
- pain
- leadership and resilience training
- psychological impact of chronic disease
- Biosimilars update and how they impact on practice
- Rheumatology Specialist Nursing Competency frameworks.



Visit [www.rcn.org.uk/Rheumatology18](http://www.rcn.org.uk/Rheumatology18)

**Specialist Nurses**  
Book your place today!



Alison and Sandra

# Self-Management Services

Self-management has been the theme this year in East Sussex and Brighton, with NRAS workshops running throughout the area. NRAS has been working alongside Sussex MSK Partnership East and MSK Partnership Brighton and Central, and with over 100 people attending throughout 2017 we've managed to make a real difference to people with RA across the 2 regions.

There are 3 distinct programmes which are offered to people at different points in their journey with RA. Whether patients have been newly diagnosed or have been living with RA for

decades, the NRAS self-management courses have offered information, help and a fantastic opportunity to meet with people in a similar situation. We've had really positive feedback and it's been a joy to meet so many people living with RA over the year.

NRAS Volunteers have been invaluable in co-facilitating the workshops and have committed enormous amounts of time to the respective courses. Without them, we wouldn't have been able to reach the number of people we have and their input has been essential. Thank you to our Volunteers; Willy, Sally, Debbie, Sandra and Alison. We couldn't have done it without you!

Join the



For just £1 a week you have the chance of winning up to **£25,000!**

## We launched the NRAS Lottery back in September 2013 and a huge thank you to those of you who have signed up

We have over 400 players and are seeing a regular stream of winners each week (including 6 people who have won £1,000!).

Our latest winner, Aileen, said, "I started playing the NRAS lottery after my Mum died in 2011. We had a collection for NRAS (and British Lung Foundation) at her funeral and after that I wanted to continue helping NRAS in a small way financially.

*I am taking my husband, sister and her partner out for lunch this Sunday, but haven't decided how to spend the rest. I'll probably put it towards the cost of our upcoming holiday at Lake Garda!"*

If you have not signed up yet or want to re-join, please sign up at [www.nras.org.uk/lottery](http://www.nras.org.uk/lottery) or visit the Unity Lottery website at [www.unitylottery.co.uk](http://www.unitylottery.co.uk) and select NRAS. You can

also help us by telling friends, family, work colleagues, neighbours and anyone else you know about the NRAS Lottery.

## 50p in every £1

comes directly to us and creates a regular income stream to enable us to help raise awareness of RA/JIA and support people affected by these conditions.





# New arthritis study finds

## arthritis drug has no placental transfer in pregnancy

The results of a new study were recently released by the European League Against Rheumatism.

The study carried out by Dr Xavier Mariette and colleagues of the Bicêtre Hospital in Paris, used a specially developed drug-specific, sensitive biochemical test to detect certolizumab pegol in newborn infants.

At birth 13 out of 14 infant blood samples (taken from the mother's umbilical cord as well as the infant's) and all samples taken 4 and 8 weeks after birth showed no measurable levels.

16 pregnant women (at 30 plus weeks, gestation), who were receiving certolizumab pegol at a dose of 200mg every 2 weeks or 400mg every 4 weeks were included in the study. The last dose, in all patients, was within 35 days of delivery.

According to Dr Mariette, *"This study is the only clinical research that demonstrates how an effective anti-TNF shows minimal to no placental transfer from mother to infant which is positive news for pregnant women with active inflammatory disease. Most anti-TNFs have been found to cross the placenta and are usually withdrawn during pregnancy."*

[www.medicalnewstoday.com/articles/318137.php](http://www.medicalnewstoday.com/articles/318137.php)



# Two new molecules found

## with the potential to treat RA and other inflammatory types of arthritis

Two new molecules have been found by Greek researchers that have potential to treat rheumatoid arthritis and other chronic inflammatory diseases. T23 and T8 act against tumour necrosis factor (TNF- $\alpha$ ) and the receptor activator of NF- $\kappa$ B (RANKL). It is well established that TNF- $\alpha$  plays a role in the inflammatory process, but RANKL, which is protein, is also thought to be involved.

The study was reported in the journal 'PLOS Computational Biology'.

Currently, there are a number of biologic drugs that target TNF- $\alpha$  and these work well for many people but not for everyone. Also, over time they can lose their effectiveness in some people.

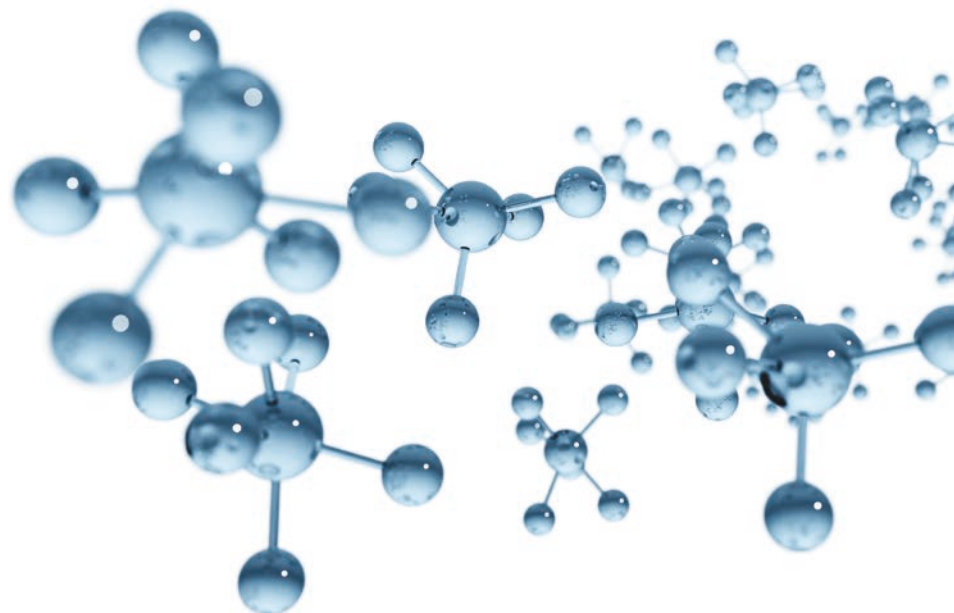
Using advanced computer technology, the structure of nearly 15,000 small molecules were looked at to see if they could possibly interact with TNF- $\alpha$  and RANKL and disturb their pro-inflammatory action.

*"This virtual experiment identified 9 promising molecules out of thousands of candidates,"* Andreas Afantis, the study's co-author said in a press release.

*"We identified the compounds T23 and T8 as dual inhibitors of TNF- $\alpha$  and RANKL"*

The toxicity of the 2 molecules was studied and was found to be potentially low, so there is the opportunity to further optimise them using drug design to provide new treatments for many inflammatory and auto-immune conditions.

<https://rheumatoidarthritisnews.com/2017/04/26/scientists-id-two-molecules-that-inhibit-proteins-involved-in-chronic-inflammatory-disease/>





# Workers may be at risk of developing RA in certain occupations



Environmental factors are thought to be involved in triggering auto-immune reactions in people leading to the development of conditions such as rheumatoid arthritis. New research now indicates that there could be a raised risk of this for people working in certain occupations.

A study carried out at the Karolinska Institutet, Sweden, by Anna Llar and colleagues, looked at information on environmental, genetic and immunological factors collected between 1996 and 2014. The data was gathered from 3,522 people with RA and 5,580 controls.

Male workers in the manufacturing sector had a higher risk of developing RA than people working in a professional, administrative, or technical setting (reference group). A twofold increase in risk of developing RA was seen in male electrical and electronics workers along with material handling operators compared to the reference group. The risk was 3 times as much in bricklayers and concrete workers.

However, for women in the manufacturing sector there was no increased risk (although this may be

accounted for by the very low number of women in this area). Women working as assistant nurses and attendants did have a slightly increased risk.

The participants' smoking habits, alcohol consumption, level of education and body mass index were all taken into account when analysing the results as these all play a factor in the risk of developing RA.

The results of this study indicate that work-related factors may potentially contribute to the development of RA, in particular, exposure to harmful airborne substances such as silica, asbestos, organic solvents and motor exhaust. However, more research needs to be done to identify specifically which of these is involved.

Once this is done then employees and employers can make decisions to reduce the risk of developing RA by limiting the exposure to these factors.

[www.news-medical.net/news/20170810/Certain-occupations-may-put-workers-at-increased-risk-of-developing-rheumatoid-arthritis.aspx](http://www.news-medical.net/news/20170810/Certain-occupations-may-put-workers-at-increased-risk-of-developing-rheumatoid-arthritis.aspx)

# New guidance for anti-rheumatic drug management

for patients having hip and knee joint surgery



Up until now, there has been little consensus about the best way to manage disease modifying medication for people with conditions such as rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, JIA and lupus undergoing hip or knee replacement.

"Patients with rheumatic diseases who have joint replacement surgery are at increased risk for joint infection," said Dr Susan Goodman, MD, Co-principal Investigator and Rheumatologist at the Hospital for Special Surgery in New York City. "As infection risk is linked to the use of anti-rheumatic medication, our goal was to develop recommendations on when to stop medication prior to joint replacement and the optimal time for people to restart treatment after surgery. Appropriate medication management in the perioperative period may provide an important opportunity to lower the risk of infection or other adverse outcome."

Now, for the first time, a collaboration of rheumatologists and orthopaedic surgeons has come together to discuss the best way of managing anti-rheumatic medication in patients undergoing these operations. In a project sponsored by the American College of Rheumatology (ACR) and the American Association of Hip and Knee Surgeons, 31 specialists from more than 20 hospitals and professional organisations formed an expert panel to discuss this issue. Input from patients was also considered in the project.

"Our project brought together hip and knee replacement surgeons, rheumatologists and methodologists to determine optimal medical management through a group consensus process. In addition, a panel of 11 patients provided input on their preferences," noted Dr Goodman.

Standard disease modifying drugs (DMARDs), biologic agents, tofacitinib (JAK inhibitor) and glucocorticoids (steroids) were included in the study. The panel looked at when to continue, when to stop and when to restart these medications as well as the best perioperative dosing of corticosteroids.

After all the evidence had been reviewed, the panel made the following recommendations:

- Non-biological DMARDs may be continued through the perioperative period in patients with RA, spondyloarthritis, JIA and lupus undergoing elective hip or knee replacement
- Biologic medications should be withheld as close to one dosing cycle as scheduling permits to elective hip or knee replacement and restarted after evidence of wound healing, typically 14 days, for all patients with rheumatic diseases

It was noted by the panel however, that these guidelines refer to common clinical situations and exceptional cases may need to be looked at differently.

[www.news-medical.net/news/20170616/New-guidelines-for-anti-rheumatic-drug-management-in-patientsc2a0having-joint-replacement-surgery.aspx](http://www.news-medical.net/news/20170616/New-guidelines-for-anti-rheumatic-drug-management-in-patientsc2a0having-joint-replacement-surgery.aspx)



# New and effective oral combination treatment

## for rheumatoid arthritis

Newly diagnosed rheumatoid arthritis sufferers are often first treated with standard DMARDs - such as, methotrexate for approximately 6 months, many responding well. Those patients showing no remission or decrease in symptoms, with certain risk factors, may be offered a combination of methotrexate and a biologic (possibly an anti-TNF eg adalimumab administered by injection).

Recent research has highlighted a new and equally effective oral combination treatment using methotrexate and tofacitinib, a Janus Kinase Inhibitor. Josef Smolen, senior author of this study has now had the results published in *'The Lancet'*.

The third most quoted rheumatology expert Smolen, Head of the Division of Rheumatology at MediUni Vienna along with a team of international researchers was able to show that this new combination was not only equally

effective, but also replaces the injection every 2 weeks with 2 tablets per day which is a potential advantage for patients. 1,100 volunteers took part in the study.

Says Smolen: *"At the same time we were able to show that monotherapy with tofacitinib does not achieve such good results as combined therapy with methotrexate, even though it is still quite effective."*

Tofacitinib inhibits certain enzymes (Janus Kinases [JAKs]). JAKs carry the signals from inflammatory messenger substances into the cell, and are therefore jointly responsible for the destructive inflammation in RA. By inhibiting these enzymes, the painful immune response is suppressed. Tofacitinib has been on the market in the US for some time and has recently been licensed in the EU.

[www.news-medical.net/news/20170619/Researchers-show-effective-oral-treatment-option-for-patients-with-rheumatoid-arthritis.aspx](http://www.news-medical.net/news/20170619/Researchers-show-effective-oral-treatment-option-for-patients-with-rheumatoid-arthritis.aspx)



Great North Run, Kate Flynn

# NRAS Runners do us proud again!

## Great North Run 2017

On a blustery Sunday morning Bronwen and Emma made their way to the finish area of the Great North run to meet our team of fantastic runners taking part in this year's popular Great North Run. As always, our team did us proud, with our fastest runner Alex coming in with a finish time of 1.45.55!

Our ladies were lucky enough to meet several of our runners to thank them for all their hard work; it's not just the running on the day, it's raising sponsorship too. The team did incredibly well and so far have raised almost £6,000 – way to go Team NRAS!

## London's Royal Parks Half Marathon

The sun was shining on Sunday 8th October across the beautiful Hyde Park in London, where 16,000 runners took part in the Royal Parks Half

Marathon. NRAS was lucky to have 9 runners in this year's event, which was also celebrating its 10th Anniversary.

Laura and Bronwen from Fundraising were there at the end to meet our NRAS team. It was especially lovely to finally meet Steph Turley who has been running for NRAS over the past year and has committed to run 30 events before she is 30 on October 23rd. Our fabulous NRAS runners all completed the 13.1 miles in great times and for some it was their first half marathon. So far, they have raised a great total of just over £4,900.

Would you like to be part of our team of runners for next year? We have guaranteed places in both of the above events. All you have to do is visit our website at [www.nras.org.uk/runs](http://www.nras.org.uk/runs) or give Val a call on **01628 501547** and book your place today. Don't worry if you aren't a half marathon runner; we will make sure you are race ready!

# External Affairs Update

## New Group in Dumfries and Galloway

An information evening was held in Dumfries and Galloway in August to launch the new Group. Special thanks to Petra Cannon, Rheumatology Specialist Nurse, for all her help in organising the evening. Dr McMahon, Consultant Physician/Rheumatologist at NHS Dumfries and Galloway did an excellent keynote speech; 'Rheumatoid Arthritis - Taking Control'. This was followed by a Q&A with a cross section of the team, Karen Brown, Rheumatology Occupational Therapist, Dr Lucy Maggiori, Rheumatology Consultant, and 3 Specialist Nurses, Petra Cannon, Ingrid Crane and Jane Murray. We hope to bring you news of ongoing Group meetings. The most up to date information can be found here: [www.nras.org.uk/groups/dumfries-and-galloway-nras-group](http://www.nras.org.uk/groups/dumfries-and-galloway-nras-group).



The Team at NHS Dumfries and Galloway

## Leeds – May 2017

Guest speakers were Dr Jackie Nam, Consultant in Rheumatology, Leeds Teaching Hospitals NHS Trust and Honorary Lecturer, University of Leeds and Dr Sarah Twigg, Clinical Lecturer in Rheumatology, Leeds Institute Rheumatic and Musculoskeletal Medicine, University of Leeds. Dr Nam presented 'Treatment approaches in Rheumatoid Arthritis' and Dr Twigg told us about 'Tackling pain and fatigue in rheumatoid arthritis – a rheumatologist's perspective'.



Leeds Information Event

## City Events 2017

Following the success of the first RA information event in London in June 2016, we decided to run 3 of these events this year. Due to the city lifestyle, community groups are difficult to establish, therefore, the NRAS External Affairs team decided to host this year's events in Leeds, London and Birmingham. London will continue to be an annual feature and different cities will be included each year.

## London – June 2017

Guest speaker was Dr James Galloway MBChB MSc CHP MRCP PhD, Clinical lecturer at King's College London and an Honorary Consultant in Rheumatology at King's College Hospital. Dr Galloway presented 'Pain, Psychology and a 'what is new' in the world of RA'.



Dr Galloway at London Event

## Birmingham – September 2017

Guest speaker was Professor Christopher Buckley DPhil FRCP, Kennedy Professor of Translational Rheumatology, Director of the Birmingham NIHR Wellcome Trust, Clinical Research Facility, Director of Clinical Research, Kennedy Institute of Rheumatology, who presented 'New Treatments for Arthritis: a team based approach'.



Birmingham Event attendees



# New2RA and Living Better with RA

Joining the suite of NRAS resources



commonly raised queries – What is it? How did I get it? How will it be treated? What does the future hold for me? What can I do to help myself? Where can I find out more? We've worked with a number of people who shared their experiences of being diagnosed and what they would have liked to have had provided at the time.

Starting any new chapter of your life, be it a new job, a new relationship, a new location etc, most of us will start by doing some preparation and finding out more – beginning your life with RA is no different. The more you find out and prepare, the easier the journey ahead. Consider this 'New2RA' booklet as your RA route-planner – plenty of signposting and optional stop off points as well as where to next!

'Living Better with RA' replaces the 'Managing Well' booklet which focusses more on those with more established disease, or following on from my metaphor above; the 'advanced or seasoned RA traveller'! Even having lived with RA for some time, there can be lots, that people are unaware of, that is impacted by their RA, or that you need to know about, but may be a bit too much to take on board when first diagnosed. This booklet includes information on managing flares, risks and complications, family planning, work and much, much more to enable you to live as full and as active life as possible with RA. Living with a long-term condition such as RA requires good disease self-management and this booklet is potentially your go to resource in your self-management toolbox.

Printed copies will be sent to every rheumatology unit in the New Year and you can pre-order your booklets today by sending your name and address to [enquiries@nras.org.uk](mailto:enquiries@nras.org.uk).

Thank you for bearing with us. It will, we're sure, be worth the wait.

Firstly, sincere apologies for the delay in getting these much-needed booklets to this point. As I am sure you can all appreciate as a charity, one of the biggest challenges we face is having ever growing demands on our limited resources and funding, and to be honest, just not enough hours in a day! Developing up to date resources requires focus groups, questionnaires, funding, a variety of contributors, editors, reader reviews, peer reviews, designers and eventually printers, so there's lots of juggling of schedules and redrafting of content but we get there in the end, so all the rigorous procedure is worth it.

The 'New2RA' booklet has been designed specifically for those who have just been, or recently been, diagnosed with rheumatoid arthritis. The user-friendly guide will, we hope, guide you through those first days, weeks and months of living with RA. Addressing the most

# Dear Helpline

I have rheumatoid arthritis and I am having trouble sleeping at night. Do you have any tips on how to get a good night's sleep?



There are things that you can do to prepare yourself for a good night's sleep

This is a question that we often get asked on the helpline and there are many things that you can do to help yourself. Firstly, you need to ensure that you have a good environment to sleep in. An important factor is having a bed that is comfortable for you, this includes the pillows and duvet. Many people find that memory foam mattresses and pillows help a lot. If you can't afford a memory foam mattress then you can get memory foam mattress toppers. For tips and advice on choosing a bed visit the National Bed Federation's website:

[www.bedfed.org.uk](http://www.bedfed.org.uk)

Having your bedroom at the right temperature for sleeping is also important and if light or noise disturbs you, try using earplugs and/or eye masks. There are things that you can do to prepare yourself for a good night's sleep. Get into a routine before going to bed and try to go to bed at the same time every night. Some people find that a warm bath helps to relax the joints and muscles. If you can't get into a bath then a

shower may help. It is easier to sleep if you have not over exerted yourself during the day. If you find that you cannot sleep because your mind is active and you are anxious or worried, try keeping a pen and paper by the side of the bed and writing down anything that is concerning you so you can tackle it the next day.

Pain can be a real problem at night. Taking slow release painkillers before you go to bed can really help and again, having the right sort of bed and mattress will help. If your sleep problems really persist then bring this up with a member of your healthcare team but remember, what works for one person does not always work for another so you may need to try a few things before you find what is right for you.

You can find out more tips and information on the NRAS and Sleep Council websites:

[www.nras.org.uk/guide-to-getting-a-good-night-s-sleep](http://www.nras.org.uk/guide-to-getting-a-good-night-s-sleep)

[www.sleepcouncil.org.uk](http://www.sleepcouncil.org.uk)





# NRAS' Peer to Peer telephone service

NRAS Telephone Volunteers invite you in for a virtual cuppa...

## Sally

"I've taken several calls now as a Telephone Support Volunteer for NRAS. The reason I volunteered initially was having been through the nightmarish horrors of the disease and 'come out the other side', I hoped I might be able to offer an empathetic listening ear alongside the positive perspective of enjoying a calmer, stabilised period in my life. My reasons aren't entirely altruistic however, as I've always enjoyed helping people, something my previous job allowed me to do. If there's one thing I've learnt from living with RA as well as depression at times, it's that having someone recognise that you're having a hard time, and that it's ok to feel fed up with your lot some days, is a lifeline. Reminding someone who feels alone, desperate, angry, guilty, frightened (any of the many emotional states RA can induce) that there is hope, that how they feel now, emotionally and physically, isn't necessarily how things will be forever, might just be enough to allow a person to think, yes, I can do this, there is someone out there who 'gets' what I'm going through. If I can make someone feel this for only a moment in their difficult day then I feel a little less alone too. In the words of Gloria Gaynor, "I will survive!"

## Lisa

"When I make a Volunteer call I get a sense of satisfaction. At last something positive has come out of my many years' experience of rheumatoid arthritis. I enjoy talking to people and if I can be of assistance to them, it feels that I am contributing. When at the end of a call and someone says, 'Thank you so much for calling, I feel better for speaking to you,' that makes me feel as if I have helped someone."

## Diana

"I have been a Helpline Volunteer for NRAS for 2 years now. I am pleased to be able to contribute to the work of NRAS in this positive way. The callers remind me of myself when I was newly diagnosed in February 2011. They are often confused and overwhelmed both by their diagnosis and the treatment options available. Frequently, they do not know anyone with RA themselves and so do not have anyone nearby

that can provide an effective 'listening ear'. Just speaking to someone further along in their RA journey is invaluable to them. As someone with RA who is in a secure remission, I am glad I can provide some renewed hope for those at the start of their RA journey."

## Sue

"When I had been recently diagnosed, I had a support call from NRAS and it really helped me to put things into perspective and not feel so alone. I promised myself then, that if I could do the same for someone else, that would make me happy! I feel privileged to share the feelings and experiences that I hear, and hope that in some way I am helping them to cope and feel hopeful about their future."

## Lindsay

"I've had RA since 2002 and felt I could use my experience, in particular when managing pregnancy and RA, to help others. I enjoy making Volunteer calls because I know a simple 30-minute chat can make a huge difference to the person at the other end of the phone. RA can make you feel so alone and a simple phone call can help you to know that you're not. This works both ways and I often benefit from the calls too. The friendship aspect is something I hugely enjoy and a lot of my calls do end up with us laughing and joking about our condition! I'm in touch with a couple of people I've made calls to and one is now a good friend."

## Joan

"Her name is Noelle ... she's really worried about moving onto a biologic." I make the call ... we speak about her concerns, talk about her life and how RA affects it. She's lovely, lively and interesting: relieved to speak with someone who 'knows what it's like'. For me it's a privilege to listen to her story. We all have a tale to tell and at times need support, empathy and maybe information. It felt as though she'd invited me in for a cup of tea: I enjoyed her company and felt that we had both benefited from the connection.

**We are always looking for more Volunteers.**

If this is something you would like to get involved with please do get in touch at [volunteers@nras.org.uk](mailto:volunteers@nras.org.uk)

If you would like to speak to one of our Peer to Peer Volunteers, please call the Helpline on 0800 298 7650.



# The greatest gift you can give someone is your time

What makes anyone volunteer for anything? Usually it is because the cause is close to your heart

My daughter Olivia was diagnosed with rheumatoid arthritis in 2010 at the age of 27. I had brought up Olivia by myself and my idea of keeping her safe and protected had been to keep her out of drugs and teenage pregnancy etc. So, when the diagnosis came, I am not sure which of us was most shocked.

This disease was never on my radar of protection. There is no history of the disease on my side of the family. At that time, I found myself feeling hugely guilty and bursting into tears at every turn, whereas my wonderful daughter took it all in her stride. Where her strength came from I have no idea. Olivia had the good fortune to be diagnosed fairly quickly, and we are both eternally grateful to the young GP who recognised the symptoms immediately. However, my daughter's journey with consultants and medication has not been an easy one. Even today she suffers with very unpleasant side effects. One incident that I remember vividly was our first visit to the RA consultative department; Olivia been asked to fill in copious forms, which I was appalled at as her hands were stiff and painful and surely a little more empathy was obvious for these patients. When we met the consultant, he confirmed the diagnosis and said she would not end up deformed; I was horrified at his insensitivity.

Like all who suffer with RA, Olivia suffers with 'flare-ups' and, as yet, we have not discovered any triggers for these. As her mother I find it hard to see her in pain and totally immobile. I am grateful for the small mercy that she has managed to stay in full-time employment and manage her stiffness and tiredness incredibly well on good days.

All this prompted me to volunteer for NRAS. I am a retired Headteacher and boastfully, I am fortunate to have gained some skills in my



*Olivia and Mum, Geraldine*

career that NRAS have put to good use. After an interchange with Kim and Gill and some video training I was unleashed. My role is to contact Helpline callers who have asked for a peer-to-peer call. This is all confidential and I only report on comments to ensure the service continues to improve.

I started with a script of 10 or so questions, which now has become only a guideline to direct the conversations for evaluation purposes. I have the honour to speak to some amazing and delightful people. Each and every one of them has a story to tell and have had to make some hard decisions in their lives. To say that they are incredibly brave is a total understatement.

I would like to thank everyone in NRAS – the staff for seeing some potential in me, and clients for letting me into their story.

Thank you NRAS for all the amazing work you do.

As her mother I find it hard to see her in pain and totally immobile



# Community Fundraisers

The Summer months have been a hectic fundraising time – with a lot of wonderful fundraisers making the most of the longer warm summer days

We have seen a variety of events from intrepid skydivers, to people cycling and running different distances, to charity concerts and dog shows, tea parties, craft stalls and even a lady doing a 24-hour sponsored silence.

We are so grateful to everyone who contacts us who wants to help us raise funds for NRAS. It really shows there is something everyone can do – young or not so young, something physically challenging if you are able or something like a quiz or bake sale where you can get friends and family from your own local community together to share in your event. We are always happy to discuss your fundraising ideas and offer all our Fundraisers support in setting up online donation pages, our handy fundraising guide, and a free NRAS t-shirt or running vest, as well as promoting your event on social media or in local press.

Meet a few of our fabulous Fundraisers from the past couple of months – unfortunately we can't name check everyone but here are just a handful who helped us raise over £14,000 between July and September.

**Ben Chamberlain** – who cycled 60 miles from London to Brighton in support of his young daughter Sienna and raised a fantastic £1,418 for future JIA services and projects.



Ben Chamberlain and daughter Sienna

**Nicola Melia** – who did a sponsored silence from dawn till dusk and, with matched funding from her previous employer, will have raised £1,600. Nicola said, "The task was very hard and my son, who's 11, said he thought he'd gone deaf! Several people have approached me since to discuss RA and felt the sponsored silence was a good idea as it's known as a silent disease."



Nicola Melia

**Trevor Phillips** – decided 100 miles in Ride London was not enough of a challenge, so on 26 July, he cycled from Hendaye on the Atlantic coast in southern France, across the Pyrenees to Argeles on the Mediterranean coast and back again - approximately 910 miles, climbing more than 110,000 feet over the mountains. Trevor raised an amazing £1,030.



Trevor Phillips and bike

We are so grateful to everyone who contacts us who wants to help us raise funds for NRAS

**Bernard Thain** kindly organised another charity event with his toe tapping group XBand. A fun night was had by all, north of the Border in Fairlie, including plenty of dancing, a BBQ and charity raffle. Bernard has been a great Supporter and a Member of NRAS now for many years and the band perform at charity fundraisers. A whopping £850 was raised on the night.



Bernard Thain lead guitarist

**Rebecca Studholme** roped her Dad and sister into her fundraising this year and they all took part in the Leeds Big Fun Run, a 5K event. Rebecca herself was diagnosed with RA 3 years ago and this is her 3rd running event she has done for NRAS. The Studholmes raised £681.



Rebecca Mark and Rachel Studholme

**Kathy Wright** and her fantastic family supported NRAS again by all getting involved with the Great Grimsby 10K. For Kathy it was her very first 10K and she was doing this to support NRAS as her little grandson Harvey has JIA (Psoriatic Arthritis). Before the event, Kathy said "Harvey is a fun, happy boy with lots of energy. He enjoys

running and ran the Grimsby 2k last year and with a good time. I started running in Sept 2016 and I'm currently training myself to run the Great Grimsby 10k in July this year to raise awareness for Harvey and all the children in the UK who have to suffer this lifelong illness. Please help me raise awareness. He is my little hero. Harvey will be competing in the 2k fun like last year." Kathy and family raised £429.



Kathy Wright and Harvey

**Anja Gilmour** did a skydive in Salisbury in August. Anja is actually a resident in the USA but spends several weeks each summer in the UK visiting family. Anja decided she wanted to support an RA charity in the USA and the UK and chose NRAS as we are the only patient-led charity in the UK dealing specifically with RA. Anja took time out of her travels to come and meet us all at our offices in Maidenhead a day before her actual jump. A huge thank-you to Anja who took to the skies and raised over £600.



Anja Gilmour



We are always happy to discuss your fundraising ideas and offer all our Fundraisers support



By Sheila MacLeod

Chair, Scottish Campaigns Network

# Scottish Campaigns Network

Casting a backward look over 2017 is encouraging – a creative and productive spell with much to report

## The line-up

Three new ambassadors – Allison, Gail and Siobhan – have been a great addition to the team, already actively involved in a range of projects. We met as a group in April and again in August to map out the way ahead and work through plans, many of which are well under way.

questionnaire and be confident that you will be making a difference. To support this exercise, four of us – Allison, Siobhan, John and I – created and took part in a short film with Sally from NRAS ably and patiently wielding the camera! Results can be seen at [www.nras.org.uk/shaping-the-ra-service-in-scotland-the-patient-voice](http://www.nras.org.uk/shaping-the-ra-service-in-scotland-the-patient-voice)

We have been invited to participate in another interesting initiative – the Healthcare Improvement Scotland project to investigate the possibility of adapting the Swedish Rheumatology Registry for use here. This has huge potential for improving the quality of the service and enhancing patient partnership. I look forward to being part of the steering group.

## Grass Roots

Scottish Ambassadors have been working with Volunteers in local areas to help establish and support NRAS Groups – most recently formed being in Dundee and Dumfries. In several other localities we are exploring the potential for further Groups and we will always be happy to help if we can. Ambassadors are also collaborating locally with other agencies whose interests coincide with ours on improving the lives of people with RA and other long-term conditions.

## The Gathering

Following the event in September 2016 in Stirling we are now planning a second Scottish NRAS Gathering – firm date is Tuesday 17 April 2018 and keynote speaker is our NRAS patron in Scotland, Professor Iain McInnes, Director of the Institute of Infection, Immunity and Inflammation at the University of Glasgow. More details to follow – please put this date in your diary and spread the word!

## ...and Going Forward

Thanks to the team at NRAS for their support. We'll continue to speak for people in Scotland with RA and JIA, seeking to help change minds, change services and change lives.



Shaping the RA service in Scotland

## Shaping the RA Service in Scotland – the Patient Voice

For some time, we have collaborated in a partnership with the Scottish Society for Rheumatology, Arthritis Care Scotland and Roche Products Ltd to design and steer SMART – Scottish Metrics for the Assessment of RA Treatment – a project designed to improve the quality of RA management by measuring and examining outcomes in the 2 years following diagnosis. The focus has now been extended to include established disease across Scotland; from October to December this year people diagnosed for a year or more will have the chance to fill in a questionnaire in clinic recording their views and experience of treatment and care. This information will be used as a basis for developing the best possible rheumatology service in line with the wishes, needs and priorities of people with the condition. If you have the opportunity, do please take time in clinic to complete the

# Updates from Policy and Public Affairs

## Northern Ireland

Belfast Health and Social Care Trust produced a Financial Planning Savings Plan document in September and October this year to consult on proposed savings. One of the proposals was to switch all patients with rheumatoid arthritis to the rituximab biosimilar. Whilst NRAS supports the use of biosimilars and acknowledges that it offers potentially substantial medicine cost savings, we have grave concerns that all patients will be switched without any consultation with their rheumatology team. We are also concerned that this could set a dangerous precedent for other Trusts in Northern Ireland and across the UK to follow.

NRAS has written to the Chief Executive of the Trust to raise our concerns. If you would like further information on this, please contact Matt at [matthew@nras.org.uk](mailto:matthew@nras.org.uk).

## Manchester Roundtable

At the time of writing, proposals for a rheumatology roundtable event in Manchester are progressing well, with our Manchester Ambassadors currently working on best practice pathways to present to the attendees. The event will bring together leaders from NHS Trusts in Manchester, Healthcare Professionals and patients to discuss the patient view of a best practice rheumatology service as hospitals in Manchester are preparing to merge.

## Disability Benefits Consortium

In September, following a survey of over 1,700 people with long-term conditions, the Disability Benefits Consortium released a report on Personal Independence Payments (PIP). The survey found that 79% of respondents felt the assessment process for PIP had led to worsening health due to the stress and anxiety caused by the assessments.

You can read the full report via the Campaign section on our website: [www.nras.org.uk/campaign](http://www.nras.org.uk/campaign)

## DBC Disability Benefits Consortium

## Prescription Charges Coalition

2018 is fast approaching, meaning that it is almost 50 years since the exemption criteria for prescription charges in England was last reviewed. The Coalition, which NRAS Co-Chairs, is planning a big year of campaigning to try and get the Government to commit to a review of the list, as NRAS feels that it is unjust that somebody with a long-term condition, such as rheumatoid arthritis, has to pay for their medication, potentially having a detrimental effect on their finances and therefore their health. You can keep up-to-date with the campaigns by following [@prescriptionCC](https://twitter.com/prescriptionCC) on twitter or looking at the website [prescriptionchargescoalition.org.uk](http://prescriptionchargescoalition.org.uk)




**NRAS Christmas Carol Concert**  
**8th December**

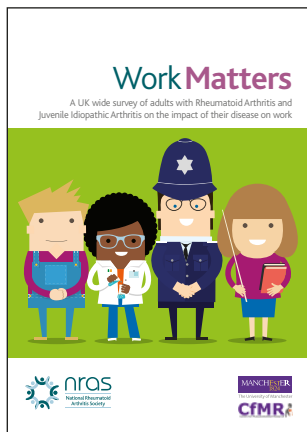
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A celebration of Christmas Music at  
**St Peter's Church, Maidenhead (SL6 7QU) at 7PM**

Please join us for a glass of wine and mince pie at the end of the evening. Our Choir will be *Vocalese*

Free entry with a collection during the evening

More Info on: [www.nras.org.uk/christmasconcert2017](http://www.nras.org.uk/christmasconcert2017)



# Work Matters

On Wednesday 11th October, NRAS launched its new report, *Work Matters*. This followed a survey of over 1,500 people with rheumatoid arthritis and adult juvenile idiopathic arthritis, which many of you will have participated in during June and July



Ailsa Bosworth, Penny Mordaunt MP and Matt Bezzant

The report was launched in Parliament and was very well attended by NRAS Members and Volunteers, Healthcare Professionals, politicians and other stakeholders. The event was introduced by our Chief Executive, Ailsa, who discussed the work survey that NRAS

undertook 10 years ago and what has changed since then.

Penny Mordaunt MP, Minister of State for Disabled People, Work and Health, also attended the event and spoke about the work that the Government is currently doing in this area. You may remember that the Government produced a Green Paper last year on work, health and disability, and the Minister discussed the progress since then as well as the Government's specific goals, such as 'halving the disability employment gap' and getting one million people with disabilities into work. As NRAS is on the Expert Advisory Group of the Work and Health Unit for the Department of Work and Pensions and Department of Health, we will continue to provide the input of our Members right into the very heart of any forthcoming legislation around work and health.

Dr Suzanne Verstappen, Senior Research Fellow at the Arthritis Research UK Centre for Epidemiology, Centre for Musculoskeletal Research at the University of Manchester, who was the primary author of the report, then

discussed the research and methodology behind the survey and report. Particularly striking was that rates of employment had improved since 2007, however retention of employees was still a major issue, particularly as the barriers to retention can often be easily overcome.

Professor Karen Walker-Bone, Director of the Arthritis Research UK Centre for Musculoskeletal Health and Work, who wrote the foreword to the report, spoke about the importance of the research and report produced by NRAS, as well as other focusses on musculoskeletal health and work. A particular emphasis is currently being placed on work as a health outcome, something which our report highlights. Overcoming barriers such as employers making reasonable adjustments to keep people in work will form an important aspect of this.

The report highlights a number of recommendations for NRAS to concentrate on over the coming months and years. One such example is to address the need for smaller employers to understand their obligations when they learn that an employee has rheumatoid arthritis. We will ensure that information is readily available for employers to raise awareness of schemes that are available to help them. This presents a good opportunity for NRAS to work with other organisations, such as the Society of Occupational Medicine, to campaign for better provision.

Another notable finding of the report was the high percentage of co-morbidities amongst people with RA, and specifically mental health issues such as anxiety and depression. In the coming months, with mental health currently high on the political agenda, NRAS will establish how best we can help people with RA who are also suffering from mental health issues.

If you would like to read the report, you can download it or order a free hardcopy version from the website: [www.nras.org.uk/publications](http://www.nras.org.uk/publications).

# How my rheumatoid arthritis has adapted to cope with me



By Dr David Longden



After training, I entered General Practice, where the treatment of rheumatoid arthritis changed very little over the next 35 years until I retired in 2011. We treated patients with different anti-inflammatory drugs similar to ibuprofen and aspirin and only referred to rheumatology when we couldn't control the symptom of pain and deformity. Methotrexate and similar disease modifying drugs were only used as a last resort when symptoms could not be controlled.

During my childhood in the 1950's my mother had severe rheumatoid arthritis. I remember very well the marked deformity of her joints, the wrist splints, the elbow crutches and the pain and suffering she endured. Then, the main stay of treatment were large doses of aspirin. Every year or so she would be admitted to The Devonshire Royal Hospital in Buxton for many weeks to try and help her, the treatment being physiotherapy and wax treatments; she always came home improved but rapidly deteriorated again. At home we had a galvanized mop bucket that was  $\frac{2}{3}$  full of wax, which was heated on the gas stove in the kitchen, and then, when at the required temperature, she immersed her painful joints. My brother and I used the wax to make candles, which one Christmas we proudly put on the tree, the resulting damage was reduced by my quick-thinking father who rushed outside with the burning tree!

During my teen years, my mother's arthritis worsened with markedly reduced mobility, the district nurses visited regularly to give injections of gold or ACTH (an early steroid no longer used).

At the age of 17, I found myself attending an interview at Leeds Medical School as by that time I wished to train as a doctor. I explained at interview about my experiences with my mother and this was well received and I was accepted. I certainly didn't add that it was in equal measure due to watching Dr Finlay's Casebook on a Sunday evening on our black and white TV!

2 years ago, I noticed my grip was poor and after a few months I developed stiffness and swelling in the joints of hands and both knees. I realised it was rheumatoid arthritis and was started on methotrexate and hydroxychloroquine. Once the dose of long acting steroid, which I was given at my first appointment, wore off at about 8 weeks, my symptoms worsened. The dose of methotrexate was increased and remission induced at 6 months.



I do not allow my RA to affect what I do, it has to adapt to me, not the other way round. I continue all my usual activities of walking 50 plus miles a week, backpacking with camping equipment, and fell walking.

My only worry at present is which tent and sleeping bag should I take on my Scottish trip next week 100 miles along the Southern Upland Way; should I take a large tent and sleeping bag heavier, but more comfortable, or take lighter less comfortable equipment? Ah these problems!



By Isabel Madge

# Hi, I'm Isabel



I was diagnosed at 18 months with **Poliarticular Arthritis**, which means that I can flare in more than 3 places at a time. I have had JIA in most of my joints but the places that I flare the most are my knees and my ankles.

I was not really aware of having arthritis until I was 8 years old. This was when I came off my medication for the first time and I flared. When I had this flare, I was in a lot of pain and my mum had to carry me into school every day. I missed out on all of my PE lessons because I could only just walk.

When I got treated for this I had an anaesthetic. This meant I was asleep for my injections and I couldn't feel anything. Unfortunately, this meant I couldn't eat anything until after my injections. This was hard for me because I love food, but this did stop my pain so that was good.

Before that event I didn't know why I was taking methotrexate, but I do now.

When I was first diagnosed I was on oral methotrexate which was the first medication I had along with Embrel. I found methotrexate horrible and it always made me sick. I can only remember my dad giving this to me and him holding a bowl ready for me to be sick into. I now find the colour yellow makes me feel sick because the medication was yellow. I came off Embrel later and went onto injected methotrexate which I preferred much more than having it orally.

The things that annoy me are when you are flaring you can't play sport and I like playing netball and I like to swim. I swim twice a week with a swimming squad and when I flare they adapt what they are doing so I can still join in.

The things I enjoy are drawing, knitting and anything that is creative. I think this is because when I was really little I couldn't run around or do anything outside so I used to sit inside and draw with my friend Betsy.

And that is my story.





# Residential weekend for children and young people with JIA and their families



At the end of September, NRAS held their first residential adventure weekend in Wales to support children and young people with JIA, their siblings and parents and carers. This thrilling adventure weekend was at the Morfa Bay Adventure Centre, a beautiful location next to the famous Pendine Sands and despite the monsoon weather conditions, mud, bunk beds and plastic plates, this weekend was a true reflection of how children and young people with JIA and their families can come together and truly benefit from peer support. Both the children and parents left feeling less isolated, and more informed and empowered.

During the weekend, families had the opportunity to listen to expert advice from Dr Jeremy Camilleri, Consultant Rheumatologist at the University Hospital of Wales, Cardiff, Mrs Jane Willock, Specialist Nurse and Anne Gilbert from NRAS. The information session was relaxed and informal allowing for a lot of open discussion and question and answers, and whilst we were all warm and dry with our coffee and tea, the children were getting absolutely filthy and

thoroughly enjoying themselves on the mud assault course!

All the feedback from parents and children was very positive and encouraging and we would like to take this opportunity to thank the Morrisons Foundation for funding this project. We really would like to offer a similar free residential weekend next year and are already looking at potential sources of funding.

*"It was useful for our daughter to see how active she can be and that JIA doesn't have to limit her abilities."*

*"My daughter was asked at school today what it was like, and she said, 'I didn't have to explain anything, everyone there just knew how it feels' and I think that feeling was understood, it's an amazing gift from you that you have given her."*

*"We were lucky to be able to attend the Family Weekend in Pendine Sands and although Geth knew he wanted to support an arthritis charity, NRAS became the chosen one after such a great weekend. We are also really appreciative of the work you have done in trying to secure a specialist JIA centre at the University Hospital of Wales."*





# Update: Wear purple for JIA

## Considering which JIA projects should be our priority

It's now September and for the past month we have been considering what JIA projects should be our priority. How best to put the money raised to work for the benefit of families affected by JIA? It has not been easy, as of course we think all our projects are worthy and we are keen to start every project as soon as we possibly can. However, we have decided to utilise a large proportion of raised funds on a parents' peer to peer support programme.

NRAS has been supporting adults with RA for over 15 years and we have been offering Volunteer telephone support to those with RA since 2004. The success of the Telephone Support Volunteer service as well as some parents offering to provide a similar service to other mums and dads has prompted us to develop a parents' telephone support service. This provision would mean that parents who are struggling, or have just recently had a child diagnosed, can be matched and receive genuine support from another parent who has experienced similar challenges. Being able to talk to someone on an equal footing who truly understands the day to day obstacles and struggles that may present themselves can be incredibly important in managing family life.

A Telephone Support Volunteer will be able to provide shared experience, emotional, social or practical help to another parent or carer.

The funds will be used to develop an interactive training video which will prepare Volunteers with skills to ensure they have all the tools to effectively support a parent over the telephone.

These include active listening, effective questioning techniques and imparting empathy. We anticipate starting this project at the end of the year.

We have also been able to produce a second animation on transition, which will be published on the JIA@NRAS website shortly. This will be helpful for parents, carers and young people going through the process of moving from paediatric rheumatology care to adult rheumatology care. These animations are so easy to follow and they simply help the viewer to better understand the transition process and, we hope, answer some questions along the way.

A further aspiration is to host an additional event in 2018 based on our annual family fun day in Ilkley, North Yorkshire. We have held a family fun day in Ilkley for the past 2 years and it has been very well attended by JIA families. The success of these family days relies on the fantastic support from local Healthcare Professionals who, in addition to promoting the event, have also provided invaluable JIA education sessions on the day. We will be looking for appropriate venues at the end of this year in the southern half of England. So, if you know of a suitable venue near you let us know.

**Wear Purple for JIA 2018** is on June 8th.

Don't forget to get in touch for your fundraising pack

[fundraising@nras.org.uk](mailto:fundraising@nras.org.uk)



# 2017: A Year in the Life of NRAS

## JANUARY

New Fundraising Guide

## FEBRUARY

NRAS Livery Event

## MARCH

NRAS Dundee Group Launch

## APRIL

New Medicines in RA Booklet

## MAY

David Lloyd Fundraising Challenge

## JUNE

Wear Purple for JIA & RA Awareness Week

Facebook reach: 535,439	Number of tweets: 403	Number of tweets: 4,000	Media coverage: 21 hits
Over 700 #behindthesmile	Over 500 RA Awareness Packs sent out	Total clicks: Over 20,000	Over 600

## JULY

RA Self-Management Pathway Workshop

## AUGUST

JIA Bushcraft event

## SEPTEMBER

Katy Pieris Article in Woman Magazine

## OCTOBER

Work Matters Report Launch

## NOVEMBER

Coming Soon...new App RheumaBuddy

Use the RheumaBuddy app to keep track of everyday life with JIA/RA.

## DECEMBER

NRAS Carol Concert

**NRAS Christmas Carol Concert**  
8th December

A celebration of Christmas Music at St Peter's Church, Maidenhead (SL6 7GU) at 7PM

Please join us for a glass of wine and mince pie at the end of the evening. Our Choir will be Vocafese

Free entry with a collection during the evening

More info on: [www.nras.org.uk/christmasconcert2017](http://www.nras.org.uk/christmasconcert2017)

Friday 8th December	<b>NRAS Carol Concert</b>	St Peter's Church Maidenhead SL6 7QU
Friday 23rd March 2018	<b>Rheum for You, NRAS Conference</b>	The Durham Centre, Durham
Tuesday 17th April 2018	<b>The Gathering, NRAS Scottish Conference</b>	TBC Scotland
June 18th - 24th 2018	<b>RA Awareness Week</b>	Nationwide
Saturday 7th July 2018	<b>London RA Information Event</b>	Holiday Inn, Regents Park
Friday 12th October 2018	<b>World Arthritis Day</b>	World Wide!



## Events Diary\*

March 2018	<b>East of England Family Fun Day</b> For children with JIA and their families supported by HCPs in the East of England <b>FREE event</b>	Fakenham Racecourse, Fakenham, Norfolk
Saturday 21st April 2018	<b>Cheltenham and Bristol Family Fun Day</b> For children with JIA and their families who are supported by HCPs in Gloucester and Bristol <b>FREE event</b>	Cheltenham Racecourse, Evesham Road, Prestbury, Cheltenham
May 2018	<b>JIA and Me Art Competition</b> Open to children with JIA between 4 and 16 years old <b>FREE event</b>	Scotland
Saturday 2nd June 2018	<b>Annual Family Fun Day</b> Open to all children with JIA and their families across the UK <b>FREE event</b>	Nell Bank, Denton lane, Ilkley, West Yorkshire
July 2018	<b>JIA and Me Art Competition</b> Open to children with JIA between 4 and 16 years old <b>FREE event</b>	Nottingham
August 2018	<b>Bushcraft Day in Leeds</b> For young people with JIA aged 10 to 16 years old <b>FREE event</b>	Leeds
August 2018	<b>Bushcraft Day in Oxford</b> For young people with JIA aged 10 to 16 years old <b>FREE event</b>	Cornbury Park, Oxford
September 2018	<b>Annual Family Fun Day</b> Open to all children with JIA and their families across the UK <b>FREE event</b>	Wiltshire

All JIA-at-NRAS events are free programmes – to register, please visit [www.jia.org.uk/events](http://www.jia.org.uk/events)

\*Some of the 2018 events are subject to confirmation

*This magazine is based on currently available knowledge and information provided by third parties that has been accepted in good faith, but has not been verified independently. NRAS cannot be held responsible for any consequences arising from reliance on such information.*

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