Members' MAGAZINE

SUMMER / AUTUMN 2018

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National Rheumatoid Arthritis Society

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By Ailsa Bosworth, MBE

Chief Executive

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** to find out more about joining.

Dear Members

There was a time when summer used to give us a little respite but not in recent years and 2018 is no exception.

The British Society for Rheumatology conference in May was in Liverpool where we launched the new NRAS information packs for the newly diagnosed and for those with established disease. The NRAS stand was buzzing as the health professionals hoovered up the eye-catching resources. The much-anticipated Fatigue Matters booklet (also included in the above packs) flew off the shelves and we had great fun snapping visitors to the stand promoting the ***"Love Your Heart"*** video programme in our Heart Shape Frame.

Amsterdam
13-16 June 2018
eular2018
Annual European Congress of Rheumatology

Following hot on the heels of BSR conference was the annual European conference in Amsterdam in June. The EULAR Congress was host to 14,700 participants from 130 countries. Clare and I were kept busy with various presentations and meetings as well as networking with patient organisations from around the globe. A Canadian patient group showed particular interest in our new resources not having anything like them available in Canada!

On a personal note it was a real struggle for me at both conferences as it had been in for the preceding 6 months or so as my eyesight progressively deteriorated due to my uveitis. I am so grateful for the support of all my NRAS colleagues during this difficult time who have given me fantastic help, especially as with not being able to drive, I've relied on them, particularly my lovely EA Lorraine, to get me to and from the office. Thank goodness for the many technological answers available for sight impairment on mobile phones and pcs/ screens etc. That really did mean I was able to keep going albeit with great frustration at times until my successful operation in July. It was with huge pleasure and great relief when I returned to work that I could once more see all the smiling NRAS staff in sharp contrast!

Getting my independence back by being able to drive again and just being able to see screens and documents (without having them enlarged) was wonderful. RA, as many of you know, is far more than purely joint problems and my recent eye issues have made me very aware of how precious our sight is. I'm eternally grateful to the wonderful health professionals who have restored the sight in my left eye.

Other good news is that Emma Sanders who many of you will have spoken to over the years when renewing or taking out membership, had a bouncing baby boy, Alfie, in April. Alfie was in a great hurry to join the world as he arrived about 4 weeks early, taking us all, including Emma, by surprise.

Congratulations to Emma and her husband Adam. While Emma is away on maternity leave, Tracy Bacher, who joined NRAS recently, will be looking after all your membership queries.

We have a very busy autumn ahead of us with lots of activity and projects including the launch of our major report on emotional and mental health on Nov 1st in parliament. I'd like to thank all those who took the time to participate in our survey on this important subject. We had a tremendous response and I think this will be a landmark report which we look forward to sharing with you all.

Ailsa

Members'
MAGAZINE

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

Editors of this issue;
Clare Jacklin & Michele Le Tissier

Christmas Gift NRAS Membership

Not a fan of Christmas Shopping? We have the perfect solution.

Avoid the crowds and start your Christmas shopping early by giving the gift that lasts all year.

If you have a family member or friend who lives with rheumatoid arthritis (RA) or juvenile idiopathic arthritis (JIA), why not consider buying them a gift NRAS Membership? For just £25 for the whole year, they will receive all the benefits of Membership plus a gift card which has a 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 are interested in Gift Membership then please call Tracy on **01628 823524** or visit **www.nras.org.uk/gift-membership** to print off the Gift Membership form.

With this issue you will also have received details of the **NRAS 2018 Christmas Cards**. They sold out very quickly last year, so be sure to order yours early to avoid disappointment.

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Special introductory membership offer

NRAS Membership for a friend or relative

If you are introducing a friend or relative with RA to NRAS, they can benefit from a special introductory offer of just £10 for the first year when paying by direct debit. If you recommend a friend, as a thank you we will send you either an NRAS Lapel Badge or NRAS Wristband, whichever you prefer. Call us on 0845 458 3969 or email us at membership@nras.org.uk

Opt in to NRAS

Do you want to make the most of your NRAS Membership? Naturally the answer is YES!

Then please update your communication preferences with us. We will then be able to keep you up to date on developments in rheumatology treatments, all the latest NRAS news, give you the opportunity to have your say on policy issues and participate in research studies and focus groups to shape the future of services and treatments. Opt in or miss out!

Don't get left out!

You need to opt-in! ☑

The law changed on 25th May, now everyone **MUST** opt in. We need you to tell us **WHAT** information you want and **HOW** you want to receive it.

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National Rheumatoid Arthritis Society

Don't miss out on everything that NRAS has to offer!

Don't Delay Connect Today

A 185-mile cycle challenge to raise funds and awareness

The EULAR Don't Delay, Connect Today campaign visited the Western Isles of Scotland in May raising funds for NRAS and public awareness of MSK conditions, ending at the far North-Western tip of Europe, the Butt of Lewis.

Organised by the University of Glasgow, a 185-mile cycle challenge took the intrepid, but very well prepared team across 10 of the outer Hebridean islands in a variety of weather! Public engagement and awareness raising events at popular tourist landmarks such as Callanish Standing Stones and local towns Stornoway and Tarbert were held along the way. A short film was made to illustrate the campaign (link below).

The Rheumatosphere team includes consultant rheumatologists, academic clinicians, scientists, PhD students and public engagement professionals from the Glasgow Science Centre, and John and Helen Paton from NRAS in Scotland gave the patient insight at the public engagement events.

The aim was to engage with those who would not normally have the opportunity to talk to rheumatology specialists or scientists, at public engagement events, due to their geographical location. Through this engagement they highlighted the importance of identifying early signs of musculoskeletal disease along with early treatment, hopefully encouraging people to connect with the rheumatology services if they suspect they have symptoms of a rheumatological nature.

Very many thanks to Rheumatosphere who raised over £3,450 for NRAS

Watch the video at **www.youtube.com/watch?v=A1lZHrkMFzE**

Pharmacy2U

An easier way to manage your NHS repeat prescriptions

Stress-free prescriptions and a superb service.

Pharmacy2U believe that when it comes to looking after your health, life should be a little bit simpler. Established in 1999, their founding pharmacists set out to provide a simple to use service which provides an easier way for patients to get their NHS repeat prescriptions in England.

This refreshing approach is perfectly suited to help those with:

- Restricted mobility
- Limited access to a high street pharmacy
- Busy lifestyles or a desire to spend less time collecting their prescriptions from their pharmacy

Such a patient-focused ethos has seen Pharmacy2U grow to become the UK's largest NHS online pharmacy, currently helping a growing community of over 150,000 patients get their medication.

An experience designed around patients

Here's how the Pharmacy2U NHS repeat prescription service can help patients manage their medication:

- Patients can order their medication from anywhere, at anytime
- Free delivery with Royal Mail to anywhere in the UK, including your home, place of work or to a safe place or neighbour
- Handy reminders so patients never run out of medication
- Tailored delivery preferences to fit around their lives

It's this modern service which 93% of patients have rated as being 'excellent' or 'good'. 89% of patients also found it more convenient than ordering and receiving their medication in the traditional way .

Here's what their patients think of the service

"I can't stand hanging around, that's why Pharmacy2U has changed my life. I need regular medications for my back pain and blood pressure and going to the doctors to pick up my prescription every month and then waiting in a queue to get it dispensed was such a waste of time. It's brilliant - all I have to do is phone the automated system, using a special device that operates the phone via my hearing aid. Stress-free prescriptions and a superb service."

Tony Mercer, Pharmacy2U Patient

"I used to have a 16 mile trip to my GP every month to request my repeats, and then I had to go back a week later to pick them up. In my job, it was a struggle to find the time. Now I get a reminder from Pharmacy2U before my prescription runs out. All I do is go on the internet and tick the drugs I need, and they get delivered in three or four days."

Phil Green, Pharmacy2U Patient

The Electronic Prescription Service

At the heart of the experience is the NHS Electronic Prescription Service (EPS), which Pharmacy2U worked closely with the NHS to help pioneer over a decade ago.

Pharmacy2U can be 'nominated' (chosen) by patients in England, to manage their repeat prescriptions for them. Once the simple registration process has been completed, they are then able to dispense and deliver the patient's repeat prescriptions from their state-of-the-art, award-winning facility in Leeds.

For long term conditions where the same treatment is typically prescribed on a regular basis, this helps patients cut down on unnecessary visits to the GP. Simply put, a team of qualified pharmacists will work closely with your GPs surgery to manage your NHS repeat prescriptions – saving you time and money in the process.

Helping frontline NHS services

43% of the UK population currently receive a repeat prescription, costing the NHS £8 billion each year . It is estimated that ordering these online can save the NHS over £300 million a year on prescription costs .

It is important to note that ordering online does not cause any additional work for your GP surgery and can actually save them around 6.5 hours of crucial time each month . This frees up valuable time for GP's, surgery staff and high street pharmacies to provide crucial clinical care to patients suffering from acute conditions.

Your GP will retain full control throughout the process. Your medication reviews are still managed by your GP and one-off prescriptions can still be processed through a nearest high street pharmacy.

New type of pharmacy, same high standards

Pharmacy2U are regulated and subject to inspection in exactly the same way as high street pharmacies. This means your repeat prescriptions are in the safe and qualified hands of a team of friendly pharmacists, who are always just a phone call or email away to answer any queries you may have regarding your treatment.

Cancelling or changing your nomination

9 out of 10 of our patients tell us they would recommend us to their friends and we hope all of our patients feel the benefit of our service. However, if for any reason you decide the service is not for you, just call or email us and Pharmacy2U will update your records instantly.

Register today

So why not make your life that little bit easier with Pharmacy2U? Register today and join a growing community of over 150,000 patients at **www.pharmacy2u.co.uk/NHS**

> *All I do is go on the internet and tick the drugs I need, and they get delivered in three or four days.*

Are you remembering to renew your prescription prepayment certificate (PPC)?

We've had a couple of calls lately from people who had been caught out when they didn't receive a reminder by email or post to renew their PPC. This doesn't seem to be affecting everyone, but can result in a fine. We would therefore suggest that if you pay for a PPC, it is worth setting a reminder in your phone or on your calendar for when the renewal is due.

For those of you who are unaware of what the PPC is, the NHS describe it as being like a 'prescription "season ticket"'. If you pay for more than 12 prescriptions a year, you will save money by purchasing a PPC, costing £104 in a single payment, to cover you for a year. If this is too much money to spend in one go, a 3 month PPC is also available, costing £29.10, and will save you money if you need more than 3 prescriptions in those 3 months.

NHS Prescription Prepayment Certificate

NHS

Certificate No: 10109572718

Name:

Valid From: 01/06/2018

Expires End: 31/05/2019

RA, stress and the autonomic nervous system

A chicken and egg conundrum?

By

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Most people living with RA find that it adds some degree of stress to dealing with their life on a day to day basis. But interestingly, when we as rheumatologists listen to our patients in the clinic, many feel not only that stressful events worsen their RA disease activity but even attribute the onset of RA to prior stressful events. NRAS has recently conducted a major UK wide survey to evaluate emotional wellbeing and mental health including psychological stress as a factor affecting patients with rheumatoid arthritis. Their report of the survey results will be launched in parliament on November 1st, 2018.

Similarly, over the past few years, researchers in the UK, Amsterdam and the US have focused attention on the science behind this question. At the May 2018 annual meeting of the British Society for Rheumatology in Liverpool, the findings of new studies were presented which may have begun to shed further light on this conundrum.

Defining "immuno-autonomics"

This brain-stress-immune concept has been recently called "immuno-autonomics". It is the interface between stress, modulated within the brain by the autonomic nervous system (ANS), and functioning of the immune system. The ANS is an integral and relatively primitive subsection of the central nervous system (CNS) responsible for all automatic functions, including cardiovascular (heart rate, blood pressure), breathing, digestion, temperature regulation, sleep and fight-or-flight survival (adrenaline). It coordinates with production of hormones by the endocrine system (pituitary, thyroid and adrenal hormones) to manage any threats to wellbeing from outside the body or within it. While the endocrine system acts slowly, the ANS responds in milliseconds.

In general, the ANS is divided into two components: the sympathetic (fight-or-flight) and the parasympathetic (rest-restorative). At night during sleep, the parasympathetic system predominates and when physical and mental performance is called upon, the sympathetic system is aroused. When one component is more active, the other is less so, and the relative balance changes depending on time of day, activities and bodily needs.

For any given person, their ANS tendency towards a sympathetic or parasympathetic predominance is controlled by genetic factors, life experiences and immediate events, such as exercise, meals and stimulants, such as caffeine. Stress intensifies the sympathetic component. Activities of healthy living activate the parasympathetic system, such as moderate exercise, a healthy diet, avoiding stimulants and nicotine, meditation, massage, acupuncture, cognitive behavioural therapy, mindfulness and other relaxation techniques.

Measuring the ANS state

The state of the ANS, and relative sympathetic versus parasympathetic activation, cannot be conveniently measured directly within the brain or the bloodstream. However, it can be quantified through assessment of its impact on one of the organs whose function it influences this is most often the heart. Resting pulse is controlled not necessarily by the heart itself, but in large part, by the brain, specifically the ANS.

Of course, resting heart rate is not static. For example, a resting pulse of 72 is not really a steady 72. It varies by milliseconds due to varying chest cavity pressure related to breathing, called respiratory sinus arrhythmia. This benign 'arrhythmia', or changes in rhythm, lead to a beat-to-beat heart rate variation. This is called heart rate variability (HRV) and is the most practical way to measure the state of the ANS.

The phenomenon of HRV has been recognized for hundreds of years. But it is only more recently, over the last sixty years, that the complex mathematical assessments required to accurately quantify the ANS state have been refined. In fact, the Russian and United States of America space programs have applied HRV to measure and improve human performance to survive the extreme physiological challenges of space travel.

As a result, assessment of the ANS state has become an essential guide for training. Today, elite professional athletes and Olympians train with the most effective and very best performing tools to measure the ANS state. On the other hand, for patients, there have only been a few available options with the accuracy required for measurement of HRV for the purposes of medical research and optimizing care, usually in cardiovascular medicine. By contrast, most consumer-grade means of measuring HRV, for example, in cell phones, apps, Fitbit, etc., offer only limited reliability.

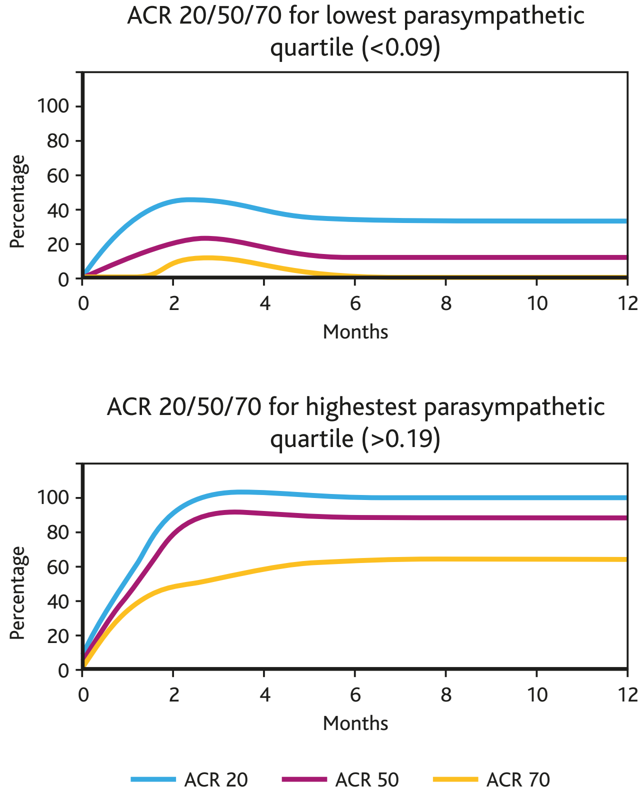
Rheumatoid arthritis and stress

Inflammation caused by RA affects the brain and emotional wellbeing. By studying the relationship between RA disease activity and mental and emotional wellbeing, we can investigate how RA influences mental health and the ability to respond to stress. But with the availability of a tool that can measure the "stress thermostat" setting in the body through accurate measurements of the ANS state, we can begin to explore to what extent stress can independently impact on RA disease activity.

Clinical research has showed that the best outcomes from anti-TNF treatment (etanercept or adalimumab) were associated with those people with RA and a parasympathetic predominant profile by HRV in a 52-week, double-blind, clinical trial. Patients within the highest parasympathetic quartile achieved ACR20/50/70 outcome at 52-weeks of 100%/88%/65%. Those in the lowest parasympathetic quartile when initiating TNFi therapy achieved ACR20/50/70 outcome at 52-weeks of 40%/12%/0% (Figure 1). (ACR is the American College of Rheumatology and the numbers indicate the percentage, 20%, 50% or 70%, improvement that can be measured following an intervention. ACR20/50/70 are standard measures applied in clinical trials).

At the 2018 annual meeting of the British Society for Rheumatology in Liverpool, a study asked the question: "To what degree is anti-TNF outcome affected by factors rheumatologists can measure?" Traditional factors (rheumatoid factor, age, disease severity, gender, HAQ (Health Assessment Questionnaire), etc.) only explained 15% of the variability of treatment outcome. In contrast, and impressively, 35-60% of the variability in anti-TNF outcome at 52-weeks could be accounted for by measures of parasympathetic activity by HRV assessed over just 5 minutes.

These interesting observations suggest that higher stress levels might diminish the chances of responding well to treatment. But which came first: the stress or the RA? Frieda Koopman at the University of Amsterdam offered a suggestion in 2016. Her team monitored patients 'at-risk' for developing RA with factors such as positive blood tests, family history and joint aches (without inflammation). Over 32 months, 31% of at-risk individuals developed RA. An important risk factor was HRV high stress sympathetic state.



The future

Stress matters! New research will confirm or refute these early findings, however, investigators in the US and UK are also working on what is potentially an entirely new way to treat RA by using electrical pulses to optimize the ANS state of the body; resetting the stress thermostat, as it were. Parasympathetic signals influence the immune system through the vagus nerve. Pilot research to date has shown that stimulation of the vagus nerve reduced RA severity by 35%. This seems to work by reducing inflammatory cytokine levels – the same inflammatory cytokines, TNF, IL-1 and IL-6, that rheumatologists prescribe biologic agents to block.

Treating a clinical condition called obstructive sleep apnea with continuous positive airway pressure (CPAP) in a person who also has RA resulted in a 35% reduction of RA joint count and CRP after 5 months. Obstructive sleep apnea is the best studied condition known to be associated with ANS dysfunction. CPAP, when effective, restores normal ANS state and reduces some of the risks of obstructive sleep apnea. Very preliminary evidence also suggests that treatment of restless legs syndrome, which is thought to be associated with a high sympathetic state, could also enhance the outcome of anti-TNF treatment.

Conclusion

Of course, all early medical research studies should be viewed with caution. Immuno-autonomics is a new concept and additional validating research from independent sources will be required prior to drawing conclusions. However, we do know that stress does indeed affect many diseases such as heart disease, for example, and cardiologists are concerned to reduce the impact of stress on their patients. Now, with the development of immune-autonomics rheumatology researchers are beginning to explore how measuring and managing ANS stress might help their patients, too.

By Jennie Jones

NRAS Trustee

Updated NICE Guideline

for the Management of RA in Adults
July 2018 – Summary of key points

A partial update of the first Guideline (2009) has been published by NICE after a 15month review. Although not mandatory, the advice given by NICE is highly influential in setting standards for care that should be available to all with those with RA in England and Wales. Ailsa, CEO of NRAS and Jennie Jones, NRAS Trustee were lay members of the committee.

NICE provides evidence based guidance and this is increasingly based on Random Controlled Tests (RCTs), but in addition, since the first review, the internationally accepted methods for systematic reviews and appraisal of clinical evidence adopted by NICE has changed. The focus on RCT data and this new approach has lead to some of the changes/clarifications in the revised Guideline. This highly specified and detailed process does have its frustrations! Frank McKenna, the Rheumatology Lead on the Guideline Committee said,

'Although I have been involved in most other aspects of NICE's work it has been my first experience of the rigorous approach NICE take towards a guideline. I think it has been an eye opener for many of us. It also means that we can be assured that this approach has led to a solid foundation of the guideline and is truly supported by data rather than opinion. I am very thankful to all the committee for your individual and collective contribution to the project. Everyone took ownership and made invaluable contributions and I think we can be proud of the outcome'.

Main changes in the new Guideline around referral, diagnosis and use of ultrasound

Referral

The main message to refer without delay is maintained in the revised Guideline, but in addition to suspected synovitis in the small joints of hands and feet, more than one joint being affected, or there had been a delay between symptoms starting and seeking medical advice of three months or more, it was also added that an urgent referral should be considered even if blood test results revealed normal inflammatory markers (CRP,ESR) or were negative for anti-CCP antibodies or rheumatoid factor. From a patient perspective this is an important message for GPs and should reduce some patients having referral delayed.

Diagnosis

The first Guideline did not specify which patients were more likely to be at risk of greater radiological progression and whether they should be treated differently as a result. Identification of this group of patients at the earliest possible stage was highlighted as key and evidence showed that the presence of anti-CCP antibodies and radiographic change were the important factors that indicate poor prognosis. Patients should expect to be sensitively informed if they are identified as having a poor prognosis to help them understand and participate in decisions about their treatment and disease management to improve outcomes. The need for patients to be told of the availability and importance of rapid access in the event of flares to avoid damage was re-emphasised.

In addition, establishing functional ability of all patients at diagnosis through the Health Assessment Questionnaire (HAQ) is proposed to establish a baseline at the start of treatment to help assess the response to treatment at annual review.

Ultrasound

The role of ultrasound in the diagnosis of RA for all patients was reviewed, and there was a lack of RCT data on the effectiveness and value of using ultrasound compared to the range of tools used in usual clinical assessment of RA. The evidence also did not support the use of ultrasound for routine monitoring. The lack of available data led to a recommendation being made for further research to quantify the value of ultrasound for all diagnoses. The Guideline acknowledges that ultrasound was most likely to be of benefit in diagnosing a sub-group of people with suspected RA but with no identified synovitis and also may assist in helping patients understand their diagnosis and improve some patient outcomes.

Treat to Target Strategy and Monitoring

The concept of the Treat to Target strategy was introduced in the 2009 Guideline. The new Guideline confirms that Treat to Target is more effective than usual care and recommends to consider making the target 'remission' (a Disease Activity Score of less than 2.5) rather than low disease activity (a DAS of less than 3.5) for people with an increased risk of radiological progression (presence of anti-CCP antibodies or erosions on X-Ray at baseline assessment). Treatment should be agreed with each patient in a shared process. The Treat to Target approach involves monthly appointments for newly diagnosed patients until the agreed target is reached (rather than most common 3 monthly appointments) am it was identified as being essential to achieving rapid and sustained disease control and improved patient and clinical outcomes. The frequency of monitoring once the target is reached was recommended at 6 months followed by annual review, with patients having rapid access to care in the event of flares or adverse events.

Where the target has been sustained for at least one year without the use of glucocorticoids, consideration may be given to reducing or stepping down drug therapy, but if the target is not maintained the DMARD (disease modifying anti-rheumatic drug(s)) regime should be re-established. The need for rapid access to the rheumatology team when a patient is experiencing a flare, information on how to access specialists and ongoing drug monitoring is maintained as part of the T2T approach.

The expectations of the content of the annual review, in addition to assessing disease activity, function, co-morbidities, etc was also extended to understanding how the disease impacts the life of the patient. The non-pharmacological management section of the guideline, i.e. psychological interventions, confirms help should be offered to those with RA to adjust to living with their condition and reference is helpfully made to another Guideline published by NICE on Depression in Adults with Chronic Physical Health Problems.

Initial Drug Therapy

First Line cDMARDS (Conventional DMARDS)

As previously outlined the research data available for the 2009 Guideline did not meet the requirements of the revised approach adopted by NICE, and some of the drugs reviewed at that time are now no longer recommended for treating RA. Hence the new recommendations are that treatment with one DMARD at a time (Monotherapy) can be used with no clinical differences being identified between this and combination therapy. A step up approach (adding another DMARD) was supported by the evidence that when there is inadequate response to the treatment on monotherapy. During the revising of this Guideline treatment strategy was also considered by looking for any evidence of which DMARDS were most effective, but no conclusive evidence was available to choose between any one of the oral DMARDS i.e. methotrexate, leflunomide or sulfasalazine. Hydroxychloroquine was the exception and was recommended only as a first line treatment for those with mild or palindromic disease (palindromic rheumatism (PR) is a rare episodic form of inflammatory arthritis - meaning the join pain and swelling come and go. Between attacks, the symptoms disappear and the affected joints go back to normal, with no lasting damage). Further research was recommended into the effectiveness of injectable methotrexate rather than oral dose, as robust evidence meeting the new NICE evidence criteria was not currently available when this review was carried out.

Symptom Control

Steroids – glucocorticoids

After reviewing the available evidence, the new Guidance re-confirms that contained in the 2009 Guidance, i.e. to consider short term glucocorticoid treatment to rapidly improve symptoms as a 'bridging treatment' to offer symptom relief to patients during the period needed for DMARDs to become effective and provide anti inflammatory effect. The recommendation was broadened to include all patients starting a new DMARD therapy rather than just those who are newly diagnosed. Long term use of steroids should only be considered after all other treatment options including biological and targeted synthetic DMARDs have been exhausted, and only then following a discussion with patients of the potential complications and side effects.

Pain Relief – Analgesics

The 2009 recommendations remain unchanged, namely that analgesics other than NSAIDS are to be avoided for long term use. The availability of data on the effectiveness of different types of analgesics in RA was reviewed and its quality was problematic, so no clear alternative recommendations or clarifications could be made. The current choice of analgesic according to individual effectiveness and the patient's risk profile, tolerance and side effects was upheld, especially as NSAIDS were not suitable for everyone because of contraindications.

After assessing an individual's situation, NSAIDS (including traditional NSAIDS and COX II inhibitors) may be considered for use where pain and stiffness control is not adequate. The lowest dose should be utilised for the shortest possible time and use of a proton pump inhibitor should be offered. Regular review of risks and adverse events should take place.

For the full revised Guideline visit:
www.nice.org.uk/guidance/ng100

NICE National Institute for Health and Care Excellence

Nicola and Megan Bennett

Celebrating JIA Fundraisers

On 20th June 2018, NRAS held an event in Parliament to celebrate some of our fantastic fundraisers who have raised money for JIA at NRAS

Freya Teal – Howard, Harriet Teal-Howard, Phoebe Teal-Howard

Andrew and Tamsin Gosney with Mum Helen

JIA is an autoimmune disease which causes inflammation in the joints, although it can also affect the eyes and other organs. There are approximately 12,000 children in the UK with JIA, which represents 1 in every 1,000 children under the age of 16. This equates to approximately 15-20 children in each UK parliamentary constituency. There are approximately 1,200 new cases of JIA diagnosed each year in the UK.

Families from across the UK came to Westminster for a reception, with speakers including the Shadow Minister for Children and Families, Emma Lewell-Buck MP and Professor Lucy Wedderburn, Consultant at Great Ormond Street Hospital.

Across the next few pages are just some of the photos of the from the event. You can see them all at **facebook.com/jiaatnras**

The Shadow Minister for Children and Families giving a talk about how policy changes can help to support young people with JIA and their families.

Polly Stonehouse with Mum Andrea

Frey Evans with Mum Sara

Lauren Edmonds with Mum Victoria

A number of MPs came to visit the children with JIA and their families.

The children and families all met prior to the event for a photo in Parliament Square

Ailsa Bosworth giving a prize to Emmie Smith

Fiona Bruce MP meets her constituents from Congleton

Sienna Chamberlain and Dad, NRAS' Bronwen Cranfield

Sophie Carr with Mum Jo and Ailsa Bosworth

Tan Dhesi MP meets his constituents from Slough

Martin Vickers MP meets his constituents from Lincolnshire

Alec Perry

Many MPs were surprised to hear that children could get 'arthritis'.

Paul Farrelly MP meets his constituents from Newcastle-under-Lyme

Stephen McPartland MP meets his constituents from Stevenage

Clara and Imogen Jordison

It was incredibly pleasing that so many of the MPs that visited pledged to support their constituents with JIA.

Finlay Richardson and Millie Kirby

Colin Clark MP meets his constituents from Gordon, Aberdeenshire

Molly How

Many of the families who attended had been raising funds and awareness through the 'Wear Purple for JIA initiative'.

Heidi wearing purple for 'Wear Purple for JIA'

Farah receiving her award from Ailsa Bosworth MBE, Chief Executive of NRAS

MP Ed Miliband

The 'Wear Purple for JIA' initiative was started by Lynette, whose daughter Farah has JIA.

High-profile MPs, such as Ed Miliband, also got involved in raising awareness by wearing purple.

James, who has done a fantastic video about living with JIA, met this MP in Parliament.
Watch the video here: **www.youtube.com/watch?v=yphkMhMdJdg&t=2s**

James meeting his MP, Damien Moore

Robert Courts MP meets his constituents from Oxfordshire

Wera Hobhouse MP meets her constituents from Bath

Feedback from the event has been great, with many of the families enjoying their day in London and their time in Parliament.

Thank you so much to all of our amazing fundraisers!

Choosing Wisely

Rheumatology Recommendations

By **Karen Staniland**

RA Patient and contributor to the recommendations

National Launch event for Choosing Wisely hosted by the Academy of Medical Royal Colleges, L-R Margaret Gould, BSR; Joyce Fox, patient contributor; Karen Staniland, patient contributor; Dr Lizzy MacPhie, Consultant Rheumatologist, Jill Firth, Rheumatology Consultant Nurse; Dr Charlotte Sharp, Trainee Rheumatologist

ChoosingWisely UK

I was delighted to be approached to join the working group which was tasked with developing the British Society for Rheumatology's (BSR) Choosing Wisely UK recommendations. As a patient with rheumatoid arthritis, I have been involved with a variety of patient participant groups over the past two years, for example, Cloudy with a Chance of Pain study; QUASAR sleep in RA study, REMORA1 and the DEPEND studies. I have learnt that experience as a patient provides a radically different perspective on any impact into such studies and I believe that co-design with patients, supported by PPI groups, significantly and positively shapes such projects and campaigns.

What is Choosing Wisely?

Choosing Wisely is a global campaign which aims to reduce unnecessary tests and treatments for patients. It has arisen in response to the recognition that having tests and treatments is not always in a patients' best interests, and that they may, unintentionally, cause harm.

Individuals differ in how much or how little medical intervention they like, and this campaign aims to empower patients and clinicians to make sure that care for patients is personalised and agreed through shared-decision making. Medical organisations, including the BSR, were invited to identify a list of treatments and procedures used in their specialty that are of questionable value and whose use should be discussed carefully with patients. Patients are being encouraged to use the BRAN acronym to ask their doctors and nurses the following questions about any proposed test or treatment:

What are the **Benefits?**

What are the **Risks?**

What are the **Alternatives?**

What if I do **Nothing?**

How were the British Society for Rheumatology's Choosing Wisely UK recommendations developed?

The BSR's list of recommendations was developed by a working group which included patients, rheumatologists, nurses, immunologists and a GP. As patients, we were equal members of the working group, participating in each stage of recommendation development. In brief, everyone was invited to suggest topics, and we then voted to come up with the top six. I devised the wording for the recommendations in a subgroup which then fed-back to the rest of the working group. Evidence summaries were collated by teams of experts within the group. Finally, we sought advice from experts from specialties also affected by the recommendations, (for example, endocrinologists, the Royal College of General Practitioners, and orthopaedic surgeons). The recommendations were endorsed by the BSR and the Choosing Wisely Committee. We were invited to a launch event in June, attended by influential clinicians, policymakers, patient representatives and charities. Dr Charlotte Sharp, who led the recommendation development, was invited onto a panel in recognition of our thorough and inclusive process.

How might these recommendations affect people with RA?

One recommendation focusses specifically on rheumatoid arthritis (RA). It highlights the importance of early referral for patients suspected of having RA, and that there is no single blood test which can determine whether someone does or does not have RA. Our other patient-facing recommendations may all be relevant to patients with RA. One highlights the need for everyone to take vitamin D during winter, explains who should take a supplement year-round, and that only a minority of people might benefit from vitamin D testing. Patients who take bisphosphonate medication, which help reduce fracture risk due to bone thinning (osteoporosis) are advised to discuss this with their healthcare professional every 3-5 years. This has already had an impact for me – I was on a bisphosphonate for 10 years without it ever having been reviewed, and as a result of this process I raised it with my GP, who was happy to review it. A DEXA scan showed that my bone density (a marker of bone strength) is now normal, so I am having a break in treatment for 2 years. Finally, it is recommended that patients with non-inflammatory musculoskeletal conditions, such as osteoarthritis, should have a conversation with their healthcare professional before accepting steroid injections, and that this discussion should include the risks, benefits, and alternatives such as exercise and physical therapy.

These recommendations for both patients and healthcare professionals are on the Choosing Wisely UK website. The full Patient Health A-Z covers a range of other conditions which may also be relevant to patients with RA. Being involved developing the British Society for Rheumatology's Choosing Wisely UK recommendations was a great experience for me and gives me faith that they are representative and inclusive of patients, as well as clinicians', views. **www.choosingwisely.co.uk**

Choosing Wisely UK Rheumatology Recommendations

Topic	Our Patient Recommendations
Rheumatoid Arthritis	If a doctor suspects that you have rheumatoid arthritis, it is recommended that you are referred to rheumatology without delay, even before any tests are done. There is no single blood test which can determine whether someone does or does not have rheumatoid arthritis.
Vitamin D	It is important for everyone to take Vitamin D supplements during winter. If you have restricted access to sunlight (e.g. if you live in a care home or cover your skin), or have dark skin, it is recommended that you take a supplement all year round. Vitamin D testing is unlikely to be useful or necessary in most people and future testing is not normally needed for those taking supplements.
Osteoporosis	Bisphosphonates are drugs that help reduce fracture risk due to bone thinning (osteoporosis). People who take bisphosphonate treatment should discuss this with their healthcare professional every 3-5 years because it may be advisable for some to have a break in treatment.
Steroid injections	It is recommended that you have a conversation with your healthcare professional before accepting steroid injections for non-inflammatory musculoskeletal conditions. So that you make an informed decision, this discussion should include the risks, benefits, and alternatives such as exercise and physical therapy. Although some people may experience short term benefit, there are potential long-term risks with repeated injections.

Dear Helpline

Why are the feet not included in DAS28?

I recently had my disease activity score (DAS28) evaluated for the first time and was surprised to find that my feet were not used in the 28 joints they examined. For me, my feet are one of the worst-affected areas, and I thought this was quite common.

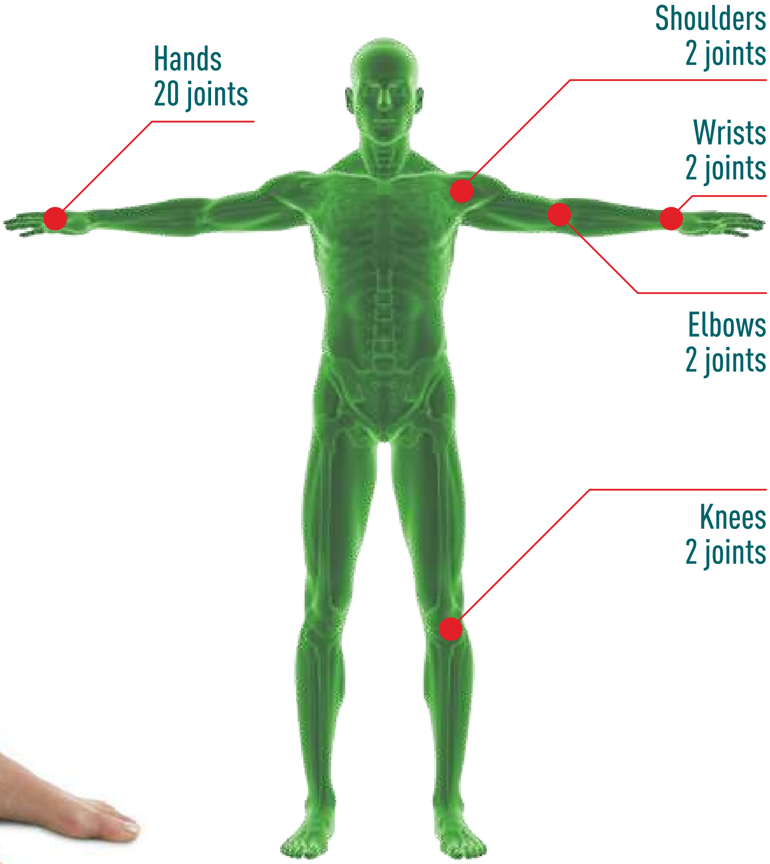
This is a question people often ask us, as the smaller joints, in the hands and feet, are the most commonly affected in RA, so it can seem strange that the feet are not included when DAS is calculated.

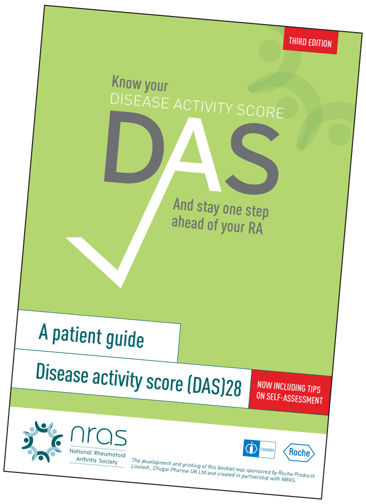
For those of you who may not have heard of DAS28, DAS stands for 'disease activity score' and is a method used by rheumatology teams (often performed by the specialist nurse) for evaluating the severity of your RA (with a higher DAS indicating more active disease). The '28' stands for the number of joints which are used in the calculation, which are examined for signs of tenderness and swelling. Points for tender and swollen joints are added to information from blood tests and an overall health score, and are put into a calculation to produce your DAS.

There have been other versions of DAS, including one called 'DAS44', which includes the joints in the feet. When this was compared in studies with a version called 'DAS28', which did not include the feet, the outcomes to the overall disease activity score were not found to be significantly different overall.

The feet are also a harder area of the body to examine effectively, as this often involves removing shoes/socks and the joints in the toes are very small, which makes it harder to assess them for inflammation. It was therefore concluded that DAS28 would be a more effective measure, easier for clinicians to carry out and not detrimental to the overall results, and this is why it is the standard measurement currently used for disease activity.

For more information about DAS 28 you can request the Know Your DAS booklet for free from NRAS and/or download the 'app' to measure and keep track of your own disease activity scores.





THIRD EDITION

Know your
DISEASE ACTIVITY SCORE
DAS
And stay one step ahead of your RA

A patient guide

Disease activity score (DAS)28

NOW INCLUDING TIPS ON SELF-ASSESSMENT

nras
National Rheumatoid Arthritis Society

The development and printing of this booklet was sponsored by Roche Products Limited., Chugai Pharma UK Ltd and created in partnership with NRAS.

Roche

Dear Helpline

Until I was diagnosed I thought that 'arthritis' was just something that old people get.

Until you or someone close to you is diagnosed with rheumatoid arthritis (RA), unfortunately this is most people's perception of the disease. This is, at least in part, because many people, including some healthcare professionals still refer to 'osteoarthritis' as 'arthritis'. So what's the difference?

Osteoarthritis (OA) is by far the most common type of arthritis. There are over 200 forms of arthritis, and the word arthritis simply means 'inflammation of the joint'. The reasons for that inflammation, however, varies between the different forms. In the case of osteoarthritis, the cause is 'wear and tear' of the joints, making the condition more common among the older population, though it is possible to get it earlier in life, especially in a previously damaged joint. Rheumatoid Arthritis (RA) is an auto-immune condition, meaning that the immune system, normally there to protect us, is attacking healthy tissue, in this case the lining of the joints. It can occur at any age, though the onset is commonly between the ages of 40 -60, and the exact causes of this immune response are unknown, though we do know that genetics and environmental factors play a part.

One third of people over the age of 45 in the UK have sought treatment for OA, whereas RA affects a much smaller number, at around 1% of the UK adult population.

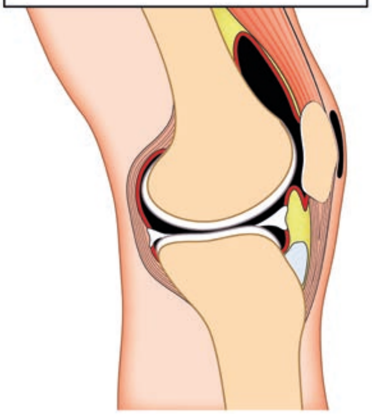
Rheumatoid arthritis is a 'systemic' condition, meaning that it has an effect on the body as a whole, whereas osteoarthritis tends only to affect individual joints. Both can cause symptoms such as pain and stiffness in the joints, but rheumatoid arthritis can also cause systemic symptoms, such as flu-like symptoms and fatigue. The stiffness that occurs in the joints also differs between the conditions. In OA this symptom often occurs towards the end of the day, after using the affected joint, whereas in RA the stiffness is worse after periods of inactivity, especially in the morning, when it can be severe and last for more than thirty minutes.

There are also differences between the joints affected by these two conditions. RA tends to affect joints symmetrically, most commonly the small joints of the hands and feet. Multiple joints may be affected, sometimes simultaneously, whereas OA will be isolated to individual joints. OA can affect the lower parts of the spine, and the finger joints closest to the nail beds, both of which are areas of the body rarely affected in RA. RA can affect different joints at different times, whereas OA doesn't come and go, although pain and stiffness may fluctuate.

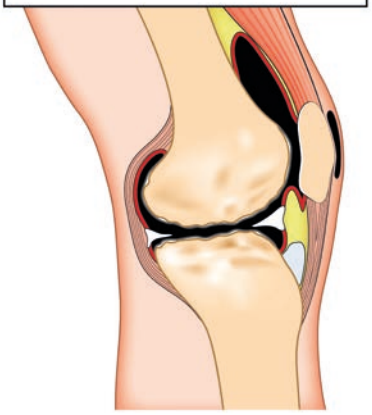
With all these differences in cause, progression, symptoms and location in the body, it is understandable that these conditions are also treated very differently. RA tends to be treated in secondary care, whereas osteoarthritis is normally managed by the GP. While both conditions can benefit from symptom relief, using painkillers and anti-inflammatories and non-medicinal relief, such as hot or cold packs applied to painful joints. Drugs known as disease modifying anti-rheumatic drugs (DMARDs) are used to try to stop RA worsening, by dampening down the over-active immune system.

Let's face it. There is no 'good' form of arthritis to get, but it can be frustrating telling people about your diagnosis and having it so commonly mistaken for a more common and often less severe condition, but knowing some of the basic differences yourself can help you to explain RA to friends, family and colleagues.

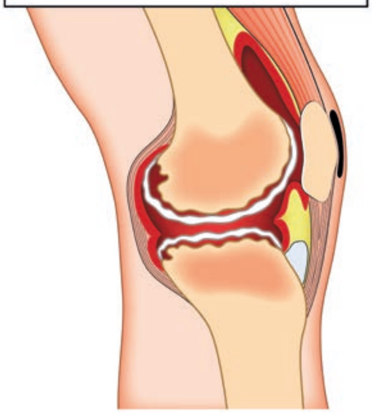
Healthy joint



Osteoarthritis



Rheumatoid Arthritis



Alzheimer's risk halved

in patients on standard DMARDs

Research into patients on standard DMARDs suggests that their risk of developing Alzheimer's may have been halved by their RA treatment.

Researchers in Southampton analysed the records of over 5000 RA patients. This was an observational study, meaning that they were looking back over existing patient records, rather than recruiting patients specifically for this study. The years they looked at were from 1995-2011. It was not possible within this study to analyse the effect of biologic drugs, but standard DMARDs covered by the study included methotrexate (which had the strongest anti-Alzheimer's effect), sulfasalazine and hydroxychloroquine.

The researchers concluded that it would be useful to assess the use of these medications for Alzheimer's in a trial setting. These findings offer new hope for Alzheimer's patients, and offer good news to RA patients, who may be at less risk of developing the condition.

Could gum disease be a trigger for RA?

There has long been a suggestion that gum disease could be linked to the onset of RA, as gum disease is more prevalent in people with RA. A recent study in Leeds has got us a step closer to understanding this connection.

The study looked at patients who were positive for anti CCP antibodies (commonly found in the blood of people who have RA, but also in the blood of those without symptoms, who are at a high risk of developing the disease). In total, the study covered 48 patients in this 'at-risk' group, who were anti CCP antibody positive, but had no signs of RA in their joints, 26 patients with RA and 32 healthy controls.

The results of the study showed that clinical gum disease was detected in significantly more cases for those more at-risk of developing RA than in healthy controls, at a substantial 73% vs 38%.

Though the number of patients in this study was relatively low, the findings of such a high proportion of gum disease in those at risk of developing RA suggest that it could be a major trigger of the disease.

Biologic Refractory* Disease in Rheumatoid Arthritis

*refractory
1. *Does not respond to attempted treatment*

Identifying treatment of refractory disease in people with rheumatoid arthritis

By
Lianne Kearsley-Fleet
Rebecca Davies
Diederik De Cock
Kath Watson
Mark Lunt
Maya H Buch
John D Isaacs
Kimme L Hyrich

and

The British Society for Rheumatology Biologics Register for Rheumatoid Arthritis

Results from the British Society for Rheumatology Biologics Register for Rheumatoid Arthritis

What was already known?

Biologic therapies have revolutionised treatment and outcomes for people with rheumatoid arthritis (RA). Over the years many different types of biologic therapies have become available (also known as different classes), each treating inflammation in different ways. The expanding choice of biologics allows patients to switch biologic if their current treatment is not working. For some patients, even after switching, their disease and symptoms may persist. The aims of this analysis were to see how many patients received at least three different classes of biologic drugs (which we called refractory RA) and identify factors associated with this.

What was discovered?

The British Society for Rheumatology Biologics Register for RA (BSRBR-RA) collects information on people with RA starting biologic therapy. Between 2001 and 2014, 13502 patients with RA started a biologic for the first time and consented to participate in the register. Of these, 6% had used at least three different classes of biologics. Many patient characteristics measured at the point of starting their first biologic drug were associated with biologic refractory disease and included being female, younger, shorter disease duration, higher level of symptoms and disability, obesity, and whether they were a current smoker. We also found that people who started their first biologic in more recent years were also more likely to become refractory, but this may be because there is now more choice of treatments.

Why is this important/what is the benefit to patients?

This is the first observational study to evaluate the extent of biologic refractory RA. This is important and provides information which rheumatologists can use to help identify which people might have refractory disease. It also provides information to help guide the development of rheumatology care. The information can also help with future treatment guideline development.

Developing RA

The link between genetics and environmental factors in developing RA

The exact causes of rheumatoid arthritis are still not fully understood, but over the years, many risk factors have been successfully identified, both in terms of genetics and environmental factors. If you have RA yourself, the chance that your child will also develop the disease is only around 1-3%, which tells us that genetics alone cannot account for why the immune system turns on the body, attacking the lining of the joints at the onset of RA.

A number of environmental factors have also been established, including hormonal changes and having other health conditions. One of the best established environmental factors is smoking. Even moderate cigarette smoking has been shown to increase the risks of developing RA, and in existing RA patients can worsen their condition and make medication less effective.

A recent study has identified an enzyme that works as a pathway inside cells in the body, linking the 'HLA' gene (carriers of which have a higher likelihood of developing the disease) with environmental pollutants from smoking. This helps to explain why smokers who carry the HLA gene have an even higher likelihood of developing RA.

Food for thought

Could bacteria found in milk and beef be a trigger for RA?

Researchers in the US have identified a possible connection between a common cattle bacteria and the onset of rheumatoid arthritis.

This study looked at 100 RA patients, who volunteered to give clinical samples for testing. Of these, seventy eight percent were found to have a mutation in the PTPN2/22 gene, and of these, 40% tested positive for a common bacteria found in cows, called 'Mycobacterium avium subspecies paratuberculosis' (MAP), which is present in around half of the cows in the US. This bacteria can spread to humans through the consumption of milk and beef or through produce that has been fertilised by cow manure.

A possible interpretation of this study's findings is, of course, that these patients may have developed RA because of increased susceptibility through carrying this genetic mutation and being exposed to this bacteria. However, it cannot be known at this point whether these elements caused the condition, or whether for any reason MAP might be more predominant in these patients. Larger studies will be needed before any firm conclusions can be made, but hopefully this is another important step towards a better understanding of how the disease is triggered, which could in turn aid prevention, earlier diagnosis and treatment.

Update on biosimilars

NRAS is working with NHSE as a member of their main National Biosimilar Programme Board to ensure that the needs of patients with RA are represented at national level in regard to switching programmes.

NRAS is also a key member of the NHSE Adalimumab Patient Working Group advising NHS England on patient issues around switching to Adalimumab (Humira) biosimilars which will be coming to the UK market at the end of the year when Adalimumab comes off patent. This will introduce another 4 biosimilar therapies to those which already exist for other originator biologic therapies: Etanercept (Enbrel) – Benepali, Rituximab (Mabthera) – Rituxan and Infliximab (Remicade) – Inflectra and Remsima.

We and patient organisations representing people with other auto-immune conditions such as Crohns and Colitis, Psoriatic Arthritis and Axial Spondyloarthritis have collaborated with NHSE to develop a 'Frequently Asked Questions' document about the introduction of the new biosimilars for Adalimumab and a template letter which hospitals can use to inform patients about switching from adalimumab to a biosimilar product. Both of these documents are now available on the Specialist Pharmacy Service website:

www.sps.nhs.uk/articles/adalimumab-resources-to-use-with-patients/

For further information about biosimilars, see the video interview with our Chief Medical Advisor Prof. Peter Taylor in this section of the NRAS website: **www.nras.org.uk/biosimilars**

CAN YOUR COMPANY HELP?

NRAS needs YOU

We're looking for new corporate charity partners for 2019

Supporting NRAS as your **chosen charity of the year** goes further than just raising money and awareness for a worthwhile cause, it can also help.

- Demonstrate your Corporate Social Responsibility strategy and your organisation's commitment to supporting worthy causes
- Increase staff morale and motivation through fundraising and volunteering activities

What we can offer from a partnership:

- Bespoke social media coverage, inclusion on our website and a variety of PR opportunities
- Feature in our members' magazine
- Charity places for prominent runs and cycle rides across the country including the **Great North Run**, the **Royal Parks Half Marathon**, the **Vitality London 10K** and **RideLondon 100**

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RA Matters Online

An update on the new NRAS webinars!

Both sessions gave the audience a chance to ask questions and have them answered in real time by the presenters.

So far, we have hosted two webinars with the first in May presented by Dr Catherine Swales on: 'Current questions and future directions - an update on research in RA'. Dr Swales is a Senior Fellow and Honorary Consultant in Rheumatology, NIHR Clinical Trials Unit and has a wealth of experience and knowledge of clinical studies and research at the University of Oxford Medical School, so this was an excellent opportunity to hear about the very latest research taking place in RA!

The 2nd webinar took place in June where our expert speaker was Dr James Galloway who presented *How to get the best out of your rheumatology service*. Dr Galloway is a clinical lecturer at King's College London and an honorary consultant in rheumatology at King's College Hospital. In this webinar, he covered *Shared Decision Making: making the most out of your rheumatology appointment* as well as statistics from the *National Early Arthritis Audit: measuring quality in the NHS*. Dr Galloway is an excellent speaker and shared some really important information and tips for communicating with rheumatology health professionals to make the most of clinic time.

As the webinars stream live, both sessions gave the audience a chance to ask questions and have them answered in real time by the presenters. Here's an example of one of the questions that was posed during one of the webinars.

Q What is the long-term outlook for people with RA and how long will biologics keep working for?

A The long-term outlook for RA is better than ever – due to a combination of the disease itself changing, earlier identification and treatment with closer supervision – i.e. treat to target approach and shared decision-making. Unmet clinical need remains (patients with multi-drug resistant disease for example) and there are huge research efforts going into this area which I expect will bear real fruit and meaningful impact on patients experience in the next few years. There's no reason to expect that biologic therapy will "fail" or disappear – but I expect that we will use them better than we do now (through the use of personalised medicine), or indeed they may be superseded by entirely new approaches. I'm not convinced that there will be a "magic bullet" that works at all stages for all patients and endures even when the drug treatment is stopped – the biology of the disease is probably too complex for that – but certainly we have reason to be excited and optimistic about the future of treatment for our patients with RA.'

So far, we've received lots of positive feedback from attendees who have really benefitted from joining us on our webinars, here's a few comments:

'One could not help but to warm to Dr Galloway for his obvious kindness and his apparently genuine concern for his patients - such honesty and reassurance from a specialist consultant!'

'Great presentation Dr Swales! How can I get a Rheumatologist like you? You sound great for patients and very good at explaining.'

So, if you haven't joined us yet, why not attend an upcoming webinar? Dates are as follows:

Monday 17th September 7pm – '*The importance of physical activity in rheumatoid arthritis*' by Professor George Metsios

Monday 5th November 7pm - *'An update on the latest medicines for rheumatoid arthritis'* by Professor Peter Taylor

For more information and to register to login for any of the webinars please visit our website **www.nras.org.uk/webinar** or send us an email to **webinars@nras.org.uk**

Rheum for you 2018

The low-down on our last two events in Durham and London!

Dr Morwenna Opie-Moran presenting

We always enjoy visiting different areas of the UK when hosting the 'Rheum for You' events. Back in March, Emma and Kim travelled all the way from Maidenhead up to Durham in the North East to host our first event of the year.

The guest speakers for the Durham event were: Dr Martin Lee, Consultant Rheumatologist at the Freeman Hospital and NRAS Medical Advisor, Dr Clive Kelly, Consultant Physician with interest in Rheumatology and Honorary Clinical Senior Lecturer at Newcastle University and finally Dawn Kirsopp and Neil Bradbury joined us from the local branch of Citizens Advice. Emma closed the day with an update on all the latest updates and information from NRAS. A great addition to break times was the gadgets table that was kindly hosted by Sushil Munakhya, Senior Occupational Therapist from the University Hospital of Hartlepool. The day was enjoyed by all who attended.

Sushil sharing his weird and wonderful gadgets!

Our annual event in London then took place in July, on a scorching hot Saturday afternoon! Clare, Tracy and Kim hosted this event and we were also joined by our expert speakers for the day, Dr Morwenna Opie-Moran, Clinical Psychologist at the London Cardiovascular Clinic who presented: *'The role of our psychology in autoimmune conditions: Why we should all have our minds in mind, and in hand'*. Andrew Nesbitt PhD, former Medical Director at UCB Pharma then spoke on *'Everything you always wanted to know about biologics but were afraid to ask!'*. Two very different subjects, but equally well received by all who attended.

We got some lovely feedback, which really makes these events worthwhile, take a look at this comment from one attendee: *'I am so pleased I attended today; there was so much interesting information presented. In a funny way, reassuring to be with [others with RA] and realise that other people have to deal with the same sort of problems that I do. Thank you NRAS'*.

Our next Rheum for You event will be taking place in Cardiff on Saturday 27th October from 2pm at the Village Hotel Club Cardiff, 29 Pendwyallt Road, Coryton, Cardiff, CF14 7EF. To register, please email **groups@nras.org.uk** or call **01628 823 524** and ask for Kim or Tracy!

We are currently planning for our first Rheum for You event in 2019 to take place in/around Manchester in the spring, please do get in touch using the contact details as above if you would like to register your interest.

Could you become an

NRAS Telephone Support Volunteer?

> 'My whole experience was very good, the Volunteer I spoke to was like a big sister'

We are currently looking for people whose RA is well controlled on conventional DMARDs alone or in combination with each other (methotrexate, sulphasalazine, hydroxychloroquine, leflunomide) due to rising number of newly diagnosed people who are contacting the NRAS Helpline requesting to speak to people who are currently on these medications and doing well.

We are also still looking for people who are currently on a biosimilar (such as Benepali, Remsima, Inflectra, Truxima) or a JAK inhibitor (such as Tofacitinib, Baracitinib, Xeljanz and Olumiant) to become Telephone Support Volunteers. If you have been on one of these medications for at least 6 months, your RA is well controlled and you think you might like to offer support to others on these topics by volunteering in this way, please contact us by email;
volunteers@nras.org.uk
or by phone: **01628 823 524**

Becoming an NRAS Telephone Support Volunteer can be incredibly rewarding, take a look at some of the feedback we have received:

'The Volunteer I spoke to was lovely, understanding (a diamond) she picked up on things and really 'gave me a lift'. I'm very grateful to all concerned.'

'By speaking to an NRAS Telephone Volunteer I felt a sense of normality and she really was a 'life saver'.'

'My whole experience was very good, the Volunteer I spoke to was like a big sister.'

Full support and online training will be offered to successful applicants.

Leave a Gift to NRAS in your Will

and make a lasting difference

The gifts that our generous Members and supporters leave to NRAS in their Wills each year make up just over 10% of our annual income and they are essential for NRAS to continue to deliver and develop exceptional information and support services.

As a charity, donations and membership fees are vital, but they are not enough to enable us to continue and expand on our good work to best meet the needs of all those living with RA or JIA. In order for NRAS to carry on campaigns to improve services, to raise awareness of these often misunderstood and invisible conditions and to keep our information and support accessible and up-to-date we rely on the income we receive as gifts in Wills.

Any gift, no matter how large or small, makes an enduring difference and will be used wisely and effectively to benefit those who need the support of NRAS and JIA-at-NRAS.

For more information or to talk to someone about leaving a gift in your Will please contact Cara Brandi, Head of Fundraising by email to **cara@nras.org.uk** or by phone on **01628 823524.**

Tribute Funds

Celebrate the life of a loved one in a very special way and raise funds in their memory.

'I feel the need to keep mum's memory alive and let the world know how amazing she was. I started a tribute fund page in her memory to raise money for NRAS.' – Sarah

When Sarah lost her Mum in March 2016 she wanted to do something special and positive to remember her, so she set up a tribute fund page in her Mum's name on Much Loved in July 2016.

Since then, Sarah and her husband Matt have added to the fund by taking part in events – with Matt completing the Silverstone Half Marathon in March 2017, and Sarah selling craft items she has created at local events. To date, Ann's tribute fund has raised an incredible £1,681 for NRAS, and Ann's memory is continuing to support others living with RA and JIA.

Tribute funds are a very special way to celebrate the memory and life of a loved one. You can create a Much Loved tribute page at any time, using your own special memories, photos, videos, words and music, and share these with family and friends. Those who you share the page with can leave donations, raise funds in your loved one's memory themselves and share their own special memories and messages on the tribute page.

'My Mum's strength and happiness through pain and suffering was an inspiration to me and the rest of my family, and now I want to pass that on to others.' – Sarah

If you would like to set up a tribute fund page in memory of a loved one please visit **www.nras.org.uk/gifts-in-memory-of-a-loved-one** or phone Bronwen Cranfield on **01628 823524**.

Sarah and her Mum, Ann

Matt completing his half marathon

RideLondon 100

A huge thank you to all the NRAS Riders, with a fantastic overall fundraising total of £4772.00!

Leigh Badham, Samantha Wilson, Alexa Cook with Tony Parker, Julian Rodriguez, Stephen Cliff, Claire Wilson, not to mention our own NRAS employees, Shivam Arora and Matt Bezzant!

Julian Rodriguez

PRUDENTIAL RIDELONDON

Sam Wilson with Cara Brandi

Matt & Shivam – our Cycling Heroes

Leigh Badham with his fan club

Alexa Cook & Tony Parker

Upcoming NRAS Events

Take on the Halloween Walk Challenge for NRAS!

Saturday 27th October 2018

Bishops Park, Fulham, London,
SW6 6EA

To register visit
www.nras.org.uk/halloween-walk

nras National Rheumatoid Arthritis Society
JIA at NRAS
Registered with FUNDRAISING REGULATOR

Halloween Walk, Saturday 27 October 2018

Take on the Halloween Walk Challenge in fancy dress to raise funds and awareness for people living with RA and JIA.

Trick or treat yourself to this 15km themed walk in London. Show us your best outfits and join in the fun! Gather your bravest guys and ghouls to bring a team or go it alone and meet like-minded walkers. So get into the **spirit**, and get **exorcizing** with us this October. It would be a **grave** mistake not to!

nras diwali
DINNER AND DANCE
in aid of the National Rheumatoid Arthritis Society

Saturday
10 November 2018
at 19:30

Baylis House
Stoke Poges Lane, Slough

Tickets £40 to include:
3 course meal & dessert
Complimentary arrival drinks
Unlimited soft drinks

DJ & Dhol Players
Henna Artists | Fire Dancer

Please book your tickets online:
www.nras.org.uk/diwali2018

Bedrooms will be available to book at the venue
at a discounted price

fundraising@nras.org.uk

nras National Rheumatoid Arthritis Society
JIA at NRAS
Registered with FUNDRAISING REGULATOR

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Diwali Dinner & Dance, Saturday 10 November 2018

Enjoy a three course authentic Indian meal, drinks and dancing to celebrate the festival of lights while raising awareness of RA and JIA. Funds raised will help NRAS improve the information and support we can offer to those living with these conditions within the UK Asian population who can sometimes struggle to find such information in accessible formats.

Funds raised will help NRAS provide the community with translators on the helpline and literature translated in different languages.

More event details coming soon.

Spring and Summer Fundraising Champions

Here are some of the highlights…

As spring and summer sizzled our fantastic fundraisers were undaunted. Through the heat and sun NRAS and JIA-at-NRAS fundraisers continued to take on some of the most incredible feats and personal challenges, raising vital funds to support those who rely on our services. They ran, cycled and climbed undaunted, and raised more than ever before.

The Book in Hand Pub, Mablethorpe held a weekend of fundraising activities, arranged by the landlady Karen Carney and her staff. The whole community got involved, generously donating prizes and taking part. An amazing £4,120 was raised!

Tracey Yapp, who works in the pub and suffers from RA herself, Braved the Shave and raised an amazing £700 with her head shave challenge.

NRAS member, Christine marked her Big '0' birthday with a head shave and raised a fabulous £398. Christine was diagnosed with RA 22 years ago.

A HUGE thank you to everyone who has given up their time over the past few months to organise an event or take on a physical challenge! We have highlighted only a few, but we are grateful to you all, because without you NRAS and JIA-at-NRAS wouldn't be able to provide essential support to all those who need us.

Thank you!

In May, Savannah Seger and her friend Jo Fuller got plastered in mud taking part in the Half Midlands Tough Mudder. Diagnosed with JIA at age 10 Savannah is keen to raise awareness. She and Jo had a great day and raised a whopping £732.

James Clifford from Kidderminster and his friends James, Dave and Craig raised a fantastic £1,838 taking on the National Three Peaks challenge.

In the 110k Trek club we have Danielle Plumb and Sian Jones who trekked from London to Brighton, raising £633 and Hayley Chambers trekked the Cotswold Way raising £1598!

Mike Spink, whose daughter has JIA, took part in the very testing 23 mile Fell run as part of the Upper Edden Yomp in Cumbria and raised a fantastic £2012.75.

Congratulations to Mr and Mrs Paul and Julie Baker! They recently got married and asked guests for donations to NRAS, raising £853.20!

Congratulations also to Shelia and Bill Thorne who celebrated their Diamond Wedding Anniversary and received donations to NRAS totalling £400 from friends and family!

Spring and Summer have seen regular supporters' events take place too, like the tea parties and coffee mornings held each year by Wendy McLaggan from Perthshire and Denise and Duncan Woodcock from Lancashire as part of annual community events. Each event raising at least £300!

We cannot forget our fantastic NRAS groups who have also raised funds for both the charity and to support their group activities.

NRAS gathering in Scotland

17th April 2018

We were delighted with the turnout for this event - about seventy participants from across Scotland and the north of England – as well as the enthusiasm and engagement evident on the day.

We had excellent presentations from our patron in Scotland, Professor Iain McInnes of Glasgow University, NRAS trustee, Jennie Jones, Dr James Dale of Lanarkshire, and Dr Mohini Gray of Edinburgh University. The 'market place' of exhibitions, science demonstrations and the physiotherapy/occupational therapy information point created a real buzz over lunchtime and we're most grateful to all those who contributed time and expertise. Many of you who took part provided valuable feedback on the event; be sure we'll pay heed to this for the future. Look out for news of the next gathering in 2019.

Shaping the RA service in Scotland

The Patient Voice

The Scottish patient experience survey of people with established disease was carried out in RA clinics across the country over the winter months 2017/18 with an excellent response rate and geographical spread.

Results were very encouraging, expressing an overwhelmingly positive view of the service we all use. Possible areas of weakness highlighted in the findings included poor co-ordination between secondary and primary care, inadequate access to self-management training, too little signposting to patient or other organisations offering information/help, some delays in offering appointments in the case of unexpected cancellation or additional clinical need arising. NRAS in Scotland has been closely involved throughout this exercise and we will now be looking at whether and when to repeat the survey, how best to disseminate the information gained, and how to use it in shaping the best possible rheumatology service for all of us. We'll keep you posted!

RA Quality Registry for Scotland

Plans for launching a pilot exercise in Lanarkshire and Paisley of this Swedish-inspired scheme have been slightly delayed by issues related to the supporting IT systems.

Once these are resolved look out for news of progress – NRAS Members and supporters in the pilot areas are being recruited to take part and there has been lots of enthusiasm.

Brief on Brexit

Potential impact on your RA or JIA treatment

At NRAS, we recognise that there are wide-ranging differences of opinion on local, national and international politics, and that is why we remain politically impartial at all times.

On Brexit, NRAS realises that there may be some unanswered questions for people with rheumatoid arthritis and juvenile idiopathic arthritis that many people may not have thought about. We have been asking NRAS Members to ask your MPs some important questions to clarify how Brexit may affect you and your treatment in the future.

Could you spare 2 minutes to ask your MP about these issues?

By following the link mentioned in the article below and filling out a very short form, an email will automatically be completed and sent to your MP, who may be able to clarify how Brexit may affect you, your treatment and health services.

The questions include:

1. **Will I still get access to my medicines?**
2. **Will there be enough rheumatology healthcare professionals to look after me?**
3. **Will I still get the latest treatments?**
4. **Will I still be able to get treatment in the European Union?**

If you hear back from your MP, let us know so that we can share the MP's thoughts with everyone else. Email **campaigns@nras.org.uk**

NRAS launches new campaign network

NRAS has launched a new initiative to enable people from across the UK to actively get involved in campaigning to help NRAS achieve its three key objectives:

- Change Minds
- Change Services
- Change Lives

The new campaign packs provide an easy-to-understand and easy-to-follow guide on how you can campaign on what matters most to you. Whether that be telling your MP about an issue important to you (e.g. your experience of the benefits system), starting a petition, or helping to improve the rheumatology services provided by your hospital.

What sort of time commitment is required? As little or as much as you would like! Signing a petition or sending an email can take a few short minutes. Other people may wish to get involved in a more structured campaigning programme by joining the NRAS Ambassador networks. Either way, we would love to hear from you! Please contact **campaigns@nras.org.uk** for more information.

Keen to get started straight away? Great news! Have a look at our campaign guide here: **www.nras.org.uk/campaign-with-us**

Campaign with us

Wimbledon wins at being Wheely friendly!

By Christine Lowe

NRAS Manchester Ambassador

I have had a LOVE (no pun intended) and HATE relationship with my mobility scooter. When we bought it the scooter salesman was so cheery and happy but he couldn't understand why my face looked like a smacked backside!!

Salesman: "Would you like to try the scooter out?"

Me: "No!"

Salesman: "Just around the corner?"

Me: "NO!!"

He nervously looked at my husband who said, "Just leave her alone she'll be fine."

He didn't understand that at the time, this was to me the last straw. I didn't want something that permanently reminded me of my access issues and disability. But I have to say now what a joy the scooter has been on my more adventurous trips.

Recently my scooter and I, with hubby in tow, went on tour to Wimbledon. We absolutely love watching tennis and applied for the 'disabled draw' and got tickets for Centre Court. My cup runneth over but then the doubt starts to creep in. With any long term chronic condition, you start to doubt whether you'll be able to manage the trip. In addition to my RA and OA I have their pals - co- morbidities - IBS, Addisons Disease and Asthma to name but a few. Questions start in your head like 'Can I find a hotel with proper disabled access facilities?' 'Will there be an adapted toilet? Walk in Shower?' Hotels will say they have a disabled accessible room and when you get there, there's steps or the shower is over the bath...it can be very frustrating.

Adapted toilet and walk in shower. They will say it's a disabled accessible room and you make the relevant enquiries but when you get to the hotel and there's a flight of stairs to the room, the lifts are out of order or the shower is over the bath it can be very frustrating. I always double and triple check. Fortunately, the Premier Inn we stayed in was perfect and ticked all the boxes for access and consideration of dietary requirements.

Having been to events before I was a bit apprehensive as I've been abused by members of the public for slowly trying to ride my scooter out when the event finished, but when you get 3000 plus people leaving a venue at the same time things will move slowly! The what if the loos were up or down stairs? What if I couldn't get the scooter through the gate or up a ramp?

So what is Wimbledon like in terms of accessibility? I had no idea what to expect. I'd browsed the website but you get only a flavour not a true picture of the facilities.

Well it was an amazing memorable experience. We applied for disabled parking and managed to park very close to the main gates. The day was beautiful and sunny just perfect for watching tennis. I honestly had tears in my eyes as I rode my scooter through the gates down the main avenue. It was such a 'bucket list' experience.

The staff were fabulous and directed us to the lifts and we were escorted to our seats. I rode my scooter to our seat level and there were a number of other disabled people some in wheelchairs and some in scooters like me, and the view of the court was amazing. We were higher up in the roof area in the shade and there was even a bit of air conditioning action going on too. The staff were so pleasant and helpful. One said to me have you got an order of play and he went off to get me one immediately.

The disabled toilets (plural, more than one) were across the corridor and very near to me and as a lady of a certain age I was immensely grateful how convenient the conveniences were! In addition, and this was the icing on the cake, the refreshment area really nearby too.

And finally, the cherry on top of the icing on the cake was that the matches we watched. We had the privilege of seeing Gael Monfils, Serena Williams and Rodger Federer. Could you ask for anything more?

So, if you like tennis but are not sure you could manage a trip to Wimbledon. Give it some thought. We had an amazing time and loved it. Thanks to Wimbledon for providing such excellent facilities for disabled people. It was first class, and also for providing such a dedicated and lovely team of staff to look after us.

And as for me and the scooter with hubby in tow we're hopefully off on tour to Chelsea Flower Show next year. This roving reporter will let you know how we get on.

As for you, where have you visited that's been brilliant and had amazing disabled facilities? Let NRAS know and do a review as it keeps us all informed and takes away some of the trepidation, anxiety and fear of visiting new places.

A "Wheely" Inspirational Story

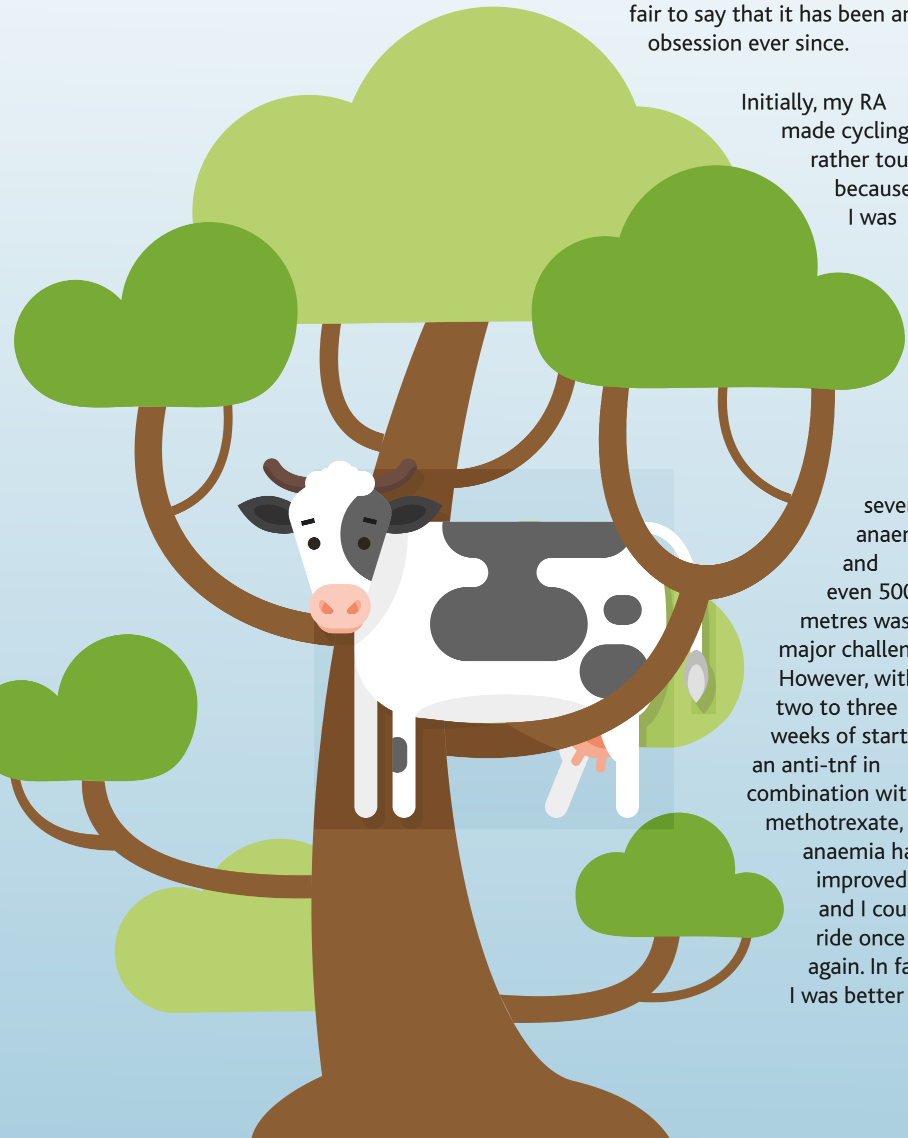
By Julian Earl

By way of introduction, I am Julian Earl and I was diagnosed with rheumatoid arthritis in the spring 2009. In 2008 it was thought to be a post-viral reactive arthritis but it did not improve as expected so the diagnosis was amended to being sero-negative RA.

I had qualified as a veterinary surgeon in 1981 and worked in Lancashire for eight years before moving to Lincolnshire in 1989. The development of swollen hands and wrists in 2008, made my work rather difficult but not impossible, although fine control of my fingers proved awkward. I just about managed with work, but I described it like working with two sprained wrists!

Outside of work, and ultimately the reason I am writing this article, I was a keen cyclist, have been since my student days. I started competing the year after leaving university. It is fair to say that it has been an obsession ever since.

Initially, my RA made cycling rather tough because I was severely anaemic and even 500 metres was a major challenge. However, within two to three weeks of starting an anti-tnf in combination with methotrexate, the anaemia had improved, and I could ride once again. In fact, I was better so quickly that I have described adalimumab as my "silver bullet"! Very soon I started preparing for racing again and progressed well. Despite some on-going discomfort in my hands and wrists, by spring 2012, I was able to complete ten cycling events, so-called "sportives" of one hundred miles or more, around the country.



Two weeks later at a race, near Alford in Lincolnshire, everything literally came to an abrupt halt! I crashed into a big bunch of eighty riders and my head struck a kerbstone outside a farm entrance. Just a few more yards and I would have landed on grass and mud! I was sent under a flashing blue-light to the specialist neurological unit at Hull Royal Infirmary. There, my wife, Annika, who had been called away from her leaving-do as a District Nurse was informed that I probably would not survive!

My wonderful consultant Neurosurgeon, Gerry O'Reilly sat next to the bed and after asking how I felt etc. He then asked me, "What am I like as a person? What do I want to do in the future?" All I could say was my honest answer, "I do not give up easily!" "All I want to do is get back on my bike!" To his great credit, Gerry replied, "It is useful if my patients are stubborn. If you want to get back on your bike, then I'll get you there!" He did not say, "Don't be daft; you cannot even stand up on your own right now!"

I was discharged at the start of 2013 and because my sense of balance was severely damaged I could not stand unaided, and the physiotherapists sprang into action. I joked that they were my dance-instructors! *"Stand on your right leg for thirty seconds; now the left leg. Step to the right, now to the left, now two steps backwards, now forwards',* and so on... I'm sure you get the picture? Nevertheless, I persisted and some friends from my club took me out riding. On the 8th September 2013 I completed a sportive of 55 miles around Lincoln and three weeks later finished another one of 100 miles. My RA was now back under control thank goodness thanks to the adalimumab. I received a club-trophy for the most outstanding performance by a member of the club in 2013! My consultant neurosurgeon, Gerry, was as pleased as I was with my trophy. No other trophy will ever mean as much to me as that one did, showing what my club-mates thought of my recuperation and my refusal to give-up or give in.

During my convalescence, Annika had an inspired idea. As a vet I had given a talk around Lincolnshire forty or fifty times in the 1990s, so Annika suggested writing it down to try and get it published which it was by Quiller Publishing in July 2016. The book is entitled "Cows In Trees" and is so-called because indeed I was once called out by a farmer to a cow stuck in a tree. People often ask how did it get there? My standard-answer is that in Lancashire where it happened, there is a special breed, that builds nests in trees. Or else it was parachuting and got stuck in a tree on the way down. Not sure why no-one believes me.

In the mean-time, due to my head-injury, I now compete as a Para-cyclist and this is just as challenging a competition as I ever competed in. British Cycling deserve huge credit for supporting this branch of the sport.

I believe cycling is good for a someone living with RA because, apart from crashing, (which I don't recommend) it is impact-free on the joints and helps control weight and particularly improves my sense of well-being. I recommend cycling to you all! I hope that this brief story of my life with RA shows that there is indeed still life to be enjoyed after diagnosis of this potentially debilitating disease. I have commented several times that "I might be getting older but as long as I ride, I will not BE old".

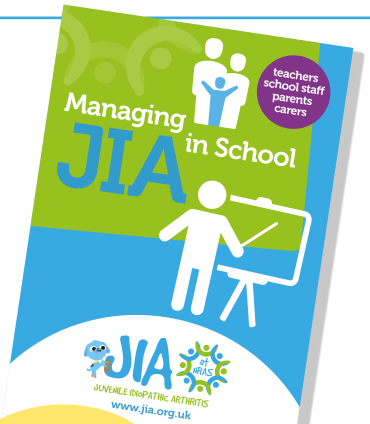
Much credit is due to so many people: Firstly, my wife Annika for her love, care and support and for going above and beyond the call of duty, Gerry O'Reilly, neurosurgeon at Hull. My friends and family who have provided great support in recent years, Also, of course, thanks to the many medical staff for whom I hope I have not been too great a burden in recent years! I am now retired from work due to my injuries but not because of rheumatoid disease.

My life now revolves around my wife, my family and my sport. This year in June, I achieved fifth place in the National Para-cycling championship, something that I never could have dreamt of when lying in hospital for several months during 2012 to 2013! Cycling has enriched my life like no other sport could do.

Some things you never get over, you just have to get through.

This an abridged version of Julian's story. To read it in full, visit
www.nras.org.uk/stories

Frequently asked questions to JIA-at-NRAS



How do I do my bit to raise awareness about JIA?

- You could contact your local MP. NRAS is producing a JIA focused campaign pack to help people contact their MP and ask the pertinent questions. To give you an idea of what this contains, please look at page 32 in this magazine. Anne or Matt can also help you personalise your letter.
- **wearpurpleforjia** – this campaign is growing into a truly national event and is great for raising awareness as well as much needed funds for JIA-at-NRAS.
- Get involved in activities that you can promote on your social media accounts telling people what you're doing and why.

My child is moving to secondary school and I'm worried they don't fully understand how JIA impacts school life?

- Ask the school your child is leaving to prepare a handover file which includes as much information as possible about your child's capabilities within the school environment.
- It's helpful if you can get the name and email of the person at the new school responsible for supporting students with long term health conditions. This may be the SENCO (Special Education Needs Co-ordinator). If the school has a school nurse or access to one, get their details too, as often the school nurse can be useful resource for support.
- Make the sure the most appropriate person in the new school has a copy of our booklet "Managing JIA in School".
- The important facts to keep in mind include:
    - Most children and young people at secondary or senior school do not want to draw attention to their condition
    - They will need to have access to use a school locker to avoid carrying heavy school bags around all day

JIA-at-NRAS hold family activities and fun days across the country for children and young people with JIA

- How to ensure that whilst not excluded from activities they should not overdo things, it's still important for your child to be involved in PE lessons- exercise is good for JIA and for team work as well as mental health
- If lessons are in classrooms upstairs, is it possible for them to have access to a lift and/or are given extra time to get there with perhaps a buddy to help them
- Busy school corridors and the cafeteria can sometimes be a nightmare for a child with JIA and whilst they don't necessarily want to eat in a different area to their friends or wait for a less busy time, it's important for the school to know that these areas can cause issues.
- If your child attends hospital or the doctors regularly during school hours, be sure to let the school know this.
- Share information on how the disease can impact every day life, for example tiredness, stiffness, and pain
- Share information on the medication your child takes, even if they don't need to take any at school.
- Re-assure the school that you want to work with them to help with ensuring your child has just as much opportunity to learn, develop and make friends as others

Where and how can my son/ daughter meet other children with JIA?

JIA-at-NRAS hold family activities and fun days across the country for children and young people with JIA. These events are free and provide a great opportunity to make new friends and meet up with old ones.

All these activities are promoted on our Facebook page and website:

www.facebook.com/jiaatnras
and
www.jia.org.uk

JIA Matters was set up by a parent who has a child with JIA. The webpage has details of parent champions all over the UK who offer support and also arrange meet ups. https://jiamatters.org/

How can I help my child with morning stiffness and pain?

It's common for most children with JIA to suffer extra stiffness and pain, especially in the mornings or during a flare.

Mornings are hard for everyone, but they're especially hard for children with arthritis. After several hours of inactivity, their joints often become stiff and painful. They also might not have had a restful night's sleep as it's common for people with arthritis to wake up during the night to adjust and stretch. Mix that with chronic fatigue, and it's not hard to see why your child might not want to leave their bed.

- Lend a hand, they may be embarrassed or feel a bit hopeless needing help but remind them that things will get better and talk about all the things they can do then. Stay positive.
- Try a hot water bottle or heated blanket at least 15 minutes before they have to get out of bed.
- Have them take their medications as appropriate before rising from bed maybe 15mins to half an hour before they have to get up if they need to take pain relief e.g. Paracetamol
- A warm bubble bath or shower before starting the day can also help

Wear Purple for JIA 2018

On June 8th schools and workplaces got caught up in a Purple Pandemic Panamanian! Everything turned purple for a day - from T shirts, to hair, bows and superhero outfits there was something for everyone! 2018 saw #wearpurpleforJIA go even bigger and better than last year with a tide of purple colour sweeping across the UK.

The behind the scenes planning had been taking shape since September 2017. Lynette Haselip - the mum whose brainchild Wear Purple was back in 2015 met with the fundraising team from NRAS to discuss the success of 2017 and how to grow the awareness day going forward for 2018. With Lynette's backing NRAS was excited to start brainstorming on how to reach a wider audience and create a fun new 2018 Wear Purple pack for everyone who wanted to get involved. With Lynette's advice and collaboration on merchandise and the backing of the charity the whole campaign really ramped up a gear.

The marketing team at NRAS brought their creative talents to the forefront, designing a brand new dedicated Wear Purple website where the wearpurple merchandise could be bought online. The Wear Purple for JIA Facebook page has 1500 followers which enabled improved communications between supporters of the campaign.

In the few weeks leading up to the big day the office at NRAS was inundated with requests for packs and merchandise as well as requests for our JIA Education packs which has proved a great way to engage with schools and open the conversation about JIA. At the final tally we sent out 358 Wear Purple fundraising packs - 176 more than 2017!

The day itself was a huge success and events from mufti days to sponsored walks, bake sales, bike rides, parties and generally having a huge amount of fun as the wider JIA family came together in every corner of the UK. The children threw themselves into it, full force and encouraged, cajoled and bribed family and friends to don their Purple T shirts and wristbands and get talking about JIA! Social media was a flurry of tweets, Facebook posts and some fabulous photos were shared. **You could say the JIA jabber was a jumpin'!**

NRAS have been overwhelmed by all the amazing fundraising stories and photographs and for all the wonderful awareness we have managed to achieve together. Along with raising awareness we have also received the staggering total of £37,000.

Saxlingham Primary School

So, what will the money you have raised do for children and families with JIA? NRAS offer a range of JIA services, funds will help with initiatives such as:

- Free family fun and information days across the UK
- Free Family Residential Weekends across the UK
- Free Activity days specifically aimed at teenagers with JIA (Bushcraft days)
- Development of free educational materials and information resources for schools and healthcare professionals
- JIA campaigning materials and activities to improve Paediatric Rheumatology services in areas of the UK where there is a need to enhance or establish services.

A huge thank you to you all for your time and involvement and we hope that in 2019 we can go even bigger and better and help to educate more people about JIA.

Here are some lovely messages we received from our army of Wear Purple People!

"...I just wanted to let you know that Lauren has raised a total of £574.44 for you with the latest Wear Purple day, Ealing Council's donation and my bake sale at work. If my request for my company, Ipsos MORI to match fund the bake sale is approved, this will go up to £712.17"

"Heidi has now collected all her sponsor money in and together with donations from her wear purple day at nursery she managed to raise £485! She loved rewarding everyone who joined us on the walk with a wear purple sticker."

"We all came to school dressed in purple to raise money for and awareness of children with JIA (Juvenile Idiopathic Arthritis). Thanks to everyone who supported. We especially enjoyed the visit from a specialist nurse, who told us all about JIA."

Home News and Events Saxlingham Primary School

RA Awareness Week

18-24 June 2018

Thank you for taking part in Rheumatoid Arthritis Awareness Week (RAAW) 2018!

We are delighted with the results of this year's awareness week, and we are still receiving emails and updates of all the amazing things you were doing in support of RA Awareness. We are pleased to announce that this year's awareness week enabled us to generate many new supporters, followers and those who are keen to raise awareness of RA through our social media, digital and traditional channels.

This year, the theme was #ReframeRA. There can be confusion around the public's perception of what rheumatoid arthritis is, which can impact their reaction when a person with RA tells them about their disease. Our aim was to #ReframeRA, to educate and inform the public about exactly what the disease is and how it impacts those with the condition, as well as their friends, family, colleagues and health care professionals.

We highlighted this topic throughout the week with the launch of our mass awareness video, personal stories and exploring different perspectives from people living with RA; friends, family, co-workers, and the public to raise awareness and challenge misconceptions. In addition, we launched lots of exciting content and materials to help the RA community in all areas of living with RA.

Key Highlights include:

- Over 97,000 views of our video 'RA Matters'. This was a huge achievement and we are delighted with the level of engagement this generated.
- We asked you to send in your video diary entries about how RA impacts your life – from the point of view of someone with RA, family members and health care professionals. We had over a dozen entries and featured them throughout the week. We were overwhelmed with the level of engagement, likes, shares and uplifting and supportive comments these video diaries received. Thank you.
- We conducted a survey with YouGov to find if the general public were aware of RA and what they thought it was. See some of the results on the opposite page.
- We send hundreds of packs out for information stands in hospitals across the UK.

See all of these RA stories and more at **www.youtube.com/NRASociety/videos**

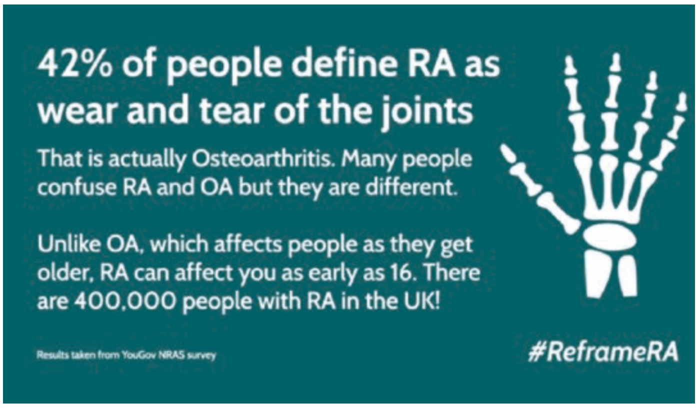
SImon's story

Dan's story

Julie's story

Kaitlin's story

Our aim was to #ReframeRA, to educate and inform the public about exactly what the disease is and how it impacts those with the condition, as well as their friends, family, colleagues and health care professionals.



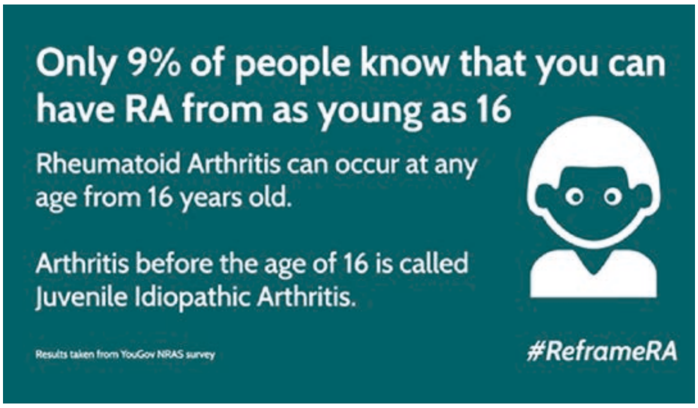
42% of people define RA as wear and tear of the joints

That is actually Osteoarthritis. Many people confuse RA and OA but they are different.

Unlike OA, which affects people as they get older, RA can affect you as early as 16. There are 400,000 people with RA in the UK!

Results taken from YouGov NRAS survey

#ReframeRA



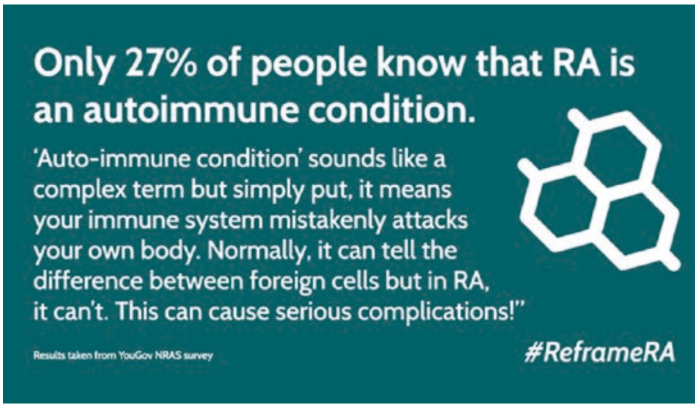
Only 9% of people know that you can have RA from as young as 16

Rheumatoid Arthritis can occur at any age from 16 years old.

Arthritis before the age of 16 is called Juvenile Idiopathic Arthritis.

Results taken from YouGov NRAS survey

#ReframeRA



Only 27% of people know that RA is an autoimmune condition.

'Auto-immune condition' sounds like a complex term but simply put, it means your immune system mistakenly attacks your own body. Normally, it can tell the difference between foreign cells but in RA, it can't. This can cause serious complications!"

Results taken from YouGov NRAS survey

#ReframeRA


© Edgepedia

Events Diary

16 September	**Saltwood Castle**. Charity Open Day.
17 September	**Webinar on importance of Exercise**. Professor George Metsios.
28-29 September	**JIA family residential weekend**. Northumberland.
12 October	**World Arthritis Day**
14 October	**Royal Parks Half Marathon**
27 October	**Rheum4U**. Cardiff.
31 October	**Halloween Walk**. London.
1 November	**Launch in Parliament of the NRAS survey on Emotional and Mental Health**.
5 November	**#RA Matters Webinar**. Professor Peter Taylor.
10 November	**Apni Jung Diwali Dinner & Dance**. Slough.
7 December	**NRAS Christmas Concert**. Maidenhead.

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