

YOUR Members' Magazine!

NewsRHEUM



nras

National Rheumatoid Arthritis Society

SPRING
2021

Thank you
to all
involved
in the
vaccine
rollout

VACCINE
ROLLOUT
SUCCESS
COVID-19

wear
your
mask



NOT
back to
NORMAL
...
FORWARD
to
BETTER



RA AWARENESS WEEK
(RAAW)
13-18 SEPTEMBER

#WearPurpleForJia
WELLBEING WEEK
14-18 JUNE

NRAS GROUPS
'ZOOM' FORWARD



By Clare Jacklin

NRAS CEO

Dear Members

We have been in the grip of this pandemic now for over a year and I'm sure you are all feeling, like me, rather fed up with it! Perfectly understandable, but we must not lose sight of the light that is at the end of this dark tunnel and we ARE getting ever closer. The one thing I am struggling to comprehend is this talk of 'going back to normal'. It is NORMAL that got us into this situation in the first place! I, for one, do not want to go 'back', I want to move forward. I want to look forward to a better, healthier world where we all take action to look after each other and our planet, far better than we have done so to date.

Even if/when every single person across the world gets a COVID-19 vaccine, this and other viruses are here to stay. New strains of coronavirus or another virus will exist and therefore our way of living has changed irreversibly. I worry that the media leads us to thinking the COVID-19 vaccinations are the total solution. They are certainly a big part of the solution, but it will require a global change in behaviour to return to the sorts of freedom of movement that we all enjoyed pre-pandemic. While that sounds negative, I do not mean it to be. I would like to see us all embrace this opportunity to hit the 'reboot' button. Mother nature is inviting us to 'reset' and 'refocus' and I am hoping I can respond positively to that invitation, but it will not be easy. Change never is easy.

At NRAS we are doing all we can to help you make those small everyday changes to hit those 'reset' buttons. The new online self-management modules we will be launching in a few months are just one way to learn more about playing an active part in managing your disease in partnership with your health professionals. The Right Start New2RA and Living with RA services are also flourishing with almost 50 hospitals now referring their RA patients to these NRAS

services. Our hope is for these interventions to be embedded into routine rheumatology practice resulting in supporting not just the individual with RA but the rheumatology nurses and consultants as well in their delivery of patient education and offering self-management resources. NRAS, working in partnership with rheumatology units, can offer a wraparound service via peer support, educational resources and reinforce the health messaging delivered by rheumatology professionals.

It has been a very difficult 2020 and already we are seeing that 2021 is certainly not going to get any easier anytime soon, so once more I'd like to reiterate my immense pride and give thanks to my hardworking colleagues who have faced many of their own challenges during lockdown but at no detriment to the quality of service to those who need us. Thank you to all the NRAS staff, Members and Volunteers who have, and continue to, demonstrate such great resilience and fortitude despite all the challenges lockdown has presented.

Your continued support of NRAS, YOUR society, is greatly appreciated. The kind messages you share on Facebook, Twitter, HealthUnlocked, via letters and emails, really give me and my colleagues a real boost. Thank you.

Warmest regards to you all

Clare
Chief Executive

P.S. I hope you're enjoying exploring the two new NRAS websites.
www.nras.org.uk and www.jia.org.uk.

NewsRHEUM

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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

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Could you be our next winner?



Entry from
£1

Sign up to play the NRAS Lottery today and be in with a chance to be one of our weekly winners. It costs just £1 per week and you have the chance to win up to £25,000!

The NRAS Lottery is organised by Unity, a specialist organisation which runs charity lotteries and, unlike most other lotteries, gives 50p from every £1 direct to the charity.

Play today to be in with a chance of winning £25,000 and support NRAS, nras.org.uk/play-the-nras-lottery.

T&C's are on the website, nras.org.uk/nras-lottery and the lottery is for players 18 years or over. UK ONLY.

Play for a chance to win up to
£25,000
with
unity

BeGambleAware.org

Members' E-Newsletters

As well as this lovely magazine, every month we send out an E-Newsletter to our Members, to keep you up to date with all the latest news in between the magazines. It's a great and cost-effective way we can keep in touch with you on all the latest research, opportunities to get involved with campaigning and much much more. If you haven't been receiving the E-Newsletters do email us at membership@nras.org.uk to check we have your up to date email address and contact preferences.



Deniz Paradot

Deniz describes his classes as having '8 active ingredients' and these are:

1. Awareness
2. Intention
3. Functional and Structural Integration
4. Active Relaxation
5. Strengthening and Flexibility
6. Natural, Freer Breathing
7. Social Support
8. Embodied Spirituality

The Power of Qigong

Deniz teaches Qigong (the origin of Tai Chi) and Mindfulness and makes them immediately accessible to people of all ages and experience levels. His approach allows students to quickly experience the joys and benefits of Qigong as 'Movement Medicine' and Mindfulness as a 'Way of Living'.

Deniz uses his 25 years of experience working with people from all walks of life. His award-winning Qigong and Mindfulness programmes are successfully used in the NHS and by Parkinson's UK and The Royal Voluntary Service to name but a few organisations. The programmes won the coveted Active Norfolk 'Activity in the Community Award' 2019 and were nominated

by the Chief Nurse of the Norfolk & Norwich University Hospitals NHS Foundation Trust for the 'RCNi Nursing Awards' 2020.

Deniz is a highly regarded award-winning authority on Qigong and Mindfulness and as the author of 'Move Life Better', his approach and method of teaching have been hailed as "the spark that will surely ignite a revolution in the way in which Qigong is practised and taught in the modern world".

If you spend any time at all with Deniz you immediately understand why so many people around the world choose to study with him.

A little history...

Undiagnosed depression and chronic pain

His journey began as a young boy in 1987 when he was involved in a terrible car accident which saw the death of his mother. For 8 years he suffered undiagnosed depression and chronic pain throughout his body and in 1995 it came to a head, when overnight Deniz went from an able-bodied person to being confined to a wheelchair as his spine had partially collapsed as a result of the car accident. Deniz underwent major spinal surgery and embarked on a difficult and long recovery. As a result of the accident, years in chronic pain and the surgery he also contracted Fibromyalgia. Deniz felt that western rehabilitative medicine wasn't helping him as he wished. He intuitively knew that he had to deal with the physical pain as well as the emotional and mental pain he had suffered, and so he started practising the Mindfulness trainings of Thich Nhat Hanh and learned one-to-one Qigong from the late Mr Lui Wei. These 'life art' practices exceeded all his expectations and now, immersed in the present moment through Qigong and Mindfulness, Deniz feels wonderfully alive and well.

25 years (and continuing) of study and training

Deniz has created movelifebetter.tv as a response to COVID-19 and part of his deep aspirations to renew and share Qigong. His methods of teaching contain the essence and spirit of traditional Qigong, but made to be more practical, relevant and responsive to people's everyday lives. For some people like Deniz, imparting words of wisdom to others comes naturally. Deniz utilises a combination of knowledge, experience, and intellect enabling him to take his life experiences and communicate to his students in a way that inspires and empowers them to see the wisdom and beauty in what is being conveyed to them.

Some of the reported ways in which Qigong and Mindfulness benefit those living with RA and include:

- Better Balance
- Less Pain
- A Sharper Mind
- Less Stress
- A Happier Disposition
- More Self-confidence
- A Stronger Heart

Deniz's desire to give back is apparent as he has offered over 400 free classes since the beginning of the first lockdown in March 2020. He teaches live every weekday at 8am and has numerous courses and classes on his website available to everyone.



For more information visit movelifebetter.tv



Volunteer Spotlight

I started volunteering with NRAS a few months ago and it has allowed me to get involved with some of their ongoing work and "chip in" with my two cents. I have always wanted to get involved to help others, like myself, with arthritis but never really knew how. NRAS has given me the opportunity to do this for which I am so grateful.

I really like the way there are so many ways to get involved, whether it be with patient research, planning events or fundraising. One of my favourite moments so far was the Facebook Live session I did with other members of the Young Voices Panel for the Wear Purple campaign last year. We spoke about our experiences with JIA throughout our childhood and it was really nice

to see that other people found our experience relatable and helpful. I have also really enjoyed getting to know the other members of the Young Voices group. It has been so nice to know that I'm not alone in my experiences and being able to connect with people who really understand you. I'm so excited to see what the future holds and get involved in more projects with NRAS!



Suruthi Gnanenthiran

New JIA Digital Membership

JIA-at-NRAS is pleased to announce we will be launching our first JIA Membership soon! Keep an eye on our website

jia.org.uk

Membership includes monthly JIA E-News, Digital JIA Magazine twice a year, quarterly JIA Members only Facebook Lives via the JIA Facebook Group for Members only, discounts on JIA merchandise via our website and priority booking to all JIA events. All for only £17 a year.

JIA covers a broad spectrum of ages from babies to adults with JIA. We know that families are also affected by JIA and we hope to bring you content that covers the full age range. In time we hope to be able to provide tailored membership targeted at individual age groups.

Please join us so that we can build a strong JIA community to support each other. If you have a story or article you would like to include in a future edition of the JIA Digital magazine or E-News please email

jia@nras.org.uk





18 years ago, I was diagnosed

with Rheumatoid Arthritis, and like many fellow sufferers it has been aggressive, and tough to live with at times. It blighted what should have been the best years of my life whilst nurturing my young family.

Hello I'm Matt, 52 years old, happily married to Claire for 22 years. We have 2 children, Annie and Benjamin. The three of them are beautiful, smart, caring and lovely and I'm lucky to have them.

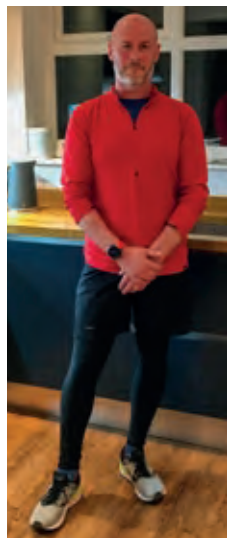
I had a relatively sporty childhood, but I was never as successful as I dreamed. I wanted to be the new Rory Underwood; I was a bit of a speed merchant.

However, I struggled with joint pains early on, and the school 'Doctor' diagnosed Osgood-Schlatter disease (Inflammation of the patella). I could have been suffering with RA, but back then it was "stiff upper lip and stop complaining lad". How things have changed, and for the better!

I got on with life until the joint pains returned but more severe this time. Mainly 'Squeaky knees', which were occasionally hot, red, and marginally inflamed. I felt more tired (fatigued) than usual, and not 'quite right'. Little did I know these symptoms were the indicators of troubled times ahead.

Finally, the day arrived, and feeling feverish, assuming an imminent cold I went to bed. I woke early with excruciating pains in my

knees, elbows, wrists, and hands. My left knee was swollen like a football. I could not believe how far my skin had stretched. My GP, with a tone of concern, care and annoyance ordered me to A&E. He phoned ahead and told them to expect a gentleman with query septic arthritis. On many occasions



My Story – Matt Gallagher

I should be the new Rory Underwood...

he and his wonderful colleagues have been my angels, and I truly cannot thank them enough.

Arriving at A&E was an experience. Before I could say, "hello my leg hurts a bit", I was on a gurney being prepped for surgery and a 'wash-out'. Almost 2 inpatient weeks later, and following numerous IV antibiotics, I was discharged but with no real answers. The next few years were pretty tough. Following numerous visits to NHS specialists I was eventually diagnosed with Zero-negative Rheumatoid Arthritis (amongst other things).

At this point My CRP and Rheumatoid factor were constantly high. I was put straight onto varied combinations of DMARDS. None of which worked, other than to help me lose a hell lot of weight and the remaining bit of hair I had left (I'd planned to cultivate a Bobby Charlton comb-over (god bless him).

During the following years, Steroid injections became my salvation. Either directly into the joint or in my bottom. I did not care a jot. All I craved was the short-term relief they offered. This was a deeply horrible, dark, depressing and upsetting period of time with no obvious end in sight. Hospital stays, extremely painful and swollen joints, constantly being drained, trying to hold down a stressful job, support my family, hide the pain, remain positive and not give in. It was hard going. There were many periods where my wife helped me dress, I couldn't walk, and I felt totally stripped of my dignity. I was also flirting with addiction to strong pain killers. I believed back then that I couldn't live without them.

During this period my disease was assessed significant to warrant biologic treatment. When I say, 'my disease', that's is genuinely how I feel about it, it's mine. I believe that if I keep some of it to myself (in my head) then I can control it, and it will never get the better of me. Personally, this has kept me sane over the years (although when it's bad I talk to it, or rather swear at it).

The first few biologic treatments failed after a while, and I started to feel defeated. However, I'm happy to report that I'm now settled and thriving on Abatacept (Orencia), and for the first time in years, I'm in remission!

I'll briefly mention - during this time a fly landed in the ointment. I had a heart attack, and the penny didn't drop until I was stented. A strange time really with many new and different drugs to remember. Again, our wonderful NHS came to the rescue. We're so lucky in the UK. No real harm done though, I'm in good health in this area too.

It's taken a while to gain confidence and trust myself but I'm now running 3-4 times a week covering approx 30-40k. Something I never believed I could do again. **Matt v's RA a significant battle won!**

I've enrolled onto my first half marathon and I'm planning full marathons thereafter (fingers crossed).

I can't believe my luck. I love it. The sense of achievement, the feeling of freedom, and above all else a sense of personal pride again.

Throughout all this I've felt supported by those close to me. Its infinite how that support has manifested - a regular text - humour - hugs - understanding looks - patience - phone calls out of the blue - a random gift - a telling off - running at a slower pace to match mine - researching RA and treatments. But one of the biggies and extremely important is...people who understand that without warning I occasionally pull out of a commitment. If you have RA you'll know what I mean, it's a confidence thing, an over whelming feeling of what if(?).

I've also had THE BEST CARE from the RA team at The Royal Hallamshire Hospital in Sheffield. Their high standards of care actually motivates oneself to keep going, and I shall remain eternally grateful to them all. That motivation and feeling that somebody has you, is acutely important. **NRAS produce great information, education and are forever there.** Reading inspirational stories from others like me, and those suffering worse than I has motivated me too. There are some truly inspirational people in our society. Not just footballers, politicians, and actors - they are regular people who put up with irregular lives with dignity and decency.

Am I not bitter?

Not really. It isn't anyone's fault I have this disease, but I'll admit it's taken me a while to come to terms with it. I believe there is a lack of understanding around RA, and it's important to help raise awareness, research funds and support.

You never know I might meet Rory one day, so I'd better look the part in a pair of shorts.

If you would like to support NRAS and sponsor Matt for his upcoming half Marathon you can do so via his JustGiving page here

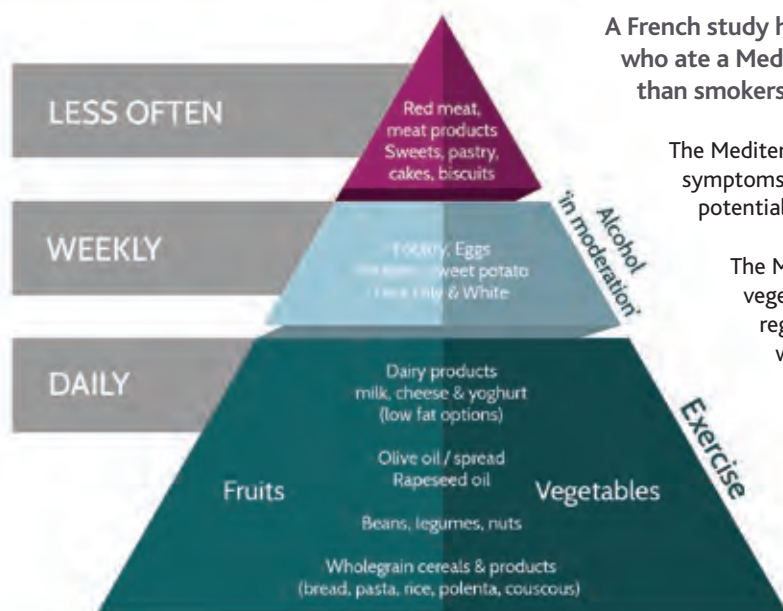
www.justgiving.com/fundraising/matthew-gallagher5

NRAS Groups “ZOOM” Forward

During the COVID-19 pandemic, several NRAS groups got in touch and requested help to facilitate online meetings via Zoom for their members. Below are just a few recollections of their first Zoom meetings from the Oxford, Swansea and Chesterfield group leaders:

Sue Thwaite, NRAS Oxford Group	Cynthia Rees, NRAS Swansea Group	Hazel Sargeant, NRAS Chesterfield Group
<p>Our meetings are normally held at the Nuffield Orthopaedic Centre where we receive enthusiastic support from the University Research Team and our lovely Rheumatology Clinicians. It sounds very academic, but their job is to make their work accessible to patients, leading to very interesting insights into the world of research and resulting in better understanding of RA for patients.</p> <p>The COVID-19 pandemic forced all clinicians into broader thinking about the way they conduct appointments to keep patients and staff safe. At this particular meeting by Zoom, kindly hosted by NRAS, Professor Raashid Luqmani and Rheumatologist Dr Anushka Soni presented a new self-assessment form to be completed by patients before their consultation. This form will be used in conjunction with other tests to enable the clinician conducting the appointment to understand the level of treatment needed. Our job as patients was to trial the form for ease of understanding and completion and we then responded with comments to help clarify the form from a patient’s perspective.</p> <p>We are, however, also aware of those patients unable to cope with technology as more meetings move online and we have been assured that staff will continue to do what they can to meet their needs.</p> <p>Everyone is welcome to attend our meetings and hopefully we will be able to physically meet again at some point in future. Meanwhile, watch out for future group meetings on the NRAS Website, and it really does work well on Zoom!</p>  	<p>2020 has been a year of great change due to the pandemic. Many of us have had to develop our skills in the virtual world of Teams/Zoom meetings, holding family and friends social gatherings via these virtual ways, even accessing NHS care.</p> <p>In November 2020 with the help of Janet Brewer, Engagement Manager at NRAS, we held our first Zoom meeting with Guest Speakers Kim Beddow Service Manager and Dr Neil Mo Consultant Rheumatologist from Neath Port Talbot Rheumatology Unit. Questions were posed and answers given to clinical management of RA.</p> <p>Zoom allowed us to reach members who were shielding, new members and even the Gwent Group could join in the discussions - Zoom allowed unlimited numbers and members did not have to leave their homes on dark winter nights. It was so successful that a further meeting was held in January 2021 and Zoom is the way forward for the foreseeable future for the Swansea Group.</p> 	<p>The NRAS Chesterfield Group meets monthly in a Community Room at a Tesco store. At the start of lockdown in March 2020, we had already held our March meeting, so it wasn’t until April that we missed our first one.</p> <p>Initially everyone thought lockdown wouldn’t last long, so it wasn’t until summer that I became aware of Zoom and its potential to allow our support to restart. I am never comfortable in front of a camera, so as a trial, I contacted a few friends to join me and we enjoyed seeing each other and catching up.</p> <p>As my confidence grew, I asked NRAS to invite everyone on our Chesterfield group email list and this brought a good response, including members old and new.</p> <p>By now thoughts were turning to Christmas and I wanted to do something a bit special, so I approached NRAS to ask if they could help with a longer meeting than the 40 minutes allowed by Zoom. Janet sought permission for this and she was allowed to use their licence to host a Festive Celebration, during which we came armed with a mince pie and a drink of choice, donning our glad rags and sparkles for chat, music and a quiz, courtesy of Bob the house elf (my husband). A bit of fun in such dark times.</p> <p>One thing I have become aware of is that Zoom meetings have enabled a lot of people from a much wider area to take part, whereas previously perhaps distance would have prevented them from attending in person. With this in mind, we hope to continue with the Zoom get-togethers even when face to face meetings return.</p> 

New evidence for Mediterranean diet



A French study has shown that women who are or have been smokers who ate a Mediterranean-style diet have less risk of developing RA than smokers or ex-smokers who did not follow the diet.

The Mediterranean diet has been shown in previous studies to improve the symptoms of people with RA, but this study is important, as it shows a potential reduction in the risk of developing RA in the first place.

The Mediterranean diet is based on daily intakes of fresh fruits and vegetables, nuts, beans and pulses, olive oil, wholegrain cereals and regular oily fish and poultry consumption. In the study, 62,629 women filled in questionnaires to assess their dietary habits since 1990. 480 study participants developed RA. Overall, the Mediterranean diet was not seen to be associated with risk of developing RA, but the association for past and current smokers was significant. Smoking itself is already known to be one of the main non-genetic risk factors in developing RA. It is not known exactly why smokers were affected by diet, but could indicate other potential differences in the way that smokers respond to RA.

To read more about the benefits of the Mediterranean diet in RA and also about the risks associated with smoking and RA (both in terms of the risks of developing the disease and the risks it poses for people who have RA), visit the NRAS website: www.nras.org.uk/diet

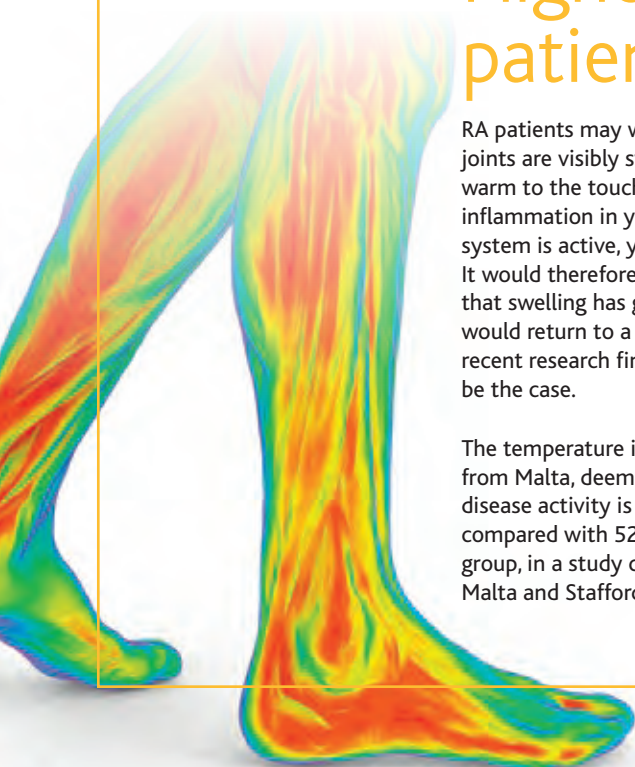
Higher body temperature in RA patients continues in remission

RA patients may well notice that when their joints are visibly swollen, they can often also be warm to the touch. In fact, any time you have inflammation in your body, where the immune system is active, you are likely to get this heat. It would therefore be logical to think that, once that swelling has gone down, the temperature would return to a normal level. According to recent research findings however, this may not be the case.

The temperature in the feet of 31 RA patients from Malta, deemed to be in remission (where disease activity is at very low levels) were compared with 52 healthy adults in the control group, in a study conducted by the University of Malta and Staffordshire University.

Significant temperature differences were detected, using thermal imaging techniques, that show different colours depending on the levels of heat detected, despite conventional methods of assessing joints being unable to detect inflammation.

Unlike some other health conditions, RA patients who go into remission are not free of their disease. RA remission occurs when disease activity has dropped to a very low level, usually determined by a disease activity score (DAS) of less than 3.2. The results of this study show that thermal imaging could be a useful tool in RA, as they are able to pick up on inflammation that is otherwise not detectable, by conventional measures such as DAS. This could also help to aid making diagnoses at an earlier stage, before visible swelling is present.



Making the most of your telephone appointments

Access to rheumatology services have been impacted severely by COVID-19, due to many health professionals being moved from their specialty area into the front line and by infection control measures in place to protect health professionals and patients alike. Most face-to-face appointments have moved to telephone appointments and whilst NICE (National Institute for Health and Care Excellence) have produced rapid guidelines for clinicians, patients have been moved to this process without similar guidelines.

It is important to understand that telephone appointments should be treated with the same respect as a face-to-face appointment. They are scheduled into your consultant's appointment calendar in the same way that face-to-face ones are. If you are out for example at the supermarket when they call at the scheduled time, you will have to be reschedule just as you would have to if you missed a face-to-face appointment.

Keeping a track of your disease and understanding your disease activity score (DAS) are particularly important steps to being actively involved in the management of your RA, even when we are not in the middle of a pandemic. NRAS supports the 'RheumaBuddy' app and 'Know your DAS' app, which can be downloaded from the NRAS website or found on your phone's app store. DAS is an assessment used by clinicians to measure RA disease activity, to determine whether the signs and symptoms have reduced or stopped and if treatment needs to be adjusted. Keeping a track of your pain, stiffness and fatigue can help your rheumatology team get a more accurate picture of how you have been managing and can help them plan care pathways with you. Not all hospitals are using the app yet, so this can be your opportunity to share some information with them, rather than the other way round.

Before your appointment, it can be helpful to write down any questions you may have or any areas you wish to discuss with them. This can help you keep focused throughout the conversation; you can also write down anything you need to remember. Make sure you are prepared and available for the call in a quiet location where you can give it your full attention. If you would not do something during a face-to-face appointment, try to avoid doing it during a telephone appointment.

If you are experiencing a flare of your disease, try to contact your rheumatologist or the rheumatology nurse, do not just dismiss your symptoms or feel you are being a burden. However, remember that most rheumatology departments are working at reduced capacity and reduced hours, so you may need to give them a few days to get back to you. You can also try your GP to ask what you should do to get you through to the next appointment. As always if you are experiencing medication reactions or distressing symptoms, call 111.

Many rheumatology departments are advising patients to call the NRAS Helpline, which we take a great deal of pride in, knowing that they trust we give good reliable information and support. We are here to support you, but just remember we are not health professionals, so we are unable to give medical advice or make individual recommendations regarding medications and we must not be taken as a replacement for the advice of your treating specialist.

For more information on the NICE guidelines for rheumatology management and the rapid guidelines, see their website www.nice.org.uk

Nadine Garland

Support Services Manager





Gaye Hadfield

Personalised medicine for your RA

Introduction

As we know there have been dramatic changes in the treatment of rheumatoid arthritis (RA) over the last 25 years with the introduction of new classes of drugs (targeted Biologics & targeted synthetic DMARDs) to limit the damaging inflammatory process of the disease. See the NRAS Medicines in RA booklet for details on treatments.

However, in the midst of all these amazing medical advances, the simple question remains - who will respond well to which treatment? This is still a frustrating and often distressing trial and error process with 40% or more patients experiencing no real benefit from each drug that is used.

Many patients often have to cope with severe symptoms of uncontrolled RA during this search, including unnecessary joint damage and toxic side effects as they cycle slowly through the NICE pathway looking for a suitable treatment.

Ailsa Bosworth, NRAS National Patient Champion commented: "I can certainly attest to the joint damage and toxic effects of cycling through drugs, trying to find something that worked for me. I have switched advanced therapies 8 times and had multiple surgeries as a consequence of damage sustained due to uncontrolled disease, so this research is so very important as you can see from the diagram below."



Zoë Ide

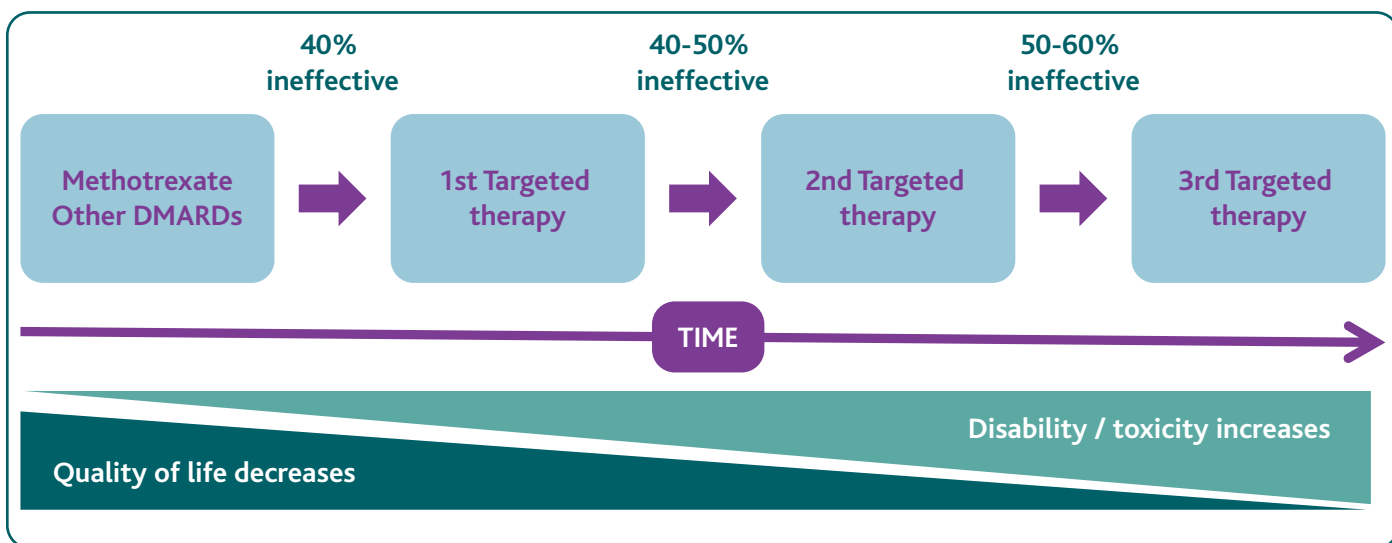


Figure 1.

What is Personalised Medicine?

Personalised Medicine involves tailoring medical treatment based on the individual's biological data – the patient undergoes tests before a medicine is prescribed for them.

The tests are used to help predict:

- Which medicine will work best for this person
- Should any medicines be avoided, or used at a lower dose, for this individual patient as the tests show they are likely to suffer side-effects

In cancer treatment it is usual for people to have a biopsy to determine the specific type of cancer and then the most effective treatment is selected, tailored to match the biology of the tumour.

In a similar way, by analysing tissue from the swollen joints of RA patients, research scientists at Queen Mary University of London (QMUL) aim to identify what parts of the immune system aren't working well and use this information to identify and prescribe the drug that has the best chance of working for the individual.

How to personalise? The search for treatment response predictors.

The QMUL team is at the forefront of biopsy led research and with the support of RA patients have been running a number of trials in hospitals across the UK and Europe.

In each of these studies a small piece of inflamed tissue is retrieved from the lining of a joint (synovium) using a needle under a local anaesthetic with ultrasound guidance.

QMUL now have a large collection of samples, both synovial tissue and blood, along with clinical information which includes what drug the patient was treated with and whether this was effective.

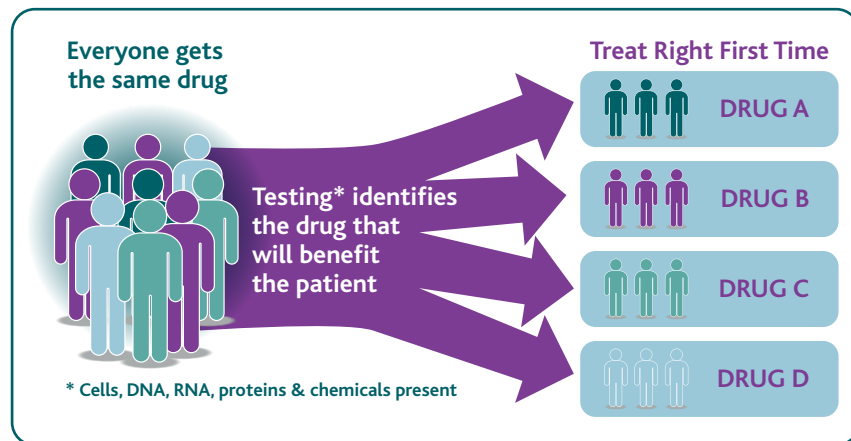


Figure 2 The promise of personalised medicine

Their experiments are showing us that RA patients have different types and levels of inflammatory cells and molecules in the joint lining before treatment and they are investigating if this information can be used to decide which treatment would work best.

Promising Research Developments to date.

Early RA study

Analysis of samples from an ongoing collection of synovial samples from people living with early RA (the Pathobiology of Early Arthritis Cohort (PEAC) study), has shown that before treatment there

are three different tissue types in patients - classified by the cells present or the levels of the molecule mRNA (mRNA directs which proteins are made in the cells).

Importantly, the disease severity and response to treatment varies with the different types indicating that different treatments may be required.

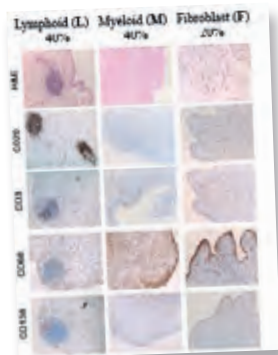


Figure 3 Different cell patterns seen under the microscope in RA patients

Researchers investigated whether analysing their synovial tissue could help determine whether they would benefit more from being treated with a drug targeted at reducing B-cells (rituximab) or the molecule IL-6 (tocilizumab).

As one of the tissue types has low B-cells they expected these patients' RA would not respond well to rituximab, and indeed they found that using the mRNA signatures (a biomarker) as the measure of levels of B-cells, these patients showed greater improvements when given tocilizumab.

This is a first step towards personalised medicine in treating RA but before this can be routinely applied in the clinic, the methods to measure the biomarker need to be refined and the results need to be confirmed in further studies which are currently ongoing. One larger study, the STRAP trial (again, a biopsy driven randomised trial) but investigating the best treatment option for patients earlier in their treatment pathway, is now in the analysis stage and will help to do this. More information on this trial can be found at www.matura-mrc.whri.qmul.ac.uk.

Whereas in previous work, treatments were randomly given and the effects measured, current projects include testing whether the biomarkers in the synovial tissue can be used to direct targeted treatments. This work is part of a large EU funded consortium known as 3TR Taxonomy, Treatments, Targets and Remission looking into why medicines are effective or ineffective across 7 different immune-mediated diseases (including Asthma, Crohn's & MS) see www.3tr-imi.eu for more information.

Results of first biopsy driven randomised trial in RA (R4RA trial)

People involved in the R4RA trial had disease that had not responded to treatment with DMARDS or anti-TNF and were ready to take the next steps with a new biologic/advanced medicine.

How can I get involved?

We hope this article has stimulated your interest in stratified medicines and has highlighted the potential of this approach to revolutionise future care for RA patients.

NRAS has been supporting the team at QMUL for 7 years through participating in research and support through our personalised medicine/Matura patient advisory group, visit the website www.matura.whri.qmul.ac.uk/what_is_matura.php for more information.

If you are interested in being part of the Personalised Medicine Patient Advisory Group, you can contact the Patient Chair Zoë Ide via email: volunteers@nras.org.uk for more information and to find out how you can get involved.

For more information visit: bit.ly/3dRRWYc

At the beginning no one was here for me...

April 2020

Gail, how are you holding up? This lockdown feels like its dragging on for quite a while now



Not so great myself if I am honest, I have been really worried about this lockdown. It's hard when you live on your own, my support network is gone. All this unknown is worrying me.



My medications need to be changed, I am waiting for urgent tests and referrals. But it's so difficult now with this pandemic 😞. Are you working from home?

Yes I am, how is your work going?



It's difficult, not having access to occupational health and work. I am having to learn a whole new way of working from home while shielding and with my RA it makes it even harder.

June 2020



How are you? I have been speaking to a lovely volunteer with the RA charity I told you about – She has RA so understands the difficulty of living with it, and how this pandemic has affected us all so much.

That's great! It must be good to have someone who understands what you are going through.



Completely! NRAS has been really useful, their Facebook lives have been helpful to get the information I need. They understand the emotional side of being diagnosed with RA.

December 2020

I'm so sorry this is still going on. Are you able to spend Christmas with anyone?



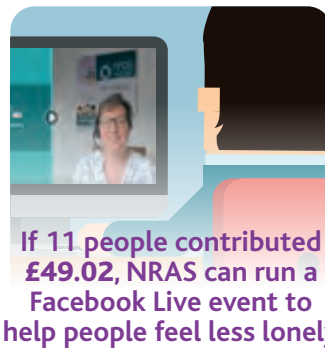
No, I will be completely alone. This is really hard 😞. Work have been supportive and I still have Poppy, my Here for You caller at NRAS, to speak with, but still I am struggling emotionally.

My name is Gail and I am 45 years old. I am an eye clinic liaison officer at the Royal Eye Hospital, I offer practical and emotional support for people with sight loss to ensure they can live life as independently as possible. One of my main hobbies is singing, of which I am part of a community choir. **Before being diagnosed with RA I led a very active life working full time, making the most of every hour.**

I was officially diagnosed with RA in July 2019 and it was a huge shock. I had a mixture of feelings, relief that I finally knew what was causing me to feel so unwell, but with hope that there was treatment that could help. As the months went by and still trying to find the right medication, it really started to impact me both physically and emotionally. Not knowing how I will be from hour to hour really influences my emotional well-being, **Having a diagnosis of RA made me feel like I lost myself and who I am.**

When we went into the first lockdown in 2020, I was really worried. My RA was unstable, not knowing how my care would be affected was concerning. Sadly the pandemic has and still is impacting the treatments that can be offered.

It costs £22.36 for the Helpline Team to answer 2 essential enquiries, helping to alleviate concerns.



I live on my own so lost my support network too with friends and felt very isolated, it affected me emotionally too.

NRAS have been amazing, I must have used their services around 30 times in the last 12 months and still continue to do so. I tuned into all the Facebook Live sessions, finding out the most recent and up to date information on medications. **These services made a massive difference and made me feel like I wasn't on my own.**

I signed up for the Here for You service, and was matched with someone who was fantastic. She helped me come to terms with my diagnosis.

It allowed me to be honest about the way I am feeling and identify what concerns me. She is a real inspiration and this service is so important to me as I know **I have someone I can turn to, it has been life-changing.**

Alongside this, I joined the RAAW wellbeing week and downloaded the publications. The Helpline team also spoke to me and answered my questions. Having the services from NRAS has not only provided me with practical information but has helped me emotionally. **They feel like a family to me.**

The support from NRAS has helped me start to explore living better and begin to embrace who I am, I am Gail first and foremost. Without them, there would be thousands of people left without the care they deserve and need, which is why **they need all the support they can get.**

The Volunteers have been amazing, supporting others while coping with their own challenges of living with RA during the pandemic.

When the COVID-19 pandemic began to take hold in March 2020, we were very conscious that many people living with RA would need support from NRAS.

Shielding and self-isolation requirements brought more challenges to everyone living with RA. We were aware that loneliness and anxiety would be significant issues and wanted to act quickly to set up support for those struggling. We felt that in order for it to truly make a difference, it was vital that any service was based around volunteer-led peer to peer support. Talking to someone who has lived experience of the condition and can really empathise with what you are going through in challenging times is vital. All those Volunteers

who were able to offer their help did so straightaway and NRAS got the Here for You service up and running.

As Gail's story shows, the NRAS Here for You service was invaluable to countless people over the last year. As the pandemic eases, Here for You will evolve and develop in the future but will always be a much-needed service for those living with RA.



Janet Brewer, Engagement Manager at NRAS

NRAS only exists thanks to the generosity of our Members and supporters. If you would like help us continue our vital services, please take a look at the donation form enclosed. Thank you

...NRAS was Here for Me



Professor George Kitas

Cardiovascular Disease Risk in people with Rheumatoid Arthritis

Introductory comment from Ailsa Bosworth, NRAS National Patient Champion:

In spite of having lived with RA for over 40 years, it was through working within the field of rheumatology for the last 20+ years, that I learned about the fact that RA is an independent risk factor for cardiovascular disease, and that approximately 50% of people with RA are likely to die from a cardiac event which may (or may not be) associated with having RA. No one specifically told me about this in the early years following my diagnosis. However, acquiring this knowledge has given me the power to influence my own modifiable risks. As a consequence, I have made changes during this period to my lifestyle. I make sure that I adhere to my treatment and eat healthily as well as monitoring things like blood pressure and cholesterol. I want to minimise any CVD risk that I have over and above the risks I can't do anything about such as my age, my genes, etc. I am a passionate believer that if we know about risks, we can do something about them (if we choose to) and this is where another passion comes in – supported self-management. A big part of what NRAS does is to provide evidence-based information and education to inform and empower you, the person with RA, to make the right choices and decisions about your own health, which suit your life and you as an individual.

We are grateful to Prof. George Kitas for contributing an article on this important subject to the NRAS magazine.

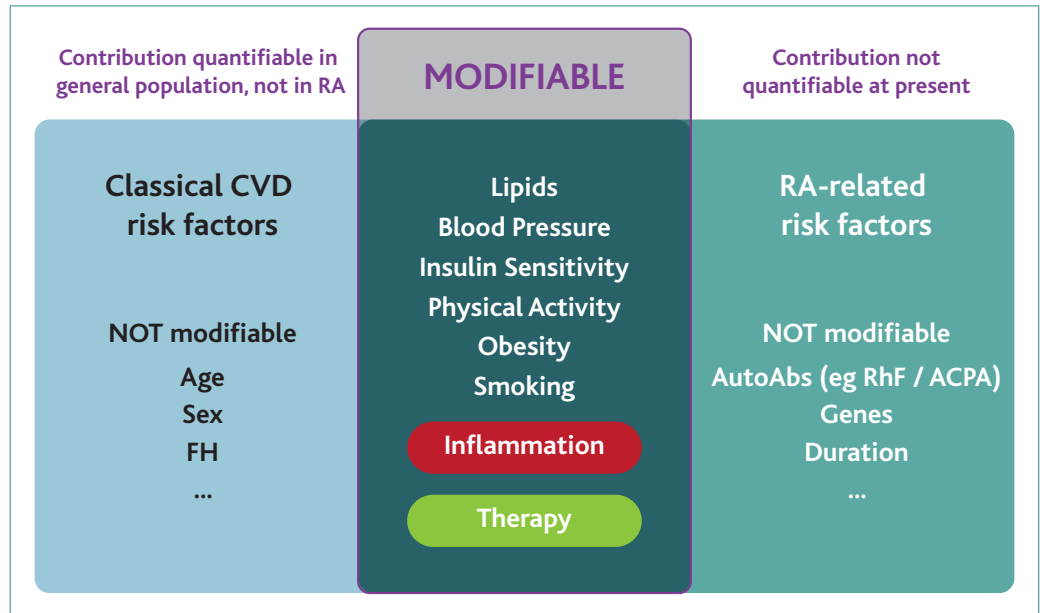
Rheumatoid arthritis (RA) is the most common chronic inflammatory rheumatic disease. In addition to its well-known effects on the joints, RA carries increased risk for several other conditions, with one of the most prominent being cardiovascular disease (CVD). People with RA have approximately a 50% increased risk of suffering a CVD event (e.g. a heart attack or stroke) or dying from CVD, compared to the general population. We would expect about 10 out of 1000 people to have an event or die from CVD every year, but in RA this raises to about 15 out of 1000. CVD can take several different forms in people with RA: the most common are heart attacks and strokes but other problems, such as heart failure, abnormalities of the heart rhythm and sudden cardiac death may also occur. The majority of these problems are thought to be due to accelerated hardening of the blood vessels (atherosclerosis), which is also the most common cause of heart disease in the general population but other mechanisms, for example, inflammation of the small blood vessels may also play a role in RA.

Accelerated atherosclerosis in RA is generally attributed to two main mechanisms and their interplay. One is the high-grade systemic (throughout the body) inflammation, which is characteristic of RA and may have significant adverse effects on the structure and function of blood vessels; the other involves the so-called classical CVD risk factors (which also operate in the general population), such as high blood pressure, cholesterol abnormalities, smoking, low levels of physical activity, being overweight, and others. These are all called "modifiable" risk factors, i.e. we can change them for the better and reduce our chances of suffering from CVD. There are other important risk factors, such as our age, sex, family history of CVD, our genes etc. that we cannot do much about (Figure 1). This gives us a clear idea about where we should concentrate our attention and interventions in order to deal with the increased CVD risk in people with RA.

There are 3 main components to a strategy for mitigating increased CVD risk in RA:

(a) Increased awareness: this applies both to all health professionals caring for people with RA (from public health to primary, secondary and tertiary care and associated services) and to the patients themselves. Unfortunately, although this problem has been known for over 2 decades now, awareness of, and concerted action to address it, remain very low, particularly when we compare it to the great strides taken in other groups with comparably high CVD risk, such as people with diabetes mellitus.

(b) Risk assessment: this depends on knowledge and regular assessment of CVD risk factors, both non-modifiable and modifiable, in individual people with RA. On the basis of these, we can then utilise specific tools (algorithms) to calculate an individual's risk of suffering a CVD event in the next few years and decide whether they need specific treatment or not (Figure 2). None of these tools are perfect at predicting CVD risk specifically for people with RA but it is better to have a systematic approach than to remain blissfully ignorant of our patients' cardiovascular risks. A major part



of the problem in achieving this, is lack of agreed care pathways and ownership of the responsibility to perform risk assessment amongst the various health professionals involved in the care of people with RA: from primary care physicians to secondary care specialists including rheumatologists, cardiologists, metabolic medicine physicians and others.

Figure 1: CVD Risk Factors in RA

(c) Risk management: this has two main targets. The first is great attention to and control of systemic inflammation (inflammation throughout the body); the second is meticulous control of individual modifiable classical CVD risk factors.

Exclusions	FRS ¹ Age >75, CVD/Diabetes	NCEP ² Age >80, CVD/Diabetes	SCORE ³ Age >65, CVD / Diabetes / TC ≥8 / LDL ≥6 / BP ≥180/110	RRS ⁴ Age >80, CVD/Diabetes	QRISK2 ⁵ Age ≥75, CVD/Diabetes
Age/gender	✓	✓	✓	✓	✓
Postcode					✓
Ethnicity					✓
BMI					✓
Smoking	✓	✓	✓	✓	✓
FHx CVD		✓		✓	✓
Diastolic BP	✓	✓			
Systolic BP	✓	✓	✓	✓	✓
TC	✓	✓	✓	✓	✓
HDL	✓	✓	✓	✓	✓
BP treated?	✓	✓			✓
RA					✓
AF					✓
CKD					✓
hs-CRP				✓	

Figure 2: Some tools to assess CVD risk

1. Schnabel, et al. *Lancet* 2009;373:739-45.
2. NCEP. *JAMA* 2001;285:2486-97.
3. SCORE. *Eur Heart J* 2012 May. Epub.
4. Ridker, et al. *JAMA* 2007;297:611-9.
5. Hippisley-Cox, et al. *BMJ* 2008;336:1475-82.

AF = atrial fibrillation;
 CKD = chronic kidney disease;
 FHx = family history;
 FRS = Framingham Risk Score;
 NCEP = National Cholesterol Education Program;
 RRS = Reynolds Risk Score

Tight control of inflammation is firmly in the hands of the rheumatology team. With the continuously increasing armamentarium of pharmacological interventions that are available to us, this target is attainable in most people with RA. Indeed, observational studies suggest that better control of inflammation with (virtually any) anti-rheumatic drugs associated with slowing down the process of atherosclerosis and improves cardiovascular outcomes in people with RA. However, as rheumatologists, we also need to be aware of the possible adverse effects our anti-rheumatic treatments may have on CVD risk factors (e.g., cholesterol, blood pressure) and assess/ manage them accordingly, if necessary, with help from other specialists. Meticulous control of individual CVD risk factors (e.g., blood pressure, cholesterol, blood sugar) is also achievable with medicines in most patients who require it. Again, the physicians involved in this, must be aware of and monitor for potential drug interactions, although a major class of medications used for cholesterol control, the statins, have been shown to be safe in people with RA. The major problem in classical CVD risk factor management in people with RA appears to be a practical one. Whose responsibility it is to do it and monitor its success in this population: the GP who is overwhelmed, the rheumatologist who may not have the cardiological expertise, or the cardiologist, who doesn't have the rheumatological expertise. Special combined cardio-rheumatology clinics have been shown to be effective and may be one of the answers to this issue.

However, we should not focus only on drug interventions. The extremely important role of lifestyle modification cannot be emphasised enough, particularly in the context of CVD (Figure 3). Increased physical activity (including structured, personalised exercise), has been clearly shown to give significant benefits to CVD risk factor control and even RA-specific outcomes such as general well-being, pain, fatigue and physical function in people with RA. A healthy diet and weight control are also likely to be important, although they have not been evaluated specifically in RA. Lifestyle modification is challenging enough at the best of times and even more so at times such as these when we are living through during the COVID-19 pandemic. Patient education is important in this context and has been shown to have beneficial effects. Psychological support and other structured behavioural interventions are being developed and assessed to help individuals with RA improve their lifestyle habits. Supportive, interactive websites and resources such as provided by NRAS are important for increasing knowledge and awareness of the problem, but their value in facilitating long-term lifestyle change needs to be formally evaluated.

Similarly, we should not focus only on caregivers and whatever they can each provide, be it education, medication or lifestyle modification resources and support. The individual person with RA and their care provider(s) both have equal responsibility for being aware of the problem at hand (or heart...), for agreeing personalised therapeutic targets and the interventions required to achieve them and for sticking to this agreement for a pre-specified period of time; until the situation, targets and interventions are re-evaluated and a new plan is agreed, if necessary.

Much can be done to reduce the risk of CVD in people with RA. Indeed, studies show that things are improving in this respect, but we should work together to improve them further. Once all relevant health professionals are aware of the importance of modifiable CVD risk factors and manage them to specific targets and if patients are supported and encouraged to achieve behavioural lifestyle change and do achieve it, this problem will be minimised, with gains for everybody: the individual person with RA and the health system. Holistic annual reviews where CVD risk is assessed are an important component of care and included in the NICE Quality Standard for RA – it must be widely implemented and successfully practiced.



Figure 3: How can we reduce CVD Risk Factors in RA?

Accreditation for UK Rheumatology

Launching April 2021, British Society for Rheumatology's (BSR) Quality Review Service (QRS) is an accreditation service open to all NHS rheumatology services across the UK. It aims to raise standards, improving patient care and experience.



The need for QRS was identified following a study conducted by BSR and the outcome showed that a formal service was needed. Dr Elizabeth Price, former BSR president and lead clinician for the QRS working group, noted: "Having seen the benefit of accreditation in other specialties, I was aware that developing standards a department could aspire to, would improve services for patients and staff." From this, QRS began!

Rheumatologists, specialist nurses, allied health professionals (AHPs) and patients from across the UK came together to create the UK's first rheumatology specific best practice standards. The standards are drawn from their experience, knowledge, and the expertise of professionals and focus on the needs of the patients who use these services.

This voluntary service aims to promote excellence in all aspects of rheumatology and targets improvement in patient care and experience. It does so by offering a professionally led accreditation service which has independent external validation.

A rheumatology service will be able to apply to be inspected by QRS. An inspection team of five assessors, including at least one clinician, nurse or AHP and a patient will use the best practice standards to assess the service. A crucial part of the inspection are the three interviews. The assessors will interview the management team, the clinical and other non-managerial staff, and the patients.

Once the inspection is completed an inspection report will be submitted to the independent accreditation panel. Formed from consultants, nurses, AHPs and patients, the panel decides to award accreditation based on the report submitted. Once accreditation is gained, the rheumatology service begins a three-year quality review cycle. An annual review will happen at the end of year 1 and 2.

All services that gain accreditation will be listed on BSR's website and a summary of their inspection reports will be available for the public to download and review. Patients will be able to see how their service does against the best practice standards.

Ailsa Bosworth, Founder, and National Patient Champion for NRAS has been a patient representative for QRS from the beginning of the project. She explains why she supports QRS: "I believe that the QRS is of significant value as programmes such as this and others, (including the National Early Inflammatory Arthritis Audit (NEIAA) and Getting it Right First Time (GIRFT) which address service quality improvement), help to drive up compliance with NICE guidelines and quality standards, which in turn improve patient care, patient outcomes and efficiency within the service."

QRS applies the same standards across all NHS services in England, Wales, Scotland, and Northern Ireland. The aim of QRS is to highlight and celebrate individual rheumatology services' strengths and to help identify areas for development. Lynne Kerton, rheumatology specialist nurse and QRS working group member says: "Without the accreditation process there is no one checking that rheumatology services meet the relevant requirements of a professional gold-standard service, which we all aspire towards."

Dr Liz Price summarises the value of QRS for the rheumatology service users: "Patients will have reassurance that their service is accountable and works to UK-recognised standards. It will have been inspected by patients themselves and patients' views taken into account during the process."

QRS has been successfully piloted across the UK with the best practice standards rigorously tested. The opening date for applications will be April 22, 2021. To learn more about QRS, please visit the website at www.rheumatology.org.uk/practice-quality



Dr Patrick Kiely

Authors:
 Elena Nikiphorou
 Hannah Jacklin
 Ailsa Bosworth
 Clare Jacklin
 Patrick Kiely

Summary of article published in *Rheumatology Advances in Practice* on 5th January, 2021

“Disease impact of rheumatoid arthritis in patients not treated with advanced therapies; survey findings from the National Rheumatoid Arthritis Society”

Background

In 2020, NRAS conducted a survey amongst its Members and non-members who had RA with a disease duration more than 2 years, who were not on advanced therapies (i.e. biologic/biosimilar or targeted synthetic DMARDs (JAK inhibitors)), with the aim of revealing the everyday impact of living with RA in people not treated with advanced therapies. It aimed to assess in detail a wide range of aspects of quality of life and everyday living using the RA Impact of Disease (RAID) patient reported outcome questionnaire and other measures of the impact RA has (on work).

Introduction

It is widely established that prompt and effective treatment in RA using tight control (treat-to-target) strategies improves disease outcomes. (For more information on tight control, please see our booklet 'Living Better with RA' and our website). The aim of tight control is to get disease into remission, or if that is not possible, as low a disease activity state as possible. The 28-joint count Disease Activity Score (DAS28) is used in the UK to determine how well disease is being controlled by current medication, and assess eligibility to move on to advanced therapies, if standard disease modifying drugs are not working well enough (current NICE guideline requires a DAS 28 of greater than 5.1 for a patient to be considered for moving onto advanced therapies).

Results

There were 612 responses from patients having an average age of 59 years. 88% were female and 37.7% had a disease duration of 2–5 years and 27.9% a disease duration of 5–10 years. In the last year, 90% had reported a flare of their RA, with more than 23% reporting six flares. As part of the survey, participants completed the RAID questionnaire which measures 7 domains: pain, functional disability assessment, fatigue, sleep, physical wellbeing, emotional wellbeing and coping. Only 12.4% of participants recorded an 'acceptable state' as measured by the scoring system for the RAID questionnaire. On an individual patient level, a score below 2 is deemed 'a patient acceptable state' on a scale of 0–10. More than 50% of participants scored each of the seven domains in the high range (indicating a worse state); 74.3% scored sleep problems and 72% fatigue in the high range.

Difficulties at work were measured using a selection of questions taken from the Work Productivity and Activity Impairment (WPAI) questionnaire. A need to change working hours was reported by 70%. The survey results showed increasing difficulties with daily physical activities. Reduced emotional and physical wellbeing in the past week were all strongly linked to levels of pain reported as well as number of flares and ability to cope. The total RAID score strongly predicted the number of flares people reported.

Key Outcomes from this study

- In established RA, patients who are not on advanced therapies, indicate high levels of suffering as reported by the RAID.
- The RAID 'acceptable state' is very uncommon.
- High levels of pain, physical disability, sleep difficulties and fatigue are key symptoms experienced.

To read the full paper, go to the news section of our website
www.nras.org.uk/news

Nursing during the pandemic

Experience from a paediatric rheumatology nurse specialist

A usual clinic day in a paediatric rheumatology unit starts with the rheumatology multi-disciplinary team setting up their clinic rooms. This team consists of a consultant, specialist grade doctor, clinical nurse specialist, physiotherapist and occupational therapist. Patients arrive throughout the day, are assessed, have thorough joint examinations to decide if their current treatment plan is working effectively and have their medication regimes monitored.

Flash back to March 2020, and this is no normal clinic as there is a pandemic in the UK. All clinic appointments had to be cancelled and some members of the team must work from home. Other members of the team were redeployed to adult wards to support the increasing number of patients suffering from COVID-19 being admitted. There were also some doctors needing to shield and isolate at home. Whilst all this was going on, our patients still needed the same support and care if not more, as lots of reassurance was needed and more questions answered e.g., does my child need to shield?

Then along came the technology; we thought oh no! How do we work this? Out came the cameras and headsets, followed by Microsoft Teams so that we could provide video and telephone consultations from our homes. In theory it sounded like a good idea. In practice though it did not always go according to plan. We were talking to patients as they walked their dogs and once when the patient was in the bath. Patients were very apologetic as they had forgotten their appointment as they were unsure of what day of the week it was.

The video consultations brought up other problems, with mums and dads running after their child trying to show us a swollen knee, trying their best to carry out a joint examination for us whilst on the other end of a camera.

By the time the summer came, restrictions were lifted a little and members of the team were allowed back into work. It was all very different, everyone wearing PPE and using tape measures for the two-metre rule. It was not surprising

that there were a few missed appointments, as families were too frightened to attend hospitals. Extra telephone calls were made to reassure families it was safe to attend and slowly the trust came back.

So, what now? What has the pandemic made us think about the service we provide? What should we do in the future to offer our patients a better service?

Telephone consultations will stay for those patients who remain stable on their treatment plan with no flares. We found video consultations were not so helpful as almost all patients following a video call were called in to be seen face-to-face so that a thorough examination of joints could be carried out. Virtual team meetings will stay and be used along with other meetings with members of the wider multi-disciplinary team as they have proved a great success.



Fiona Brown

Paediatric Rheumatology
Nurse Specialist





A look back at...

#WearPurpleForJIA2020

NRAS were amazed yet again by all our wonderful JIA families and the schools who were not going to let COVID-19 deter them from getting involved with this now annual event in the JIA-at-NRAS calendar.

We had taken the early decision that the original June date would not happen and pushed it back to November, hoping that life would be back to a more normal state – but obviously it didn't quite pan out like that. However, all our JIA families that support this key event in our JIA calendar were not going to be beaten and became even more inventive than usual.

We had some fantastic amounts raised and some truly jaw dropping challenges from some of our younger fundraisers. Families organised giant online raffles, craft days, trampoline bounces and lots and lots of running and cycling. A few schools were able to support the day and raise awareness as it is especially important that the classmates of children with JIA understand more about the disease. We salute you all and would like to say that all your hard work and effort you put in has raised a truly fabulous:

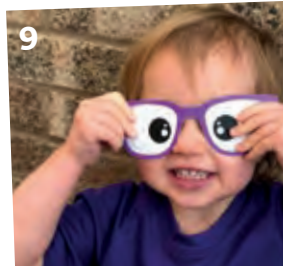
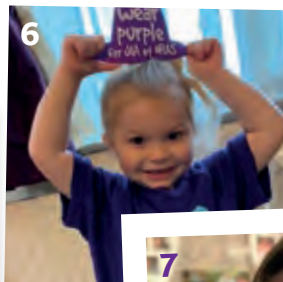
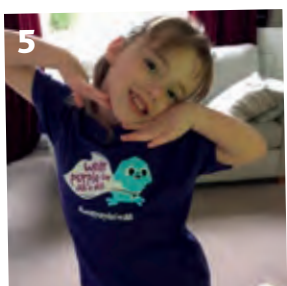
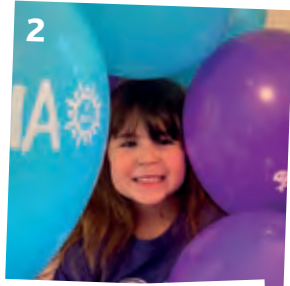
£20,600 for JIA at NRAS

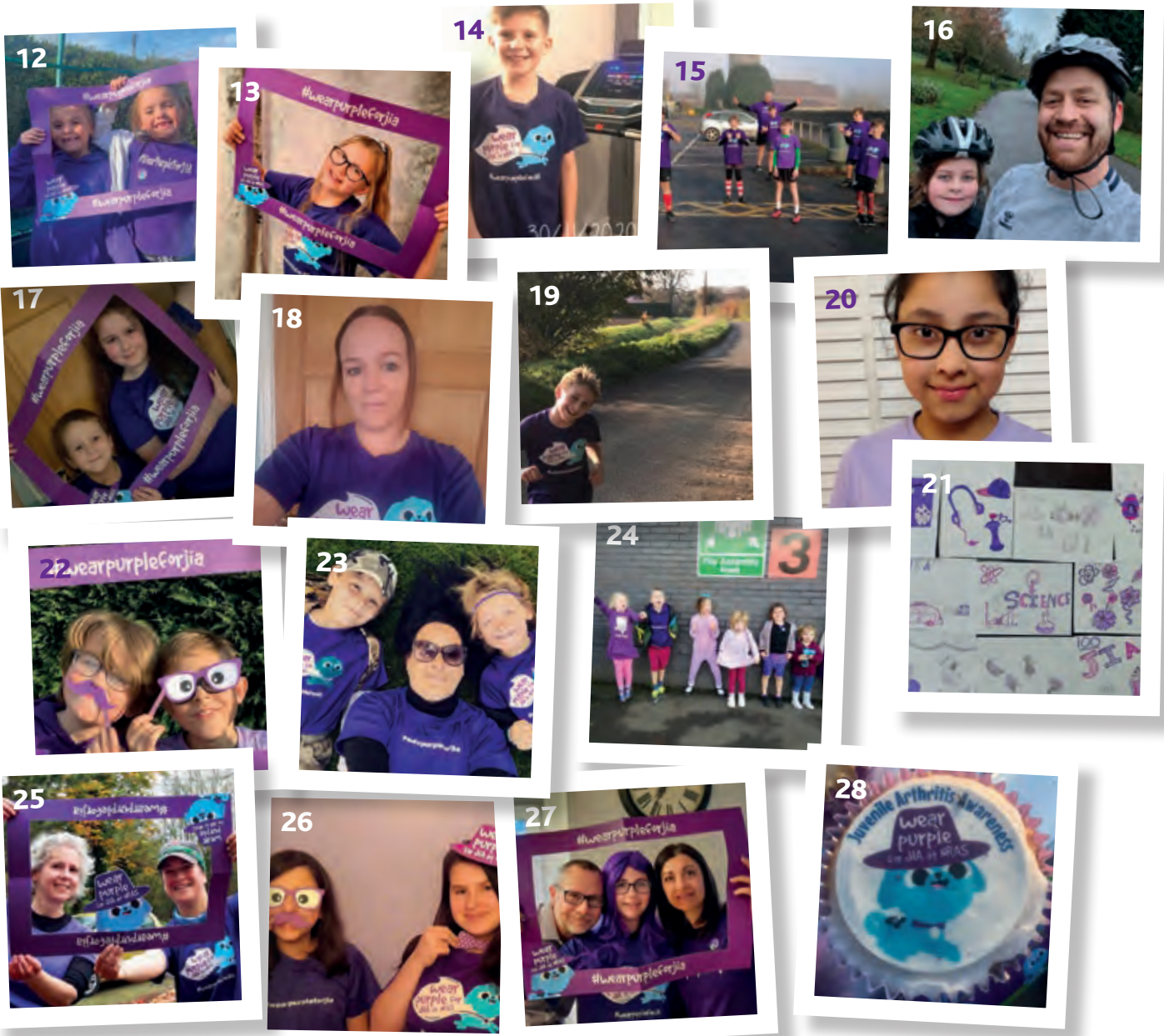
A huge **Thank You** to all our #WearPurpleForJIA fundraisers for 2020!!

The money raised will be used to develop more services and resources for children and young people with JIA, and support for parents. These include:

- peer to peer support for young people (including a text service)
- resources including podcasts from our Young Voices Panel
- virtual conferences specifically for parents
- conferences for young people living with JIA
- continuing to raise awareness of JIA.

We now have a new Young Person's Project Co-ordinator in place – Debbie Wilson and she will be driving forward all the new services and initiatives.





1. Rosie Kozyra and her sister Lauren who organised a 'Hunt Josie the JIA Bear' raised £553
- 2 & 11. Grace's Mum Clare organised an online raffle and they raised £781
3. Lily Gacon-Smith who lives in France won the Bonnie the Dog competition
4. Scarlett Silverman who set up a Facebook donate page and raised £220
5. The Silverman Family
6. Ava Tidmarsh - her Mum Lauren set up a Facebook donate page and raised £325
7. Charlotte Gregory and her family organised a Craft day and a Pamper hamper which they raffled and raised £480
8. The Gregory family crafting
- 9 & 10. Faye Kwasiuk (with cut out glasses) and her brother (with hat) - Faye's parents organised a huge online Raffle in their village and raised an amazing £2,000 - Faye's nursery school also raised £71
12. Heidi Willis and her twin sister Freya who did 1000 jumps on their trampoline and raised £758 this included a Company donation that their Dad Karl secured from his company.
13. Scarlett Burchett designed her own posters and got her school involved with a Mufti Day giving a talk about JIA in assembly at St Joseph's RC School in Oldham. She raised a fabulous £1,450
14. Seth and his family challenged themselves to run 500km during the month of November - and raised an astounding £4,960
15. Seth and his football team Newcastle Emlyn Under 11s who also took part in their support bubble.
16. Freya aged 10 with her Dad Matthew supporting her, rode 26 miles over a week and raised a fantastic £1,397 - Matthew Evans also got himself a slot on local BBC Radio Leicester to help promote awareness about JIA
- 17 & 18. Farah and Bradley and Mum Lynette Haselip raised £277 with their inventive football cards online. Farah and Lynette our founders of Wear Purple and now Patrons for this event
19. Henry did a personal challenge of running a marathon distance over a week and raised a great £476 he even roped in his dad!
- 20 & 21. Amiya baked cakes and did a sponsored doodlethon and raised a wonderful £272
21. St Mary's School in Henley got involved and raised £749 pupil Caleb who has JIA made a video to share with the school to help others understand more about living with JIA.
22. The Westwoods set up a Facebook fundraising page as fundraising in the traditional way was trickier and collected donations of £150
23. Oliver Westlake and his classmates at St Helen's school in Exeter wore their purple clothes and raised £190
24. Harry Teale-Howat challenged herself to a number of runs over the year and raised £205
25. The Teale-Howat girls supporting their mum with her running.
26. The Bennett family getting into the spirit with Megan sporting purple hair.
27. Alison Morris held a socially distanced cake sale outside her home and raised £173



Interview with Nancy Edwards

In September last year, a lead nurse at Nottingham Children’s hospital got in touch with JIA-at-NRAS to say that a 15-year-old girl newly diagnosed with juvenile idiopathic arthritis has been doing some amazing art inspired by her illness. Our Young Persons Project Co-Ordinator spoke to the family and they shared Nancy’s artwork. She is a very talented artist, and we are very pleased to share some of this artwork. Nancy has also agreed to do an art class during our Wear Purple Wellbeing week in June. To find out more about the artist and the inspiration behind her art, Nancy has answered some questions for us:

Q: How would you describe your style of art?

As someone who reads a great deal of oriental comics and manga, I enjoy working in a semi-realistic art style, with bright colours and bold rendering. I also work with realism-portraits, but that’s more for GCSE art purposes (they’re not keen on digital mediums).

Q: How has your art helped with cope with JIA?

My art is a coping method for any struggles I have. I cannot say it has specifically helped with my diagnosis, but maybe that’s because it wasn’t too difficult to accept. I felt the diagnosis was actually a positive result and brought clarity to my concern.

Q: Do you feel your art has helped you cope with lockdown?

Yes, to the point that any new ideas constantly occupy my mind and all I can think about is what I can create next. I definitely overdraw, finding myself awake until 3am most nights to carry on working on private projects which aid my productivity. This helps in a time where most distractions become meagre rather easily.

Q: Apart from art, do you have any other interests/hobbies?

As previously mentioned, I enjoy music (I play 3 instruments), and I love international artists. I’m a 1st Dan in Shotokan karate (black belt), and also have a keen interest in couture and design. I’ve always been drawn to creative writing, and in time hope to bring these strengths together in future projects.

Q: When were you first diagnosed with JIA?

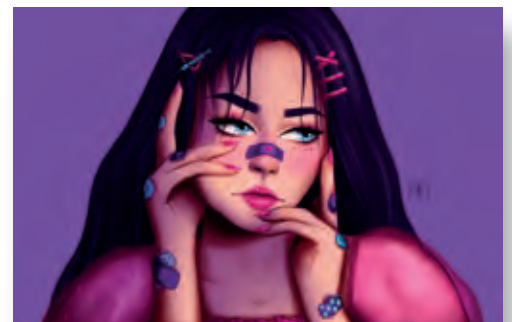
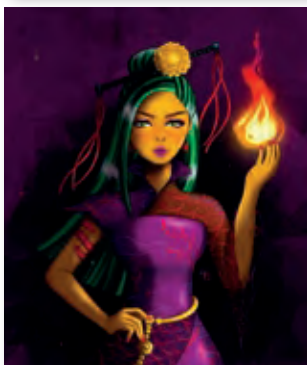
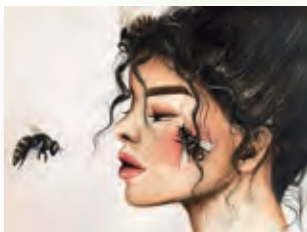
I was diagnosed in September 2020, but I first began noticing symptoms about a year beforehand.

Q: How did you feel when you received the diagnosis?

I received my diagnosis in a particularly difficult week which already happened to be overloaded with medical issues for other members of my family, so it was a lot to handle at the time. However, it was comforting to finally have an answer, despite being completely unexpected. The prospect of self-medicating for such an extended period of time was daunting; but it was reassuring to know that it would make a difference.

Q: What attracted you to art?

I had an equal interest in music around two years ago, but it was more difficult to express my ideas or present them to people in a musical form. With visual art the options are endless - and in an Instagram posting format, universally accessible. I started working on pieces obsessively, to perfect my visions in a physical form. I liked that it offered escapism and individuality, and I could gain instant responses – unlike with music.



You can follow Nancy on Instagram at [instagram.com/soleilunie](https://www.instagram.com/soleilunie)

Finding the Positives with JIA

I was diagnosed with juvenile idiopathic arthritis (JIA) when I was 11. I am now 25 and have lived with arthritis longer than without it, it is most definitely a part of me and has shaped the person I am today. Having a chronic illness has taught me the value of communication, resilience, and knowing my limits. All these lessons have led me to where I am today, working as an international fashion model, having gained a BSc in biology, and many other achievements.

Learning the value of communication has been so important and I would advise anyone diagnosed to find the language they need to discuss their illness. This can be all the details or a brief overview – but anything that makes the classic 'why do you take that medication' or 'why do your joints look like that' questions easier. I know when I was younger, I struggled to know what to say, but my parents really helped me find the words to both normalise and explain what I was going through.

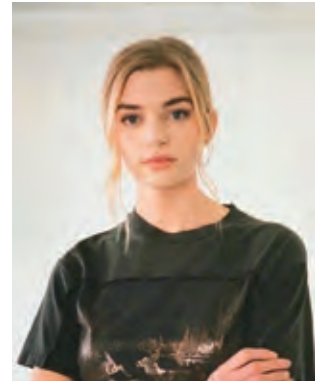
There are so many avenues of communication to be explored as someone with arthritis. You can talk anonymously on forums, talk over the phone with NRAS's helpline or 'peer to peer' service, or join more specialised support groups. During the pandemic, the value of maintaining communication with friends, family, support networks and healthcare teams cannot be overestimated so please do reach out. As a teenager I was reluctant to join support groups, but now, having joined the NRAS Young Voices Panel (YVP) I truly see the value of discussing my illness with people who are in the same boat as me.

Resilience is a value shared by all with a chronic illness and can look like many things to many people. When I was younger, resilience meant suppressing signs of JIA and recuperating at home. I now take resilience to mean my ability to cope and overcome any difficulties I may face, without hiding the fact that I have JIA. I feel resilience

is especially important to people with JIA, as it is a condition overcome with misconceptions; that we are too young, too healthy-looking, we'll outgrow it. Being resilient in the face of the ill-informed is difficult, but something I have learnt to do.

Finding your limits is something most people do in their 20s or 30s, however as a young person with a chronic illness I got to know my limits much earlier. Knowing how much sleep I need, how much exercise makes me feel good and always remembering my gloves is important. This is definitely not rock'n'roll but leads to a less stressful and ultimately less painful life. Everyone's limits are different and can even vary day to day with flares and life events. As a teenager, giving my all at school and playing sports meant coming home and having a pre-dinner nap thanks to JIA fatigue, but that was a trade-off I was kind of happy with.

While it hasn't always been an easy road, it's certainly not all bad either. Too often, we reflect on what we have lost through having a chronic illness, but it is nice to appreciate what we have gained. Through having JIA, I have met some great people (shoutout to the YVP) and I encourage you to also try and find the positives, and always remember NRAS and your support network will be there for you.



Annabel Longden





Dr Janet McDonagh

Clinical Senior lecturer in Paediatric and Adolescent Rheumatology

Young Minds Matter

Introduction

The mental health of all young people is being increasingly recognised as being in need of urgent attention. It is known that mental health disorders like depression and anxiety increase during adolescence (10-19 years), particularly in girls. Half of all mental health disorders which continue into adulthood start by the age of 14 and three quarters by the age of 24 so the adolescent years are an important window of opportunity for the promotion of mental health.

Young people with long-term health conditions like JIA or lupus are at increased risk of depressive

and/or anxiety symptoms, though many go unrecognised in rheumatology clinics if not specifically asked about. The recent COVID-19 pandemic has had a significant impact on the lives of all young people, including those with rheumatic disease. Although the majority of young people are not considered clinically extremely vulnerable and are not at increased risk of complications as adults are, they are hugely affected by the resulting loss of opportunity to see their friends, go to school/college, enjoy their valued leisure activities, do physical exercise as well as experiencing the anxiety of either they or their loved ones getting the infection.

A Young Person's Perspective

As someone who has lived with JIA their entire life, I have felt that the psychological impact of this disease can sometimes be worse than the physical symptoms themselves. The burden of living with chronic pain, fatigue, the side effects from multiple aggressive drug treatments, the fear of relapse and uncertainty about the future can be really difficult to manage at a young age when a child has no life experience or coping skills to call on. Many young people are also unaware of the differences between an autoimmune condition like JIA and osteoarthritis due to old age. This can lead to feeling very misunderstood by peers and that your struggles are being invalidated. When a child is first diagnosed with a chronic condition like JIA, I think it's extremely important to offer them psychological support right from the diagnosis. This proactive approach could save a lot of suffering for the patient, as opposed to care being reactive and waiting for any issues to arise, since by this point a child's mental state is likely to be much more difficult to treat. I also think it's extremely important for parents to be educated about the possible psychological impact of their child's condition right from the diagnosis, since spotting the early signs of a mental health condition could be invaluable for early intervention.

The impact of having a long period of remission at a young age, only for a young person's disease to flare once again in adolescence shouldn't be overlooked. I found this time in my life particularly hard to deal with, since most very young children have very little knowledge of

their condition. Therefore, when a young person's condition returns in adolescence, not only does the young person now understand the quality of life they're missing out on, but every aspect of their life has now been taken over by a disease, in a time when they crave independence and control the most.

For me, one area of life particularly affected by the psychological impacts of JIA, was body image. It can be extremely difficult for a young person to form a healthy relationship with their body when their body is the thing causing them pain and suffering. It can also be very difficult to exercise during a flare which can understandably lead to weight gain. In addition to this, the physical side effects of treatments (such as steroids) include weight gain, acne and stretch marks, which are the last thing any young person wants to deal with. Due to these reasons, I believe regular screening for eating disorders should be an important part of monitoring the mental health of young people in rheumatology clinics. As a young teen I remember feeling isolated and lonely since my peers couldn't relate to what I was going through. Joining the 'YourRheum' youth panel (www.yourrheum.org) allowed me to meet other people who knew exactly how I felt, and these connections were invaluable in making me feel less alone. I think all rheumatology clinics should offer young people the chance to meet other young people with similar conditions wherever possible, whether this be group physiotherapy sessions or a youth advisory panel like 'YourRheum', since this is likely to have a positive impact on a young person's mental health.



Eleanor Edgar

What can be done about it?

Although rheumatology professionals are aware of the importance of the emotional wellbeing of the young people in rheumatology clinics, some may not feel they have the adequate knowledge and skills to address it and there is an urgent need for better training in mental health for all rheumatology professionals. Perhaps we need to establish a mental health "First Aid" course to provide professionals with the knowledge and skills to start those often difficult conversations in clinic. And, as Eleanor clearly highlights, it is never too early. At the time of diagnosis, as well as talking about the physical impact of the condition, professionals should be encouraged to acknowledge the psychological impact a diagnosis of a long-term health condition during adolescence both on the young person as well as the parent and family. This initial acknowledgment can then empower young people to ask for help when the need arises.

The understanding of adolescent brain development has advanced dramatically in the last decade and is key for health professionals so they can tailor their communication skills

appropriately. The right environment is also important. Young people often open up easier without their parent in the consultations so rheumatology services should establish dedicated adolescent clinics where this is standard practice for at least part of all visits. Confidentiality must always be assured for the young person whilst remaining inclusive of the family e.g., bringing the parent back in at the end of the consultation so that the plan for management can be discussed. Such practices however often need longer appointments than the 20-minute standard follow-up appointment, so we need to continue to lobby for the positive impact of enough time for such discussions. Unfortunately, there is still limited access to formal psychological support in many areas in the UK, but it is important to find out what services are available at a local community level which rheumatology teams can signpost to. So, in summary, let us remember our heads are part of our body and mental health is important for all. For more information on emotions and mental health, and our video on mental health please see jia.org.uk/resource/emotions-and-mental-health/

New Guidelines on the management of chronic pain in children

The World Health Organisation (WHO) have issued new guidelines on the management of chronic pain in children including those with arthritic conditions i.e., JIA. WHO is a specialised agency under the United Nations responsible for public health. Guidelines are there to support countries and their partners to develop and implement national and local policies, regulations, pain management protocols and best practices for pain relief.

Based on the most current scientific evidence, the new WHO guidelines for the management of chronic pain in children aged 0 -19 years recommend three areas of interventions for pain relief:

1. Physical therapy
2. Psychological therapy
3. Pharmacological management

This new guideline replaces the previous guideline recommending pharmacological treatment of persistent pain in children with medical illnesses. WHO have now recognised that chronic pain in conditions such as JIA are complex and multidimensional and cannot be treated with medication alone. The guidelines include 10 best practice statements which apply to all aspects of the clinical care of a child with chronic pain, including the planning, implementation, and delivery of physical, psychological, and pharmacological interventions.

For further information see www.who.int/news/item/01-02-2021-who-issues-new-guidelines-on-the-management-of-chronic-pain-in-children.





Kate Mowbray
Study Coordinator

Help shape the future of the JIA Biologics Register

The UK JIA Biologics Register is the collaboration of the Biologics for Children with Rheumatic Diseases study (BCRD) and the British Society for Paediatric and Adolescent Rheumatology (BSPAR) Etanercept Study. These studies have been running for over a decade and have over 3,000 children and young people with JIA registered. Some of the questions already answered using this data are: will treatment for arthritis affect a child's growth? How well is JIA really controlled in the first year of treatment with Enbrel? Is it OK to switch biologic therapies if the first one does not work well enough or causes a side effect?

Information that is held within hospital notes regarding changes to treatment, how active the participant's JIA is and any new illnesses or adverse events that are experienced are sent from the paediatric rheumatology teams to the research team. The information is analysed to answer questions like the ones above, and many more.

If you have JIA and are starting a new treatment of biologic/biosimilar therapy, you are eligible for the register. Your paediatric rheumatology team

should approach you for your consent to being involved. However, if you are unsure and would be interested in participating, please contact your rheumatology team directly, who will be able to advise if they are able to enrol you.

How you can help this important research study

If you have any questions that you think would be interesting to investigate about JIA or its treatment, then the team at the UK JIA Biologics Register would love to hear your ideas. It is so important that the voices of people with JIA are heard! No question is too big or small and there are no "silly" questions!

More information on the UK JIA Biologics Register and details of their discoveries so far can be found at their website: sites.manchester.ac.uk/bcrdbspar/for-participants/our-discoveries/ - click on the 'Contact Us' page if you want to get in touch with them about any ideas for questions that the team could look at.



Wear purple for JIA at NRAS

Wear Purple Wellbeing Week!

This year we have a new spin on our Wear Purple campaign with full week of sessions and events running from **Monday 14 June to Friday 18 June** – with the 18th being our traditional Wear Purple day!

Here is a taste of what might be in store....

Wellbeing sessions for children

Facebook lives with Experts

Tailor make your Wear Purple pack this year

New merchandise for 2021

Arrange a Quiz Event with our downloaded templates

Editable Certificates

Stay Updated!

Join our online community: facebook.com/wearpurpleforjia
Check for regular updates on our website: www.jia.org.uk



Registered with FUNDRAISING REGULATOR

For help with ideas, get in touch with the team

fundraising@nras.org.uk




NRAS is a registered charity in England and Wales (1134859) and Scotland (SC039721). A company limited by guarantee. Registered company in England and Wales (7127101). JIA-at-NRAS is a part of the National Rheumatoid Arthritis Society.

Early treatment with biologic shown to improve outcomes in JIA

Early treatment with a biologic therapy has been found to give a greater chance of remission and an improvement in disease outcomes in general, according to new research.

This research was presented at the annual 'American College of Rheumatology Convergence, which was held virtually towards the end of 2020.

These findings came from a 'retrospective' study, meaning that they were examining existing data from patients. 55 patients were enrolled in the study, at an average diagnosis age of 8 years old, all of whom had been on a biologic therapy within 24 months of diagnosis. Of these, over 80% were prescribed a standard (i.e. non-biologic) disease modifying anti-rheumatic drug (DMARD) at some point within the same time period. Of the patients studied, 55% were given a biologic drug within 6 months of diagnosis, 27% within 7-12 months, 13% within 13-18 months and 6% within 19-24 months.

Two years after diagnosis, 78% of patients were in remission from their JIA. The study found that patients who started a biologic

within 7.5 months of diagnosis were more likely to go into remission and had less active disease than those who started it after 7.5 months. In addition to this, the earlier patients started treatment for JIA, the shorter the time from treatment initiation to remission was likely to occur, highlighting the need to start treatment as early as possible.



Why do multiple biologics fail for some patients?

Since their arrival in the late 1990s, biologic medications have been an invaluable innovation for many patients with RA, in getting their disease under better control. Yet for some, failure with multiple biologic drugs can occur, reducing the treatment options available to them.

New research findings are shedding some light on some of the key factors that make this failure of multiple biologics to work more likely. In particular, they identified two, independent risk factors (these being younger age and the presence of joint erosion) that lead to higher risk of multiple biologic drug failure.

Gaining an understanding of why some people experience this lack of response from multiple biologic drugs could help clinicians to determine the best course of treatment for individual patients, rather than having to go through a 'trial-and-error' approach. More research will be needed to determine the best treatment plan for patients in this category, perhaps with non-biologic drugs such as the relatively new 'JAK inhibitors'.





Paul Amlani-Hatcher

Paul Amlani-Hatcher is Chair of the Patient Panel and member of the NEIAA Project Working Group

National Early Inflammatory Arthritis Audit (NEIAA) wins award for Patient and Public involvement

When I received a phone call from Ailsa Bosworth MBE from National Rheumatoid Arthritis Society (NRAS) asking if I'd be interested in volunteering to be involved in "a very important piece of work" with the British Society for Rheumatology (BSR), little could I have imagined the significance in my reply. Now some two years later, I'm proud to lead the patient involvement in the National Early Inflammatory Arthritis Audit (NEIAA). This work has recently won the Richard Driscoll Memorial Award, recognising outstanding work in patient and public involvement.

The NEIA audit aims to improve the quality of care for people living with inflammatory arthritis, collecting information on all new patients over the age of 16 in specialist rheumatology departments in England and Wales. The audit assesses seven key metrics of care for people with new symptoms of arthritis attending rheumatology services for the first time:

1. How quickly do primary care health professionals refer people suspected to have inflammatory arthritis?
2. How soon after referral are people seen in secondary care?
3. How long does it take to start treatment?
4. Do patients receive prompt education about their condition?
5. Are treatment targets set and agreed?
6. Do patients have access to emergency advice?
7. Are annual reviews taking place?

My role is to chair the Patient Panel, to coordinate the production of the Annual Patient Report and to represent the panel at the Project Working Group. The Patient Panel is made up of 11 people and includes a co-ordinator from BSR. With many of the panel members shielding this year it has been an interesting challenge to



keep the work going and meetings have continued through video conferencing. Although it is sad not to meet face-to-face it has also been less tiring as the “work from home” option cuts out travelling to central London. This adaptability was part of the reason that we won the Richard Driscoll Memorial Award.

One of the key areas of work that we are involved in is the Patient-Reported Outcome Measures (PROMs). PROMs are questionnaires about health and quality of life which help to understand how patients’ conditions change and this affects day-to-day activities. Historically, rheumatology departments collected this information at the time of appointments using paper forms. Due to COVID-19, rheumatology departments have had to adapt to new ways of working. Many appointments now happen by telephone, which means teams cannot collect paper questionnaires.

In August 2020, BSR launched a new ePROMs platform, available for free to rheumatology departments. The platform sends out questionnaires to patients by email and shares the information back with the clinical teams. This switch to online has the benefit of allowing patients more time to reflect on their condition away from the clinics, where perhaps there’s a tendency to put a brave face on, play down symptoms, or gloss over issues such as low mood.

One of the questionnaires you might have been asked to complete is the self-reported DAS (disease activity score). Thanks also to the REMote MONitoring of Rheumatoid Arthritis (REMORA) initiative patients can now have more confidence on completing their DAS28

with a video created for self-assessment which you can view on Youtube (youtu.be/SBSJKMYNOaw). Other questionnaires ask about how severe your symptoms are, how much your disease impacts on your ability to do tasks and work, and questions about your mood.

To date, the participation levels of patients in PROMs has been good, although we continue to explore ways of making it better. At baseline, covering some 5,000 participants to date, patients reported a high impact of the disease, with significant levels of functional and work impairment, depression and anxiety. Improvements however were seen across all domains after 3 and again after 12 months.

In terms of the overall audit results (see summary of latest findings below) there have been significant improvements in performance against the first three NICE quality statements. Overall, the results provide some grounds for optimism, but also highlight aspects of care requiring more focus.

As somebody diagnosed with rheumatoid arthritis in 2015, I feel it is vital that this audit continues and in particular that PROMs are continued to be used to provide the 'qualitative' element to the assessment of patient welfare, as the disease can have such a negative impact on mental health and the ability to work. The process of PROMs can also help facilitate patients to become more pro-active in the self-management of their condition.

Summary of latest findings: nras.org.uk/resource/the-national-early-inflammatory-arthritis-audit-neiaa-2/

Why can I never say no to Ailsa?

Christina Macleod - Avios Prize Winner

My name is Christina Macleod, I have been a rheumatology occupational therapist in The Royal Hampshire County Hospital in Winchester for 25 years. Last year, Ailsa contacted me to ask if I would do a little video to explain why I was using the NRAS New2RA Right Start service for my patients. I agreed but then came the problem of getting something filmed. With some help from a colleague and the son of my friend, it was completed and NRAS transformed our little film into an amazing introduction to New2RA Right Start on their website.

Then confession time, I had to tell the rheumatology team at Winchester (the communication team at the hospital had already given permission). The link was sent, and one of the older rheumatologists who has known me for years, without my permission, sent the link to the Chief Executive and the WOW award team (an internal hospital team that patients and staff can nominate staff who deserve recognition of their work).

No one was more surprised than me when I received an email to say I had been chosen as one of our hospitals’ winners for a 60,000 Avios points courtesy of British Airways Executive Club Members. There are several times over the years that I have been nominated for things that I have given more energy and time to, but this time Dr Buchanan wrote the most amazing supporting email, and I won!

Over many years many people have supported my career, firstly my patients have given me inspiration for the way they cope and accept the difficult challenge of living with RA. Colleagues have encouraged me to apply (even writing applications for me!) for professional grants, NRAS have supported my career, recognising that silver ring splints can give confidence and help prevent deformity. NRAS have ensured that we the professionals know of anything that can help you the patient and provide all the resources for teaching others – an example of this was when they supported me, running a silver ring splint workshop in Liverpool. NRAS is somewhere that as a health professional I will go to when all other avenues of support for patients have run dry. Together we (patients, nurses, doctors, therapists amongst other members of the medical team) push for better treatment and support and hopefully one day a cure for RA.



In Westminster over the last decade, there have been a number of attempts by Health Secretaries to make wide-ranging changes to the way the NHS is run. The NHS is Europe's biggest single employer, so this is no straightforward task.

The UK government's new White Paper for NHS services in England states on the first few pages that it does not mandate a new reorganisation. However, the paper does detail very significant changes, notably plans to reverse a key part of the Andrew Lansley reforms introduced under David Cameron. This change of direction is intended to help commissioners and healthcare practitioners to plan more person-centred care, which has been welcomed by many in the NHS.

At the same time, the Health Secretary is shifting the dial back towards more political oversight of England-wide NHS decisions. Power will be taken away from NHS England's Chief Executive—currently Sir Simon Stevens, who has featured in several of the government's coronavirus press conferences and handed back to the Health Secretary. This means that NHS England's biggest spending decisions will end up on the Health Secretary's desk.

Another NHS reorganisation?

A first look at the government's White Paper for the future of the NHS in England.

From competition to collaboration

In 2012, the Coalition Government announced plans to introduce more competition in the NHS, giving the Competition and Markets Authority (CMA) a statutory role and meaning that more services had to go to tender.

The current Health Secretary, Matt Hancock, is removing the role of the CMA in the NHS altogether, opening up more flexibility for the NHS to offer joined-up care. This could lead to improvements for people living with more complex care needs, including those living with long-term conditions like rheumatoid arthritis. Rather than viewing healthcare as a series of one-off services that can be provided most efficiently through a bidding process, the White Paper acknowledges that treating complex care needs requires collaboration: different parts of the NHS need to work together; different healthcare teams need to talk to each other.

This 'integrated care' is a key part of the Health Secretary's plans. Around one in three people admitted to hospital today has at least five health conditions, it was one in ten at the time of the 2012 changes. Huge successes in care over the last few decades have brought with them the new challenge of helping more people to live with an increasing number of long-term conditions like RA. The government's plans seek to help the NHS perform this new role, supporting people to live well, with a new focus on 'years of good health'.

To make these changes happen, the Health Secretary will formalise the role of Integrated Care Systems (ICSs). An ICS is a collaboration between NHS services, local councils and other healthcare providers. This way of working is intended to help different providers collaborate—for example, to help your GP, community-based care and rheumatology services work more like a single team.

Living healthier for longer

The White Paper proposes a new 'triple aim' of three overarching focuses for the NHS in England:

1. Better health and wellbeing
2. Better quality of health services
3. Sustainable use of NHS resources

All this could mark a shift away, for example, from a focus on waiting times in political debates. These are important, of course but targets can be artificially rigid. By shifting the focus to population health, decisions about care should hopefully become more holistic and long-term. This could mean, for example, a greater focus on addressing chronic pain or improving access to specialist services in areas where this would have more of a positive impact than a singular focus on bringing down waiting times.

Taken together, these changes are intended to bring about more flexibility in how healthcare teams work together, and how they measure success, with better outcomes for people living with more complex care needs. On the face of it, this is an encouraging prospect.



Holyrood and Senedd Elections

Introduction

This edition of NewsRheum arrives on your doorstep as elections take place in Wales and Scotland. We took a look at some of the issues for rheumatology in both UK nations. Many of the same policy questions came up, for example regarding access to services in rural communities. The issue that looms largest across the UK remains that of getting through and recovering from the most serious pandemic in a century. Rather than simply 'building back' to where we were before COVID-19, however, there are lessons to learn from this past year on how to bring our health and wellbeing forward into the future.



Holyrood election 2021: key issues facing the new administration

The new government at Holyrood will face some important decisions for healthcare in Scotland.

Recovering from COVID-19

The last year has left many of our local rheumatology teams exhausted and facing a huge catch-up challenge. There are opportunities to 'build back better'. In particular, the 2020 Scottish Quality Registry for Rheumatology (ScotQR) highlights shared decision-making and self-management.

Next year will be a decade since a Public Health Scotland report on rheumatology highlighted a need for more GPs to receive rheumatology training, and wait times for a first rheumatology appointment have been rising.

Rural communities

Scotland is blessed with some wonderful landscapes, but with beauty often comes remoteness. Ensuring people in rural areas have good access to services is a priority.

Telemedicine

For all the devastation of the pandemic, advances in telemedicine have been a rare positive. Video and phone appointments can play a bigger role in providing care and choice, while online self-management and joined-up community services can help achieve the ambitions set out in the ScotQR.

Senedd election 2021: Next steps for health in Wales

As in Scotland, health care provision in rural areas should be high up the agenda for the new administration.

Waiting times

Prior to COVID-19, waiting times for diagnosis and commencement of treatment were variable across Wales, and this trend will once again come into focus as services seek to recover after the pandemic.

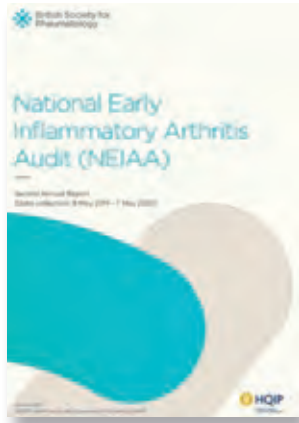
Green shoots in Cardiff Bay

Among the UK's most significant advances in non-COVID care during 2020, a newly established paediatric rheumatology team in Cardiff has been seeing its first patients. It is the first and only such dedicated unit in Wales and it must be well resourced to cope with rising demand in the months ahead.

Rural communities

Video and phone appointments have helped the NHS in Wales—as elsewhere in the UK—to cope with the pressures caused by COVID-19. In the next few years, this big jump forward in telemedicine should add to the choice of services available to people living in rural communities.

National Early Inflammatory Arthritis Audit (NEIAA) Second Annual Report



What is the BSR NEIAA and its purpose:

The British Society for Rheumatology’s (BSR) clinical audit has reported another very successful year due to the hard work and commitment of the rheumatology clinical community. NRAS have been supporting and contributing to this incredibly valuable health improvement initiative since its inception. The purpose of the NEIAA is to improve quality of care for people living with inflammatory arthritis by measuring care provided against the seven quality statements (QS) set out in the NICE (National Institute for Health and

Care Excellence). These quality statements were updated during the 2nd year of the data collection and are now reduced to five statements. This audit still focuses on the previous statements to allow direct comparison with the first year’s data.

During the period being reported on from 8 May 2019 to 7 May 2020, data relating to 13,578 patients was contributed and 96% of all NHS rheumatology services in England and Wales participated.

Statement 1	People with persistent suspected synovitis affecting the small joints of the hands or feet, or more than one joint, are referred to a rheumatology service within three working days of presentation.
Statement 2	People with suspected persistent synovitis are assessed in a rheumatology service within three weeks of referral.
Statement 3	People with newly diagnosed rheumatoid arthritis are offered conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy within three months of onset of persistent symptoms.
Statement 4	People with rheumatoid arthritis are offered educational and self-management activities within one month of diagnosis.
Statement 5	People who have active rheumatoid arthritis have their C-reactive protein (CRP) and disease activity measured monthly in specialist care until they are in remission or have low disease activity.
Statement 6	People with rheumatoid arthritis and disease flares or possible drug-related side effects receive advice within one working day of contacting the rheumatology service.
Statement 7	People with rheumatoid arthritis have a comprehensive annual review that is coordinated by the rheumatology service.

Snapshot of results

A target of 5% improvement in respect of early referrals of people with suspected inflammatory arthritis was set in the audit’s quality improvement plan, and thankfully this has been met and exceeded. In this second annual report it shows a 6% improvement on the previous year, however that means that still less than 50% of those with suspected inflammatory arthritis are being referred into specialist care within three working days of referral by a GP. 48% of the patients referred were seen within 3 weeks and 64% were started on disease modifying anti-rheumatic medications within the 6 weeks of referral.



What has the audit shown us so far?

The second year of the audit has been successful, with excellent recruitment despite the impact of COVID-19 on data collection. Patients continue to complete more questionnaires than other comparable national audits.

Mortality, joint replacements and unplanned admissions to hospital after receiving a diagnosis of inflammatory arthritis have also been reported

for the first time. Over time, this data will help us understand the factors that can influence these outcomes.

Although the data from year 2 show improvements in the quality of care provided to many patients when compared to year 1, performance against the NICE standards is still below the target of 100%. There continues to be significant variation in performance across England and Wales, with some rheumatology services performing better than others. There needs to be further work to help understand the reasons for these differences.

Where does the audit go from here?

The audit will continue to collect information on early arthritis care across the NHS in England and Wales. The next report will consider the impact of the COVID-19 pandemic on the quality of care provided. The information collected will help rheumatology units to improve the quality of care that they deliver to patients with early RA.

To read the full annual report, and to see how your local Trust/Health Board has performed, go to rheumatology.org.uk/practice-quality/audits/neiaa.

NRAS remains very supportive of this audit and urges patients and rheumatology units to participate as fully as possible with the data gathering. It is only by gathering and monitoring such data that we can evidence the need for change and identify where more investment, support, education etc is required. The NEIAA is a wonderful example of a professional body, clinicians, patients and patient organisations working in partnership to improve the lives of patients and care providers for the benefit of all and the NHS.





Louise's Story

The NRAS Helpline is a vital service, this is Louise's story



Hello Louise, this is Debbie from the NRAS Helpline. Is now a good time to have a chat?

Hi Debbie, thanks for calling me call back. [pause] actually...I am feeling quite desperate to be honest...., I don't know who else to turn to, I am in so much pain that I'm close to tears every day... My Rheumatologist has said that I am in remission, but I don't see how, I'm in agony. They have taken me off my medication.

I'm very sorry to hear that Louise and I am glad you have called us today so we can try and help you. Whereabouts are you in pain? And may I ask, when did the pain start?

I have pain in several joints as well as issues with swelling, despite my blood tests showing my inflammation is in the normal range. This pain began around three months ago.

It sounds like you are experiencing a flare in your symptoms Louise. Can I suggest that you start keeping a pain diary making a note of your pain levels on a scale of 1-10 daily? Maybe go back a few months and note when you can remember having severe pain alongside any significant changes in your life or significant stressors. You can then take this evidence to your next rheumatology meeting and it will paint a picture of how much you are struggling.

Okay, yes that sounds like something I could do quite easily.



Let's make a plan going forward about what you can do alongside the pain diary. If you do not get a response from your consultant this time round, I would then suggest asking your GP to refer you for a second opinion?

Yes okay, that sounds like a good plan Debbie.

If the secondary consultant doesn't think your pain is being caused by the RA, but by another issue, that issue will then need to be treated so you can carry on with your life.

Yes, I agree. Thank you so much for your help Debbie and for just listening to me. You have really brightened my day.

That's not a problem at all Louise, if there is anything else you need, please feel free to give us another call and we will do our best to help you.

Three weeks later the NRAS Helpline Team received an email from Louise:

"Hi, I spoke to Debbie three weeks ago, after feeling so desperate for help and being in pain. I'd got to the point where I wanted to give up on life. Debbie was such a big help with her advice.

I was so worried about not receiving any help after being in so called 'remission' for 4 years and being taken off all disease-modifying antirheumatic drugs. The rheumatologist I'm under made a visit to clinic today just to see me when she heard how desperate I was for help even though it's her admin day and not a usual clinic day. She didn't want to keep me waiting another 3 weeks. So, I've been to see her today at lunchtime and I'm pleased to say she prescribed me a depo steroid injection which the nurses gave me and has also prescribed methotrexate injections.

I feel such a relief and wanted to pass on my thanks to Debbie for the support and advice she gave me. I have now got hope for the future, knowing my rheumatoid arthritis has flared up again 'with a vengeance', in the rheumatologist's words, but it is going to be treated.

Kind regards. Louise."



Our freephone helpline is open from 9.30am - 4.30pm Monday to Friday (closed bank holidays) or you can contact the Helpline Team by email on helpline@nras.org.uk

For more information on the support we provide, please visit our website here: nras.org.uk/get-support

COVID-19 vaccines and RA



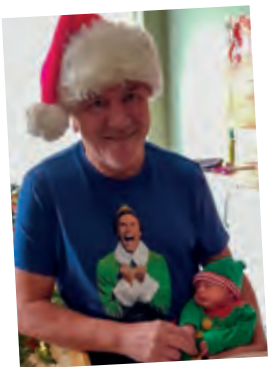
The Helpline has been inundated with calls regarding the COVID-19 vaccine for people with RA. We would like to reiterate the information we have on the NRAS website that encourages having the vaccine when it is offered.

All patients with RA are encouraged to receive a COVID-19 vaccine. This includes people taking disease modifying anti-rheumatic drugs (DMARDs) such as methotrexate, sulfasalazine, leflunomide and hydroxychloroquine and/or advanced therapies such as biologics, biosimilars and JAK inhibitors. The only potential exception is for those on rituximab when it is recommended having a consultation with your treating rheumatologist before you have your COVID-19 vaccination.

There is no preferred vaccine for people with inflammatory arthritis. The Pfizer/BioNTech, Moderna and Oxford/AstraZeneca vaccines are all considered safe for immunocompromised persons. The Oxford/AstraZeneca vaccine contains a live component that cannot reproduce in humans, so cannot cause infection and is therefore considered safe for people who are immunosuppressed.

Patients should not stop their immunosuppressant medications. Frequently, the immune response of people on immunosuppressants to these vaccine antigens is not as good as that of people who are not. However, a reduced response is safer than no response. People on rituximab need to speak to their rheumatology team to discuss the timings of the vaccination and your infusion of rituximab. The general rules are that you should hold off on rituximab for 4 weeks after the second dose of the vaccine. The studies into the degree of immunity gained in immunocompromised people are ongoing, and we will publish information as we have it.

Some rheumatologists are suggesting that individuals withhold 1 or 2 doses of methotrexate after each dose of the vaccine, however this is based on their knowledge of the individual patient and the general advice is that you should continue taking all DMARDs and biologics.



Stephen with his grandson Axel Eric Gunby at Christmas

A Daughter's Story

My dad (Steve) was diagnosed with rheumatoid arthritis (RA) about 3 years ago, which was under control with medication. This did not hold him back from retiring early in his late 50's, getting out and about with the dog and taking as many holidays with my mum (happily married for almost 40 years) as he possibly could, anywhere warm was the only stipulation. He had a good social life with his brother, going on any rugby do or stag do available (eventually being dubbed 'Stag Do Steve'). He had a wonderful relationship with my brother and myself, and in December 2019 became a Grampy for the first time. Life was very happy.

Around the time my son was born early December 2019 (pre-COVID-19), my dad developed a cough. As he had stopped smoking, we all put this down to his lungs clearing themselves. At this stage, we were all still under the illusion that RA just affected the joints, hence 'arthritis' in the name. We had no idea of its

wider impact on the internal organs and were not inclined to look up any further information as the condition was being treated at the hospital and with local doctors and nurses.

By the time we got to June 2020, he was no longer able to get up the stairs or walk the dog

Introducing Right Start to my local rheumatology team



Back in the autumn of 2017, the Health and Social Pathway Partnership here in Manchester held a large roundtable meeting with all the heads of various Manchester Hospitals. Members of the NRAS team participated and so did I as an NRAS Ambassador.

We worked together to plan a single hospital service for new patients being referred to Rheumatology.

Progress was made over many meetings with health professionals in the various hospitals and a 'Pathway to Better Care' had been developed that was in the final stages of development, prior to rolling out. Then COVID-19 hit and progress stopped.

An opportunity

We all appreciate how much rheumatology has given over the last year. Part of the 'Pathway to Better Care' scheme is the 'Right Start' referral service offered by NRAS for all new patients. While the wider scheme was clearly on hold, we could see that Right Start could provide immediate support to hospital staff by taking patient referrals.

With that in mind I decided to set up a meeting between the Specialist Nurse team and other health professionals at Manchester Royal Infirmary and NRAS, to discuss introducing the Right Start service right away to support their

work while the more wide-ranging Pathway project remained on ice. I talked to NRAS, who were more than willing to attend.

We held the meeting on Microsoft Teams, and despite being 'virtual' it was an immediate success. The Specialist Nurses were very impressed and enthusiastic about offering Right Start to new referrals right away. The fact that the programme has been taking referrals from other hospital trusts right through the pandemic shows that referring patients does not take up any significant amount of healthcare teams' time.

Next steps

As well as discussing how we could work together to show the cost savings Right Start can bring about, we have agreed to contact other hospitals in the Trust in the next few months to offer the Right Start service more widely across Greater Manchester.

This is particularly helpful just now because there are people out there who have not been diagnosed and it is so important for them to get treatment early. New patients may feel isolated and will often have concerns and questions, alongside the need for reassurance from someone who has been in their position previously. While the wider recovery from COVID-19 will take time, this is a service any rheumatology team can start referring to straight away, in any part of the UK.

By Ralph Bell

NRAS Ambassador in Manchester

As a result of the meeting, NRAS is now working with Manchester practitioners on an enhanced Right Start offer.

due to being short of breath. My parents even cancelled a holiday, which is unheard of! Skipping the details, he was taken into hospital for the final time and passed away just 2 days before his 61st birthday on the 16th June 2020. It all happened so fast. We know it could not have been prevented but if we had been aware of the impact on his lungs, we would have seen the signs 6 months before.

Every year my employers – IMCD – a specialty chemical distributor, support a local charity. I have nominated NRAS to help raise awareness and support others and their families who might be in a similar situation to what we were. Also, to celebrate IMCD's 25th anniversary, the company have set aside a large chunk of money to support many charities globally with NRAS being nominated from the UK.

Rebecca Gunby



Stephen with Rebecca and her mum Linda Gameson

For more information on the effects of RA on the lungs visit: nras.org.uk/resource/the-effects-of-ra-on-the-lungs/

Gifts in Wills

Gifts in Wills, whatever the size, make a big difference.

A gift in your Will enables NRAS to continue to deliver vital services to those living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA), now and in the future.



"When my husband and I made our Wills, one of my key intentions was to leave a gift to NRAS. After providing for family, I wanted to ensure I left something to NRAS.

This organisation is an important part of my life and I know it delivers valuable services for the hundreds of thousands of people living with both RA and JIA across the UK. Our gift will help NRAS to continue providing essential support and services for all those, like me, affected by RA and JIA."

2 in 5 lonely or desperate calls to our helpline would go unanswered without Gifts in Wills



If you are considering leaving a gift in your Will or if you would like more information, please contact Emma with any questions you may have.



Tel: 01628 501 548
Email: espicer@nras.org.uk

Please see our website for more information about leaving a gift in your Will nras.org.uk/resource/gifts-in-wills/

Healthcare at Home

Grateful for their continued support in 2020

It all started with a quick email to our main charity contacts Jessica Bell – Health and Wellbeing Business Partner and Bethany Reed - Communications Executive at Healthcare at Home towards the end of March 2020 to say we would all be working from home for a few months and let's keep in touch. Who could have known that nearly a year later this would still be the case!

Fundraising was going to be a challenge in 2020 with no face-to-face events able to take place. Through the company's own generosity and virtual events undertaken by Healthcare at Home employees, over £6,000 was donated to NRAS. Their fundraising included payroll giving through the Pennies from Heaven scheme, a Christmas pack called "Family Fun Festivities" and continued car share scheme donations which had been committed prior to COVID-19. Healthcare at Home also helped us raise awareness of RA across their social media during National Arthritis Week in October. Their support has made such a difference in a challenging year for many small charities and will enable us to continue to provide vital support to those living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA).

Healthcare at Home colleagues have worked tirelessly throughout the pandemic to continue with essential deliveries of medicines and nurse/clinician appointments supporting the wonderful work done by the NHS.

We are so proud and pleased to be a charity partner of Healthcare at Home going into 2021 and let's hope we can meet up again soon at their offices in Burton-on-Trent and that their staff can soon be together again and enjoying taking part in social and fundraising events.

Commenting on the charity partnership, Chief Executive Officer Darryn Gibson said: "During this difficult time we are very proud that we have been able to continue to support NRAS, one of our main charity partners. We hope that the monies raised by our colleagues, will play a part in assisting the NRAS team in maintaining their very valuable work in supporting others. This is particularly important at a time when, sadly, many similar organisations are facing existential challenges. We are committed to building our relationship with NRAS, particularly as we share very similar outlook, values and patient focus."



Jessica Bell and Bethany Reed (Healthcare at Home) at a fundraising event for NRAS (photo taken pre COVID-19)

Fundraisers face the challenge head on!



As 2020 ended and we moved into a new year, life was still proving to be a challenge and not as normal as we would all like it to be. NRAS are still fortunate to have supporters raising crucial funds for us. People were using the lockdown to really push themselves and take on these very personal challenges, keeping mind and body exercising and in a fit and happy place! Here are some of our wonderfully determined fundraisers.

Sam Rowe from London decided with the restrictions put in place around Christmas Day, rather than consume his body weight in turkey he would get out and run a Half Marathon on December 25th! Sam raised a fabulous £763 for NRAS, a charity close to his heart.



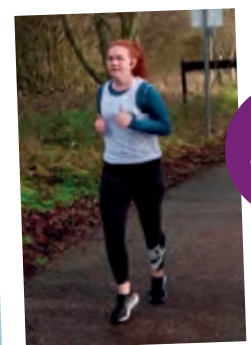
£763

Louise Perry and her four fantastic friends hit the ground running in January 2021 – literally! After seeing their friend Nancy Fearfield complete the same challenge the previous year, when Nancy ran for the whole of January, they decided it was their turn. So, Ellen, Louise, Joely, Hannah and Hattie donned their running gear and set off to run every day during the month of January. They had been inspired by Nancy who had been diagnosed with RA in 2019 during her final year at University. They wanted to show Nancy how proud they were of her, who is now well on her way to becoming a physiotherapist. The girls achieved their challenge, never faltering over the 31 days and raised an amazing £1328!



£1328

Katie Culbert from Northampton decided as part of her Duke of Edinburgh award it would be a really good idea to raise awareness about people living with RA. Katie's Mum and her running buddy Emma both have RA so she knew only too well the effects this can have on everyday lives. Katie had decided to sign up for a half Marathon, but COVID-19 prevented her actually participating in a mass event. Undeterred though, Katie decided to do her own virtual half-marathon, so all her training had not been in vain. With £403 pledged on her JustGiving page Katie completed her run in mid-December.



£403

Beverley David had her sights set on the world's fastest Zip Line experience in North Wales with stunning views as you whizz over the mountain lakes. Sadly, however the pandemic put a stop to Beverley's brave challenge. Beverley was determined to do something and to raise funds and awareness about JIA, as her young granddaughter had recently been diagnosed. So, on 23rd October 2020 she managed to book a place on the equally awe-inspiring Olympic Park Slide in London. Beverley has raised a staggering £2,055 with great support from family and friends and she also got matched funding from Barclays Bank who donated £750 to her overall fundraising.

£2055





By Clare Jacklin

NRAS CEO

Introducing the NRAS Professional Advisory Board

For many years NRAS has had an amazing Advisory Board with rheumatology consultants and health professionals from across the UK supporting and advising the charity.

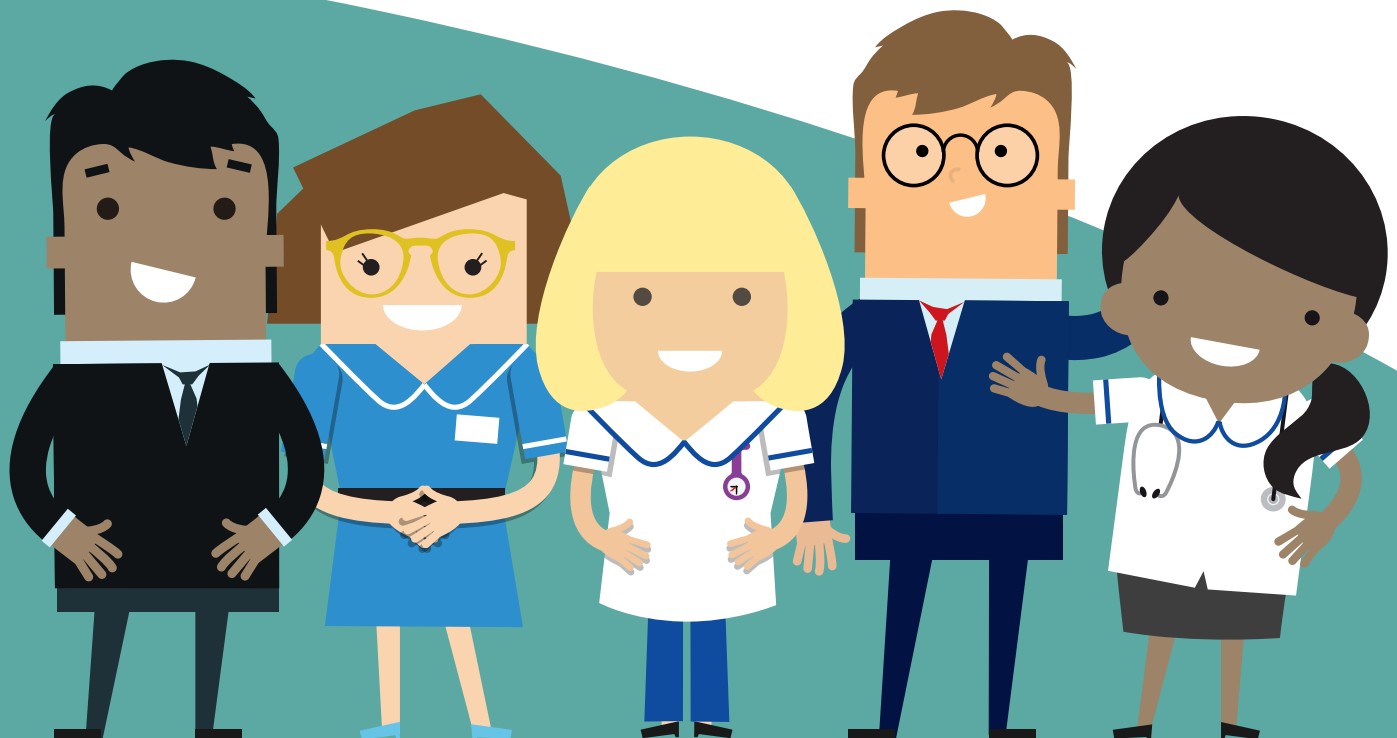
In March we held the first NRAS Professional Advisory Board virtual meeting at which we introduced some new members to the Board, agreed key areas to focus on as well as how the Board would operate going forward as NRAS and the world of rheumatology recovers from the pandemic.

Professor Peter Taylor remains our Chief Medical Advisor and Prof Iain McInnes as our Scottish Patron and Medical Advisor. The role of an Expert Advisor to the charity is varied, each Board Member will contribute to our information portfolio by providing content for the websites, magazine and booklets, as well as peer reviewing articles submitted by other professionals prior to publication. Advisors will champion the work of NRAS in their own areas of expertise, as well as advise NRAS on queries that may come to us that require expert opinion. The role of the Board

is also to communicate to NRAS how we as an organisation can campaign, support, contribute to or help with local or national issues that would support rheumatology departments either locally and/or nationally, as well as their patients. The patient voice is an incredibly powerful one when harnessed in the right way to communicate in harmony with rheumatology professionals with stakeholders such as NICE, Department of Health & Social Care, NHS, CCGs etc.

My hope for our newly re-structured Professional Advisory Board is that for each Board Member it will prove to be a mutually advantageous partnership. I look forward to working with all the Board Members in what we know will be challenging years ahead, post pandemic, as well as with the 'reorganisation' of the NHS, but I am confident that together we can meet all challenges and ensure that rheumatology patients are front and centre in all we do. Change is inevitable and with the help of this newly formed Board I am sure we will not 'go back to normal' but will go 'forward to better'.

There are still some vacancies on the board, so this is not yet a complete list.

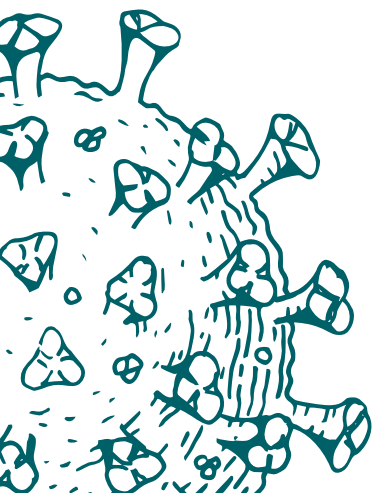
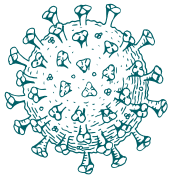
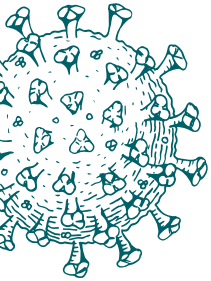


NRAS Professional Advisory Board Members

Name	Position/job title	Organisation/Hospital/Trust
Professor Peter Taylor	Norman Collisson Professor of Musculoskeletal Sciences, Head of Experimental Rheumatology	Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford
Professor Iain McInnes	Vice-Principal and Head of College of Medical, Veterinary and Life Sciences, Muirhead Chair of Medicine/Versus Arthritis Professor of Rheumatology	University of Glasgow
Dr James Galloway	Senior Clinical Lecturer & Honorary Consultant in Rheumatology	King's College London/King's College Hospital
Dr Marwan Bukhari	Consultant Rheumatologist & Honorary Senior Lecturer	University Hospitals of Morecambe Bay NHS Trust/ Manchester University
Dr Kanta Kumar	Lecturer at University of Birmingham and Hon Professor, PGI, India. Programme Director: MSc Advanced Practice in healthcare (International), Module Lead: MSc in Advanced Clinical Practice	Institute of Clinical Sciences, College of Medical and Dental Sciences, University of Birmingham
Professor Patrick Kiely	Consultant Rheumatologist/ Professor of Practice, Clinical Rheumatology	St George's University Hospitals NHS Foundation Trust/ Institute of Medical and Biomedical Education, St George's, University of London
Dr Nick Wilkinson	Lead for Paediatric Rheumatology and Chronic Pain	Evelina London Children's Hospital
Professor Ernest Choy	Professor of Rheumatology	CREATE Centre, Section of Rheumatology, Cardiff University School of Medicine
Dr Gavin Cleary	Consultant Paediatric Rheumatologist	Alder Hey Children's Hospital, Liverpool
Dr Luke Sammut	Consultant Rheumatologist	Portsmouth Hospitals University NHS Trust
Professor George Kitas	R&D Director – Academic Affairs Consultant Rheumatologist	Dudley Group NHS Foundation Trust
Julie Begum	Lead Nurse Rheumatology, Chair – RCN Rheumatology Forum	Luton and Dunstable Hospital NHS Trust
Dr Elena Nikiphorou	Consultant Rheumatologist & Adjunct Senior Lecturer	Centre for Rheumatic Diseases School of Immunology and Microbial Sciences, King's College London
Dr Samantha Hider	Reader in Rheumatology & Honorary Consultant Rheumatologist	Haywood Hospital, Midlands Partnership Foundation Trust and Keele University
Professor Christopher Edwards	Consultant Rheumatologist	NIHR Southampton Clinical Research Facility, University Hospital Southampton NHS Foundation Trust, Southampton
Dr Daniel Murphy	GP & Associate Specialist Rheumatologist	Honiton Surgery & Royal Devon & Exeter Hospital
Will Gregory	Consultant Physiotherapist	Salford Royal NHS Foundation Trust, Manchester Metropolitan University
Dr Lorraine Croot	Consultant Rheumatologist and Clinical Lead	Barnsley Hospital NHS Foundation Trust
Dr Elizabeth MacPhie	Consultant Rheumatologist, Associate Medical Director (Physical Health), Clinical Lead for Central Lancashire Moving Well	Lancashire and South Cumbria NHS Foundation Trust
Andrew Potheary	Lead Pharmacist, Rheumatology & Biologics	Royal Cornwall Hospitals NHS Trust
Dr Jenny Humphreys	Presidential Senior Clinical Research Fellow, Centre for Epidemiology Versus Arthritis, Honorary Consultant Rheumatologist	University of Manchester Manchester Royal Infirmary, Manchester University NHS Foundation Trust
Dr Emily Willis	Consultant in Paediatric and Adolescent Rheumatology	Manchester University NHS Foundation Trust
Dr Joanne May	Consultant Paediatric Rheumatologist	Children's Hospital for Wales, Cardiff
Heather Smee	Nurse Specialist Paediatric and Adolescent Rheumatology	Bristol Royal Hospital for Children
Dr Jon Packham	Medical Director Rheumatology	Haywood Hospital, Stoke on Trent

EULAR COVID-19 Database

for rheumatologists and other clinicians



The EULAR COVID-19 Database is a European paediatric and adult database (in collaboration with the Paediatric Rheumatology European Society (PReS)) to monitor and report on outcomes of "Coronavirus Disease 2019" (COVID-19) occurring in patients with rheumatic and musculoskeletal diseases (RMDs). This data gathering will help guide rheumatologists and other clinicians such as specialist nurses in advising and caring for their patients.

EULAR is grateful to international colleagues who have established the COVID-19 Global Rheumatology Alliance and helped establish this database. Anonymised data will be shared with this international registry, based in the United States.

EULAR and NRAS encourage rheumatology clinicians from across Europe and other EULAR countries to report ALL cases of COVID-19 in their rheumatology patients, regardless of severity (including asymptomatic patients detected through public health screening). Understanding less severe cases or even mild cases will help the rheumatology scientific community understand further those who develop the most severe form.

EULAR COVID-19 Vaccine (COVAX) Registry

The COVID-19 pandemic has severely influenced all aspects of life in 2020. This pandemic also affected patients with Rheumatic and Musculoskeletal diseases (RMDs) and impacted the care given to them. With the development of vaccines, the future is becoming brighter. However, the possibility of vaccination also raises questions, especially for patients with inflammatory RMDs and patients that are treated with drugs that may influence their immune system. EULAR has therefore set up a simple survey to capture responses to the vaccines. Please notify your Rheumatology Department, when you have had the vaccine and encourage them to report via this easy to complete online form.

It is therefore important for people living with RA or JIA to inform their rheumatologist if they have tested positive for COVID-19, even if asymptomatic so that they can contribute to this essential gathering of information. Through broad scale participation and collaboration, it will be possible to answer very pressing questions that rheumatology patients and their caregivers have.

As of 1st February, there have been 4934 patients' data reported to the registry from 36 countries, (15% (739) from UK), 39% (1911) required hospitalisation however it is important to consider that the EULAR COVID-19 Database is based on doctors voluntarily reporting cases, meaning that patients included do not necessarily represent the majority of patients with rheumatic diseases and COVID-19, but those who their doctors reported data to the database. Additionally, this database does not account for non-COVID-19 patients. Therefore, results cannot be directly extrapolated to the entire population of patients with rheumatological conditions and COVID-19 and should be interpreted cautiously.

Top reported symptoms are fever at 64%; cough at 58% and shortness of breath at 37%. If you are experiencing any of these symptoms, we'd strongly recommend you call 111 and if you're diagnosed with COVID-19 report it immediately to your rheumatology team so that they can contribute to this registry.

Message for Health Care Professionals

- Please report all COVID-19 vaccinated RMD patients, with inflammatory or non-inflammatory conditions.
- Please report all COVID-19 vaccinated RMD patients, with or without vaccine-related adverse events.
- Please submit reports at any time after the 1st or 2nd dose of the vaccine.
- Please do NOT report adverse events that are definitely NOT related with the vaccine administration.

For patients without adverse events the questionnaire should take 1-2 minutes to complete. For patients with adverse events the questionnaire should take less than 5 minutes to complete. Reporting the maximum number of cases, including cases without adverse events, is extremely important as this will allow the rheumatology scientific community to understand better how common a certain adverse event is. This database is for clinician-reported cases only - please do not report a case if you are a patient but do encourage your clinician to do so.

Visit www.eular.org/eular_covid19_database.cfm

A tribute to Daphne Franklin

(21st June 1936 - 13th October 2020)

Last year Graham, and his family, chose to set up a personalised Tribute Page in memory of his mother, the late Daphne Franklin, through our charity partner, MuchLoved. The page has already raised over £1,300, for which we are incredibly grateful. Graham also kindly agreed to share Daphne's story with us, in the hope it might encourage others to support NRAS in this very special way.

Daphne was born in Tring, Herts into a large family of six brothers and sisters she was very close to. When mum was only 13 my dad arrived on the scene. He was stationed at nearby RAF Halton, visited Tring Salvation Army and was made very welcome by her family. They formed a friendship straight away but mum had her schooling to finish and dad was 18 so he decided to take an overseas posting to Gibraltar where he wrote to mum as a penfriend and so the lifelong romance began which thankfully saw them celebrate 65 happy years married just last summer.

Family was very important to our mum and she had many happy times with her 3 children and partners, her 8 grandchildren and 2 great grandchildren. She loved a big family get-together and enjoyed the wonderful trips we used to make to Wycombe Park to play cricket and rounders, or a good Christmas get together. She had immense pride in each and every member of her family and never really stopped mothering and showing her core qualities of love, thoughtfulness and care.

Daphne had a strong faith and her warmth radiated to those she spent time with at the Salvation Army and then more latterly in the Baptist Church, Tring. She would always find time to visit family, friends and church members who were poorly, lonely or in need of cheering up.

Daphne was diagnosed with RA in 2004 when she was referred to our local Rheumatology Department at Aylesbury, Bucks, and lived with it for over 15 years. Sadly, she suffered the characteristic misshapen hands and feet for a long while but never complained and, with the help of good comfortable shoes, was able to keep walking everywhere right to the end of her life as she couldn't drive.

Her RA was kept reasonably stable over the last 5-6 years with some of the excellent newer biological treatments and mum was always grateful for the regular care, blood tests and help with injections she received from her local district nurses, who she had so much trust and confidence in.

We chose NRAS to receive gifts in her memory as we wanted to raise the profile of RA and the excellent work that NRAS does, and to help towards improving care for other sufferers and their families

With the added challenge of holding a funeral in these times it was very important for us to have an online tribute site for our mum where friends and family could feel part of her funeral, post tributes and photos, make a donation easily and enjoy sharing and reading memories and stories. We settled on the MuchLoved Tribute page and would certainly recommend it to others.



During these difficult times, online tribute pages have become increasingly popular as a way of bringing family and friends together to celebrate the life of a loved one. If you would like to find out more about Cherry Blossom Tribute pages, please visit the NRAS MuchLoved website nras.muchloved.org or contact the fundraising team on 01628 823524 or email fundraising@nras.org.uk





Event Dates - 2021

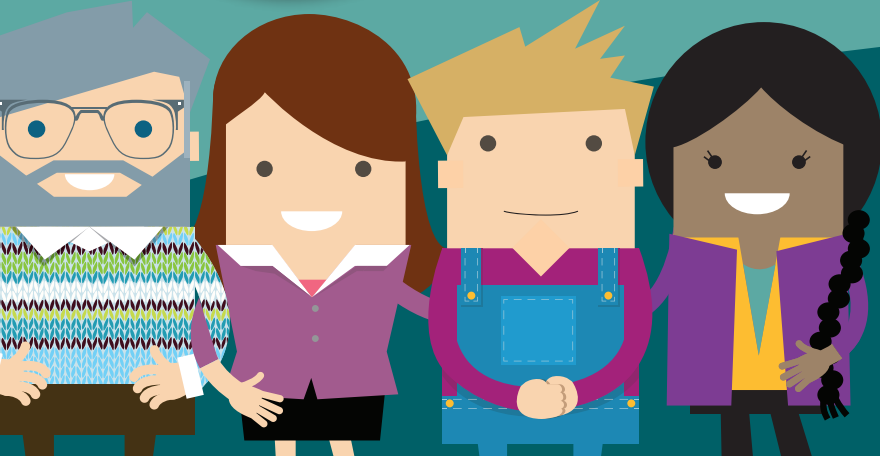
Vitality 10K	31st May 2021
#WearPurpleForJIA 2021	14th June 2021 – with WP Day on 18th June 2021
Great North Run	12th September 2021
Brighton Marathon	12th September 2021
RAAW 2021	13th September – 18th September 2021
London Marathon	3rd October 2021
World Arthritis Day	12th October 2021
NRAS Christmas Show	Friday 3rd December 2021



RA Awareness Week! (RAAW)

Dates for your diary:
Monday 13th – Saturday 18th September 2021

The feedback from our Members from last year's RAAW campaign was so positive we have decided to continue with the same theme of Mental and Physical Wellbeing, especially considering the ongoing COVID-19 pandemic which has impacted so many lives, including many of you living with rheumatoid arthritis.



Some of the areas of focus will be:

Being more physically active,
mindfulness, nutrition and
some NEW sessions too!

Keep an eye on our website
for more information: www.nras.org.uk

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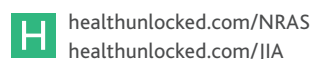
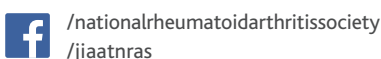
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