

YOUR Members' Magazine!

NewsRHEUM



nras

National Rheumatoid Arthritis Society

**WINTER
2020**



**UPDATE ON NRAS
WORK SURVEY**
.....

**INTRODUCING NRAS
YOUNG VOICES**
.....

**THE SUCCESS
OF RAAW 2020**
.....



By Clare Jacklin

NRAS CEO

Dear Members

I had hoped that by the time the Winter NewsRheum came around I'd be writing with great optimism and be relieved that the worst was over. Unfortunately as of this week we are heading into another England lockdown and already many of our friends in the devolved nations have been experiencing tougher restrictions due to the cases of COVID-19 increasing at an alarming rate. There is so much we are unsure of and we really don't know what the future will hold, but one thing we can be certain of is that COVID-19 is here to stay for quite some time to come, and life will never be the way it used to be.

However, out of adversity comes opportunity and initiatives that can improve our lives and the way we do things, which hopefully will be better than the way things used to be especially regarding our healthcare systems, but also the way we work.

I am very much a glass half full sort of gal and I am amazed at how well some people have adapted to this new COVID world. Many of you have already had video or telephone consultations with your health professionals instead of having to travel to the clinic. This has advantages for many – reduced travel expenses and worries (i.e. travel on public transport or stressing to find a parking space); reduced anxiety about visiting the hospital environment; increased ease of having a family member with you at a virtual appointment; less time off work for appointments; keeping our NHS staff safer as well as freeing up clinic time for those in urgent need of a face-to-face appointment. As we move forward, we hope to see a 'blended' model of clinical care that will harness the use of digital technology to improve health and health services which will benefit us all.

NRAS has also needed to adapt and I am so pleased to say that RA Awareness Week was a tremendous success thanks to so many of you participating in online wellbeing sessions and our Facebook Live discussions. You will read more, later on in NewsRheum, regarding the number of people we connected with during the week;

many for the very first time, and we'll be sharing with you some of the feedback we got about the difference we made. While it is important that we have this one week per year to highlight awareness of RA, it is equally important that we keep these messages going all year round. We RA Priority – Our Minds RA Priority. I would encourage you all to continue to share NRAS posts, tweets, messages etc. as much as possible because you continue to be our priority.

Already I am beginning to see mince pies, tinsel, and Christmas paraphernalia in the shops, so by the time you read this I hope you will have got your NRAS Christmas cards ordered and maybe already in the mail!

2020 has been a year that many of us will be glad to see the back of and while it has been the most horrible of times for so many, don't let us forget the good things we've witnessed too. Remember clapping for the NHS... making new friends in the long line outside the supermarket... rediscovering nature in your garden... being grateful for every hug... neighbours looking out for each other... But, most of all, I will remember how amazing each and every one of my colleagues at NRAS are and YOU, our brilliant supporters. Thanks to all of you, NRAS is facing 2021 with some unexpected optimism.

I wish you all a very happy and safe Christmas, but most of all my wish for 2021 is for a life without the impact of COVID-19.

Clare
Chief Executive

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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Members Virtual Zoom Conference



We will be holding a Members only virtual conference on 27 January 2021 over Zoom to give you an update on your society and talk about the year ahead. Places are free and we will have some exciting guest speakers. Keep an eye on our Members E-News for how to book your free place.

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.

NRAS Christmas Cards, Gifts & Games

It's still not too late to purchase your Christmas cards and a few games for family and friends to enjoy!

Here is the web address to buy:

www.charitycardshop.com/nras

Last date to place your order is:

Thursday 10th Dec 2020



Introducing

THE INSPIRATIONAL NRAS YOUNG VOICES

In May of this year, NRAS began recruiting young people to a special advisory board to act as the voice of young people living with RA and JIA. The aim was for the group to help inform NRAS on how to develop their services for teenagers, young adults and parents of children with JIA.

Dr Catriona Boyd

Catriona, 24, is a doctor working in Manchester. She was diagnosed with RA aged 19.



The group held their first meeting in June and soon decided to name themselves the Young Voices to reflect their role in raising awareness of the issues affecting young people living with these chronic conditions. In the short time the Young Voices have been in existence they have been really impressive with their passion and dedication and have already started to influence service development - helping to recruit an NRAS Young

Persons Project Co-Ordinator, developing project ideas and running a Facebook Live session during RAAW Week.

You can meet the group members below, and if you are a young person or parent of a child with JIA who would like to get in touch with the Young Voices, please drop an email to our Young Persons Project Co-Ordinator, Debbie Wilson debbiew@nras.org.uk

Ellie Farr

Ellie, 25, is the current Miss Cheshire and a professional photographer. Ellie has RA.



Malachi Neat

Malachi, 16, is a student at sixth form college. He enjoys music and is an active member of a choir. Malachi has JIA.



Ellie Potter

Ellie, 24, is Chair of the group and an NRAS Trustee. She works in the Treasury office. Ellie has JIA.



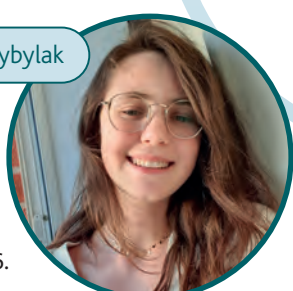
Annabel Longden

Annabel, 24, has a degree in Biology and is currently working as a Fashion Model. She has JIA.



Magda Przybylak

Magda, 20, is a medical student at the University of Cambridge. She was diagnosed with JIA aged 6.



Hannah Roberts

Hannah, 26, is a school staff nurse. She has two young children aged 1 and 2. Hannah has JIA.



Anita Masih

Anita, 27, is the Digital Marketing Officer at NRAS. She is currently studying for a Masters Degree. Anita has RA.



Suruthi Gnanenthiran

Suruthi, 22, recently graduated with an integrated Masters in Chemistry from the University of Bath. Suruthi has JIA.



Rich Flowerdew

Rich works for ScoutsWales and is a Trustee of NRAS. He is the Trustee assigned to the Young Voices and advises on safeguarding.



Launch of first E-Learning modules in our SMILE-RA programme



NRAS has delivered group, face-to-face supported self-management programmes in RA since 2011 when we launched 'RASMP' (RA Self-Management Programme), our 6-week programme. This was developed in collaboration with the Expert Patient Programme CIC, as it was then known, and now is Self-Management UK (SMUK). In 2015 we developed two further short, three-hour programmes, 'New2RA' for the newly diagnosed and 'Living Better with RA' for people with established disease. RASMP was delivered by trained health professional and lay tutors, working equally and collaboratively in a team and the two short courses were delivered by trained volunteers who were themselves living with RA. These programmes have empowered many to learn more about their disease and take control of their lives and, for some, have been literally lifechanging. Here's what some people said about them:

Very interesting literature (leaflets and handouts). I feel a lot more informed now about living with RA. This course is a must for all who have this life-changing disease. I feel more positive.

Very relevant course. Have taken on board a lot of the advice and understand setting achievable goals.

Very well delivered by Karen and Liz, Katie and Alice – I feel much more positive and informed and looking forward to the future

Absolutely fantastic course, it has helped me enormously

Debbie and Sue made us all feel important, relaxed and I feel that it was excellent altogether.

In recent years we have found it increasingly difficult to get these courses funded, either by direct commissioning (England) or by Health Boards (Scotland, Wales, N.I) as the NHS has become increasingly cash strapped.

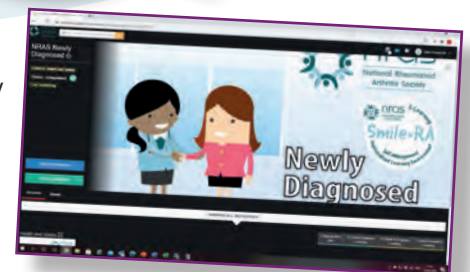
As a consequence of this we took a decision in 2018 that we would invest the considerable amount of money needed to develop a complete suite of modules on all aspects of RA to be delivered via an e-learning platform. In 2019 we were fortunate to receive enough grant funding to commence the development work. Before COVID-19 struck we had started work on the Foundation module and a first module for the Newly Diagnosed. The pandemic halted our progress as NRAS put a temporary hold on some of our projects in order to enable us to focus all our energies on our frontline services, supporting people understandably concerned about COVID-19 and the personal risks the pandemic posed.

However, as of September, we were able to pick up this important work again and, whilst there will be more modules on different aspects to come next year, we plan to launch the Foundation module, the Newly Diagnosed module and one on the topic of 'Meet the Team' (which explains who will be involved in your care) early in the new year. The purpose of the Foundation module is to explain who NRAS are

and why learning to self-manage effectively is so important as well as collect baseline patient reported outcome data.

We know that the ability to self-manage well contributes to better long-term health outcomes and we also know that it is not going to be possible to get back to normal 'pre-COVID-19' levels of access to rheumatology care any time soon. The reason for deciding to launch the first modules of SMILE-RA early in the new year rather than waiting until later in 2021, is because we believe the need for this kind of resource is even greater in the situation of the current pandemic.

We have an Advisory Board comprising health professionals, people with RA and experts in self-management working with us to advise on all aspects of the programme. This is a completely new and unique programme which we hope will help the many thousands rather than the 'hundreds', which was the limitation with the face-to-face programmes. We are also very aware that one of the main things people like about face-to-face, group programmes, are the benefits gained from talking directly to others who live with the same issues as you. We are therefore looking at innovative ways to simulate this peer interaction as best we can within SMILE-RA. We really hope you will like SMILE-RA and find it of benefit.





By Dr. Kathy Vogt, PhD

The University of
Huddersfield
& NRAS member

Rheumatoid Arthritis and Shielding

A Study Conducted at the University of Huddersfield

Shielding has been a surreal experience for many of the 2.2 million people who were identified as clinically vulnerable and subsequently advised to shield, in order to protect themselves from the threat of COVID-19. Some people even decided to shield themselves, despite not receiving the status of clinically vulnerable in the form of a shielding letter. The shielding guidelines are/were extensive and, unless people were living by themselves, also affected the other members of the households they lived with. Shielding really was a family affair, in many cases.

To better understand what the experience of 'shielding' was like for those individuals and their families, our team around Professor Ann-Louise Caress at the University of Huddersfield has teamed up with over twenty partner organisations (including NRAS) and conducted a large online survey. In the survey, we covered things like experiences of shielding, concerns about going forward, and the support needs of people who are/were shielding and their family members. You might remember seeing the links to our online survey being shared across NRAS social media and newsletters, or you may even have taken part in the survey. Almost 1500 people took part; 263 of whom accessed the link

via NRAS. Via NRAS, 263 individuals with RA who were shielding, and 55 family members took part - in fact, participants who accessed the survey through NRAS represented the largest disease-specific group of respondents (despite other much bigger charities taking part!). As a health psychologist and researcher with rheumatoid arthritis (RA) myself, I was extremely pleased that NRAS wanted to be involved with our research and the fact that we managed to recruit such a large number made me feel quite proud. Thank you to all of you who have taken part; we are currently analysing the data.

However, it does not just stop there: currently, we are doing follow-up studies with some of the participants who took part. There are a number of different projects, for example, a more general study on housing, physical activity, and wellbeing during shielding. But there are also more specific studies, like the one I am currently conducting. Currently, I am doing follow-up interviews exploring the shielding experiences of patients with RA. Of course, this is a topic that is close to my heart. I am very lucky that I have an excellent research assistant helping me with this research study, Bethany Griffin (BSc, Hons) and an extremely supportive study lead, Professor Ann-Louise Caress. I am positive that we will be able to share our results with you in the next edition of NewsRheum.



The partner organisations involved in the survey

Rachael reaches new heights

Rachael has been involved with NRAS since she was first diagnosed with RA at the age of just 22, back in 2012. Over the years Rachael has been a great advocate and supporter of the charity and in 2017 became one of our Telephone Volunteers, offering her time and sharing her own experiences with others who might be facing similar challenges or have been newly diagnosed.

Rachael has always been great at her fundraising too, getting involved with lots of events and challenges over the years and making sure all her family take part with her too!

This year Rachael signed up to challenge herself to trek Mount Snowdon with the support of her husband Lee who she married last August, and her Dad John Till who has often been her sporting buddy! Sadly, like many events this year due to COVID-19, Rachael was unable to travel and attack Snowdon in May this year. Undeterred, Rachael came up with a novel way to complete her challenge and collect her sponsorship money that had been pledged.

On 8th May Rachael started her indoor lockdown challenge climbing 7120 steps by going up and down her flight of stairs! No mean feat, as it worked out to 475 flights of stairs! It took Rachael 3 hours to complete but complete it she did – never one to be defeated or give up. She raised a fabulous £335 for NRAS – Well done!



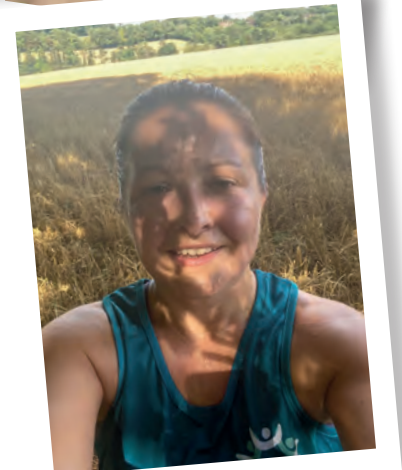
Before and After the challenge!

Katy Runs 100 miles in 10 Days

After taking part in the Indoor Relay back in May and being released from shielding in June, Katy said she was really inspired by a whole new world of intrepid runners to take on a new fundraising challenge. Katy wanted to raise money for NRAS as a thank you for the support the charity has provided to those living with RA during the pandemic and said:

"NRAS has helped me so much since my RA diagnosis 9 years ago. At that point I struggled to make tea, dress. I have been a regular Volunteer, and this really makes me help give back, however with mass participation events being cancelled and postponed many charities are struggling to survive. If I can raise funds with my 100 miles in 10 days challenge, I could help NRAS campaign for better health services for people like me."

Katy completed her 100 miles in just 8 days running over 25 miles on the last day and raised £216! You can follow Katy and learn more about her RA journey on Instagram @joint.adventure.





By Dr Sue Peacock

It was a great pleasure and very interesting to speak to Dr. Sue Peacock when I interviewed her during RA Awareness Week in September, in a Facebook Live session on the subject of sleep and sleep disturbance in rheumatoid arthritis (RA). This was a session I had looked forward to as I can't remember when I last had a good night's sleep and am aware that I'm not alone in this. There are many thousands of people with RA who struggle with sleep for all kinds of reasons and this is not a problem which is widely and thoughtfully addressed in routine follow-up care. As a result, we thought it would be a helpful addition to our Winter magazine if we asked Sue to write an article to follow up on her engaging Facebook session. Thank you Sue!

Ailsa Bosworth MBE,
National Patient Champion

To sleep or not to sleep? - that is the question

Imagine it's dark, it's nearly 2am, and you still haven't slept despite going to bed at 11pm. You toss and turn, count sheep, pull the bedcovers up, then throw them off, you look at the clock again and it's only 5 minutes since you last looked, but it feels like forever!

Your pain is getting worse and you have taken all your allocated medication, you're tempted to take extra, but you would have to get up and it's cold so you continue lying there, feeling frustrated and getting more and more wound up because you can't sleep. Everyone in your house is asleep, your partner's snoring is echoing through the whole house, you nudge them a bit, then a bit harder because you really want them to wake up and chat, because everyone in the whole world is sleeping except you!

If this is you, read on!

Why can't I sleep?

The top reasons people experiencing pain can't sleep are:

- You notice your pain more as there are no other distractions at night
- Your medication for pain or low mood makes you drowsy in the day so you sleep at irregular times

- You are not in a regular routine, so your mind and body are confused about when it is time to rest
- You worry about how your lack of sleep will affect you the next day
- You are experiencing mood changes that create tension in your body
- You are not comfortable in your bed or you are disturbed by sounds or light in your bedroom.

Understanding the science of sleep

Sleep varies throughout the night and varies from person to person! It is an active process with physical, mental and emotional components. Sleep is orderly and made up of different cycles which are repeated through the night as illustrated in Fig 1.

In addition to these sleep cycles, sleep is also controlled by our circadian rhythm (body clock) and homeostasis, which control your levels of sleepiness and your need for sleep.

A "normal" night's sleep can be anywhere between 5 and 10 hours. It's a myth that we all need 8 hours sleep – this is an average. We all have different sleep times. How much sleep you need will vary and depends on your age and your situation.

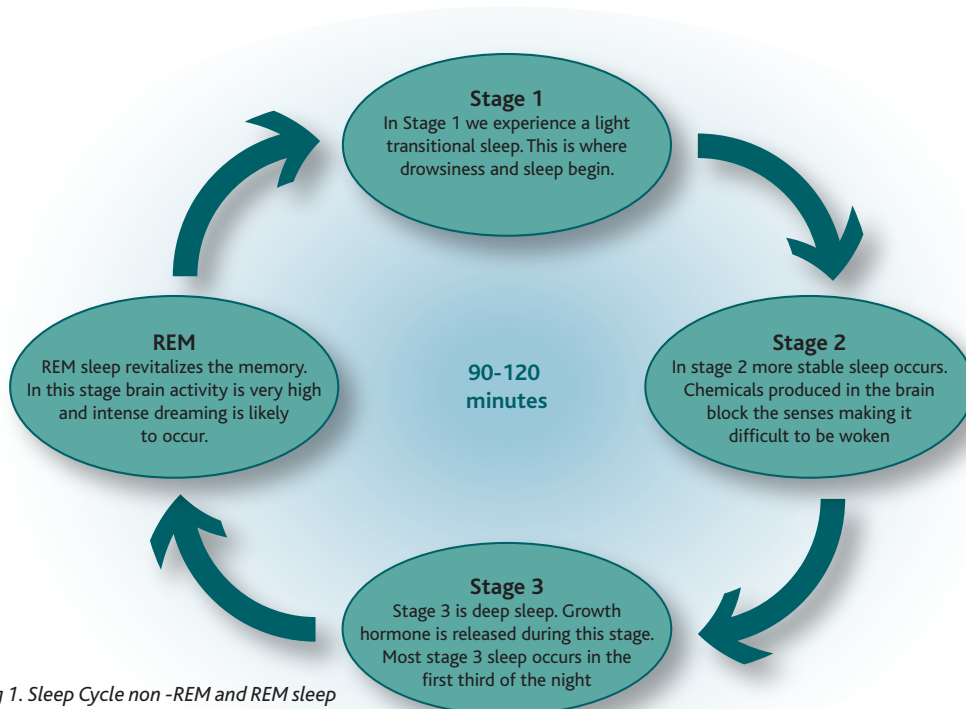


Fig 1. Sleep Cycle non-REM and REM sleep

Health issues that could arise from sleep deprivation

It's important to distinguish between sleep deprivation and insomnia. Sleep deprivation is a lack of opportunity to sleep i.e. in shift workers. Insomnia is difficulty sleeping despite opportunity.

A lot of research looking at health issues is in people with sleep deprivation. The effects of sleepiness on mental health and our physical health are well documented.

What is the optimum sleep routine?

Bedtime routines are important as sleep is a learned behaviour; a bedtime routine is a repeated set of behaviours that prepare your body and mind for good sleep. Over time, our brain recognises these behaviours as a precursor to sleep, which makes it easier to sleep once you get into bed.

Our ideal routine begins in the daytime, ensure that you drink plenty of water, exercise and manage your stress well and then go to bed and, more importantly, wake up at the same time each day.

Clear your mind by writing in a journal/notebook a few hours before bed, what went well, what didn't go well, what can I do about it? Add a 'to do' list for the next day. This is important as it will stop your mind mulling over the day and worrying about tomorrow.

Switch off screens and technology, partly to give ourselves a break between work and sleep, and partly reduce our exposure to blue light which disrupts the body's circadian rhythm.

Have a warm bath or shower, as the body temperature reduces, our bodies prepare to sleep.

About 20 minutes before bed, start slowing the body and mind by dimming the lights, try reading, colouring, knitting, meditation or relaxation.

It's important to go to bed when sleepy tired (eye lids feel heavy, maybe yawning) rather than just go to bed because it's 10.30pm and you think everyone goes to bed then. If you go to bed sleepy tired you are more likely to drop off to sleep more quickly.

Changing our behaviour can feel daunting at times, so just try one of these suggestions at a time until they become second nature.

What are the alternatives to sleeping pills?

Many health care providers are reluctant to give out sleeping pills as some people can become dependent upon them if used continuously for as little as 2 weeks. Here are some alternatives for you to try in figure 2.

Figure 2 - Alternatives to sleeping tablets

1	Two of the most well-researched alternatives are camomile and passionflower tea. Also, one of the amino acids in green tea is thought to have a calming effect.
2	Lavender: it's often suggested that stimulating the senses at 10 min. intervals, 30 mins. before bed, will increase relaxation and you experience deeper sleep and more energy in the morning
3	Magnesium: this mineral is often called nature's tranquilizer because of its calming properties and because it can help the body relax and unwind at the end of the day. You can eat it in foods such as kale, spinach, broccoli, nuts and seeds and pulses, which are great before bed.
4	Studies have shown that magnesium taken through the skin can have an even more instant and calming effect on sleep than tablets. You can bathe in magnesium, use it in a foot soak, enriched body oil and/ or moisturiser, allowing it to be absorbed through the skin.
5	Morning light is important as it is most effective at setting our body clocks. If you can't get outside, then sit by the window with your cup of tea in the morning.
6	Stop worrying about sleep – to break the cycle, try going to bed an hour later and just allow yourself to rest, rather than worrying about not sleeping. Worrying arouses our flight/fight/freeze response which then prevents us from sleeping. Try thought stopping techniques such as saying the word 'THE' in your mind, over and over again.
7	Various breathing exercises are very helpful, also relaxation, hypnosis, self- hypnosis or meditation.
8	Cognitive Behaviour Therapy for Insomnia (CBT-I).

Suggestions for a good night's sleep

The sleep-wake cycle, is directly influenced by behaviour. That means being exposed to too much light before bed or not getting enough light within an hour of waking, can impact one's body clock. Remember that we feel, function and are healthiest when we work with our circadian rhythms and keep them in-line with the 24-hours, so establishing routines with



eating, sleeping and exercising as best as possible, maintains our rhythm and encourages good emotional and physical health.

Check your basic sleep hygiene, look around your bedroom. Is it too hot/ too cold? Too light/ too dark? Is your bedroom cluttered? Make adjustments, as optimum sleep conditions are cool, dark and tidy. Consider reducing your caffeine intake and have a last coffee at least 4 hours before bed.

People often don't sleep because of sleep anxiety. They get caught in the vicious cycle, not sleeping, feeling anxious about not sleeping, so don't sleep! It helps to change the way we think about

our sleep rather than 'I'm not going to get any sleep', reframe this to 'I will get some sleep' as inevitably we do get some sleep.

Relaxation will help, but it's a skill, so will take some practice. It can be used effectively to reduce anxiety. Many people who experience sleep anxiety have other anxieties, so reducing or removing those will help sleep.

Relaxation helps to focus your mind away from intrusive and worrying thoughts. Relaxation exercises can give you more of a sense of being in control – of your breathing, your muscles and your mind. Try this brief relaxation exercise in figure 3.

Thought-blocking techniques are effective, working best with trivial information that just comes to mind, rather than more serious problems. It works by stopping other thoughts from getting in. When interrupting thoughts come to you in the middle of the night, start thought-blocking immediately before you are wide awake. Here's how to stop those thoughts.

1. Close your eyes and repeat the word 'the' slowly and calmly every 2 seconds in your head
2. 'Mouth' the word rather than saying it out loud.
3. Try to continue this for about 5 minutes (If you can).

The word 'the' is meaningless and has no emotional effect. By repeating this word, it stops other thoughts getting into your mind, hence the term, thought-blocking.

I hope that you find these strategies are helpful in improving your sleep – Sleep Well!

Figure 3: Brief relaxation to help you sleep

1	First look around and notice where you are.
2	Then close your eyes and notice the sounds around you, whether that's noisy neighbours, car doors shutting, horns honking outside, allow yourself to be there with the sounds.
3	Take one deep breath to settle yourself.
4	Then follow your breath, from the moment the air touches your nostrils as you inhale, feeling it fill up your chest and belly, and as it leaves your body as you exhale, noticing if the air feels warmer or colder.
5	Repeat this for five deep breaths.

New 300mg Strength Hydroxychloroquine Tablet launched in the UK

Hydroxychloroquine (HCQ) has long been a mainstay in the treatment of autoimmune disease with established roles in rheumatology and dermatology. It works by toning down the body's immune response. You might have heard HCQ described as an anti-malarial. That is because it is a quinine based drug, originally developed for treatment of malaria in the first half of the last century (although it has origins which date back much further!).

Its use in rheumatology has more than doubled in the past 10 years in the UK. Almost 100,000 packs of HCQ are dispensed each month in the UK. At least 150,000 patients are currently taking the product, over half of these are RA patients.

It is an effective treatment as monotherapy for lupus, and alongside methotrexate makes up the most used combination therapy in rheumatoid arthritis (RA). It is popular because it combines clinical benefits with a favourable safety profile. HCQ needs no regular monitoring blood tests and has very few interactions with other medicines.

The treatment dose for HCQ varies according to body weight. Optimising the dose is important to ensure benefits and minimise any chance of side effects. In January 2020, the Royal College of Ophthalmologists (RCOphth) published guidelines suggesting that no more than 5mg/kg/day is an appropriate maximum dose to use for avoiding toxicity to eyes. HCQ eye damage is thankfully very rare, but it is now better understood that long term treatment (especially 5mg/kg per day and above for longer than 5 years) is associated with higher risks. The new ophthalmology guidance help minimise these risks.

References: Hydroxychloroquine and Chloroquine Retinopathy: Recommendations on Monitoring – RCOphth Jan 2020; Wallace et al, Lupus Science and Medicine 2019; SPC Hydroxychloroquine sulfate 300mg film coated tablet.

However, there is an unusual quirk. The ideal dose for a person of 60kg is 300mg daily. For historic reasons, HCQ 200mg is the only strength tablet available in the UK. Weight based dosing can lead to some individuals needing complex dosing schedules to deliver daily doses between 200 mg and 400 mg. This can include taking different doses of HCQ on different days of the week or splitting tablets in half. Such dosing strategies can make it harder to take the drug, potentially impacting on adherence.

To address these challenges, a 300mg HCQ tablet has recently been launched in the UK by Blackrock Pharmaceuticals limited. So, if you are between 60 and 80 kgs in weight, and taking a complex HCQ regimen now, your rheumatologist or nurse specialist may speak with you about whether this new strength tablet is right for you.



Co-Authored by

Rupert Davies

Director
Blackrock Pharmaceuticals

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Fundraisers rise to the challenge

The past few months have been challenging times, to say the least, and like most charities, our individual fundraisers are the backbone of our charity fundraising. During these few months, it has given many of us time to reflect, set new goals, or really decide to achieve something we might have only ever had sitting on our bucket list!

Here are just a few we would like to mention who have stretched themselves to fulfil amazing personal challenges in all sorts of guises.



£505

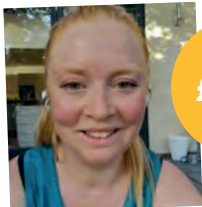
Tracey Hughes and Jan Manuel walked an incredible 137 miles over the August bank holiday weekend. They had overwhelming support along the way with friends joining them for sections of the Glyndwr's Way Walk, feeding them at pit stops and supporting their efforts with donations. We were delighted they raised £505 for NRAS.

£766



Claire Harrison and her husband David were looking for the ultimate adrenaline rush – so sky diving it was and what a very different way to celebrate a birthday in these difficult times. Claire herself has had RA for over 10 years and sky diving requires no physical training as such – just nerves of steel to leap out of a plane at 15,000 feet! Claire raised a fantastic £766 for her bravery!

£350



Suzanne Norman from Bristol has lived with RA for 10 years and had been shielding. However, she decided that she needed to set herself some goals so decided, not only to do some charity fundraising, but to take up running – something new to her. 50 miles in one month was her target. It was not an easy challenge and by her own admission there was some walking and running involved but complete it she did! A great £350 was donated to NRAS.

£664



The Ultimate Trifecta was the challenge John Leng decided to tackle with not one event but three virtual challenges in total. There was 100 miles of running across July, gaining maximum elevation by climbing one of the UK's mountains and finally competing in a 10k virtual race on the 26th of July. With just 23 days to complete, John had chosen to support NRAS as his mother had been diagnosed with RA a few years ago. John raised a wonderful £664.

£532



Finally, Karen Morris who had been diagnosed with RA just a year ago, had like many others found lockdown particularly hard, especially for her motivation. So rather than veg out on the sofa, she decided to set herself a challenge of walking 1.7 million steps from July to the end of September. With an average of 18,500 steps every day this was no mean feat! In fact, it was the equivalent of walking Lands' End to John O'Groats. Karen did an amazing job and raised £532, as well as upping her motivation and exercise levels.

Health and Quality of Life Update

Patient-reported outcome measures (PROMs) are questionnaires about health and quality of life which help to understand how your condition changes and affects day-to-day activities. In rheumatology, we use several well-established PROMs, which are used worldwide. Collecting information regularly helps your rheumatology team understand your condition and see how it affects you over time. It helps them talk with you about your management and focus on the things that are most important to you.

Historically, departments collected 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, the British Society for Rheumatology (BSR) launched a new ePROM platform, available for free to rheumatology departments in the UK. The platform sends out questionnaires to patients by email and shares the information back with the clinical teams. If your department has signed up, they can register you in the system. You will then receive an email link to fill in questionnaires online. Your responses are voluntary, and the primary purpose is to share information with your clinical team. Your healthcare professionals select which PROMs are most relevant to you, as well as how often you should complete them.

One of the questionnaires you might be asked to complete is the self-reported DAS (disease activity score) and NRAS has produced a helpful information pack to help complete this questionnaire. 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.

Sometimes in clinic appointments, it can be easy to put a brave face on, play down symptoms, or gloss over issues such as low mood. Collecting PROMs by email, outside of appointments, can allow people to reflect on their condition and how it affects them – and the information can then direct conversations with healthcare professionals.

I see the new BSR ePROMs platform as a major step forward for the rheumatology community and hope it will help shape the way care is delivered in the future.



Dr Elizabeth MacPhie

Consultant Rheumatologist and Chair of Clinical Affairs Committee at the BSR

It is time to make RA a priority

For some years, RA has been seen by many as 'just not a priority'. There has been a perception that it is generally well controlled and understood. The reality is that it's far from the case. RA is in need of better awareness and greater action. Earlier this year, Gilead Sciences decided to take on this challenge and came together with NRAS to launch a new campaign: We RA Priority. This was informed by insights from you, people living with RA, and aims to show that when RA is treated as a priority the impact can be life-changing.

In September, during RA Awareness Week, Gilead with the support of NRAS, launched the campaign on the website www.weRApriority.co.uk as well as on social media and in the media. The aim was to show a different side to RA, giving those affected a voice and improving understanding that RA is not OK, more needs to be done and that even little changes can make a huge difference.

Through an in-depth survey with the NRAS community it was found that 99% of people with RA felt that their condition is misunderstood

by the public. In addition, 93% still felt that RA is perceived as an 'older person's disease', and 85% had experienced stigma because of their RA being invisible. These kinds of figures show just how much work still has to be done.

Over the coming months the campaign will be releasing new content and more stories, showing the varied perspectives of RA. It will continue to highlight that RA is not just 'old people', not just 'wear and tear' and that for some it can be managed, yet for many, it is debilitating. Above all it will show that we can all do more to support those affected.

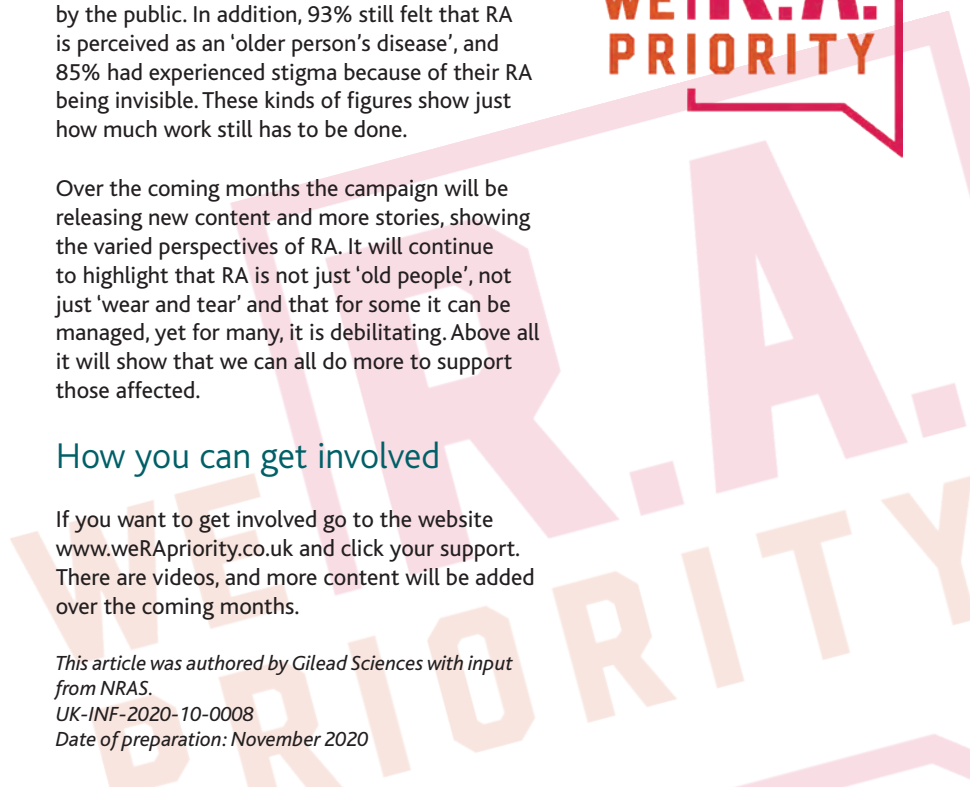
How you can get involved

If you want to get involved go to the website www.weRApriority.co.uk and click your support. There are videos, and more content will be added over the coming months.

This article was authored by Gilead Sciences with input from NRAS.

UK-INF-2020-10-0008

Date of preparation: November 2020



Early findings about COVID-19 and autoimmune conditions

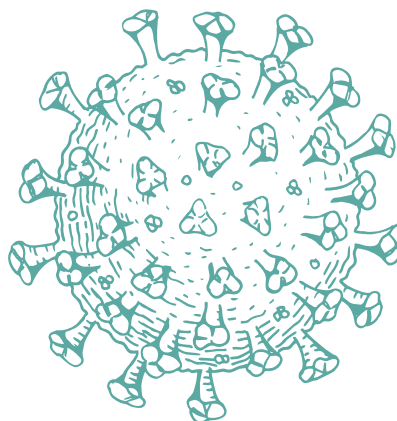
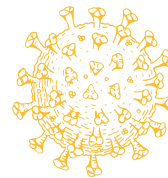
The advice to those living with autoimmune conditions (and indeed the advice to the public at large) about COVID-19 is ever-changing. This can be frustrating, especially when new guidance comes out that seems to completely contradict what you may have been told the week before. Unfortunately, this is to be expected with a new and fast-spreading virus such as this, where it can take time to get statistically significant data and still longer to know the long-term effects of the virus. While we await a vaccine, treatments will be trialled on drugs approved for use in other conditions and our understanding of the virus and what we expect from it will come from the behaviour of previous viruses.

So, what is the data currently telling us for people with RA, should they test positive for COVID-19? Current studies suggest a bit of a mixed bag. A recent study in Milan looked at 41 patients with 'immune-mediated inflammatory diseases' (IMID) who had either a positive test result for COVID-19 or where the virus was highly suspected due to symptoms. 5 of these had RA, 4 had psoriatic arthritis and the rest had other conditions included psoriasis and Crohn's disease. 24% were taking some form of immunosuppressant. Of these, 17% were on steroids and 68% were on biologics. There was one death in the group, of a lady who was elderly, with long-term disease (since childhood) and underlying health conditions.

Those hospitalised were more likely to be the older patients and those with co-morbidities (as we would expect from what we know about COVID-19). Rheumatological patients who were hospitalised were more likely to need oxygen than those with other

conditions (such as inflammatory bowel disease or psoriasis). Those taking steroids were also more likely to require oxygen if hospitalised, whilst patients on biologic drugs were not seen to be more likely to either be hospitalised or need oxygen.

We must be cautious about drawing too many conclusions on such a small scale study, but this study found that the major risk factors putting IMID patients at greater risk for severe cases with COVID-19 were increased age, other underlying health conditions (such as obesity, diabetes and chronic lung disease) and treatment with steroids, whilst treatment with biologics was not seen to be a risk factor. This will hopefully give a good basis for wider studies over time to test these findings.



New Faces join the Board of Trustees

Over recent months, NRAS has undertaken a comprehensive recruitment drive to attract new Trustees who can complement and enhance the skillset and diversity of our Board. In doing so ensures that we can deliver best-in-class services to all our beneficiaries. I am delighted to welcome four new Trustees to the Board who have brought a high level of expertise in many of these areas.

Simone Webb lives with RA herself. She was born and raised in London and is a first-generation Jamaican migrant. After being diagnosed with rheumatoid arthritis (RA) as a Biology undergraduate in 2018, Simone chose to focus her academic research on the immune system and what constitutes a 'normal' immune system. She is now a PhD researcher in Bioinformatics and Immunology at Newcastle University where she researches how blood and immune cells form during foetal development.

Simone has several years of experience working within decision-making bodies in the charity sector, which began with a seven-year service on the UK and International Youth Advisory Panels for the children's rights charity, Plan UK. Simone is keen to bring her knowledge of science, diversity and inclusion and RA diagnosis in young people to the future work of NRAS. Simone also enjoys cooking and listening to music in her spare time.



Lindsey Cook is a visionary leader and networker with over 20 years' experience working alongside executive-level authorities in pharma, charities, and the NHS. Her expertise and experiences of working with several NHS organisations, charitable organisations and blue-chip private sector companies, makes her

a valuable source of information for the charity. It was Lindsey's compassionate and supportive nature that attracted us to her, and her to us, and I am sure she will be invaluable in helping NRAS deliver business expansion and secure new funding sources to ensure our future sustainability.



Eleanor Potter was diagnosed with severe JIA when she was 12 and therefore has followed NRAS for many years and greatly appreciates the work that we do. When an opportunity to represent the under 35s with inflammatory arthritis as a Trustee was proposed she jumped at the opportunity to apply. Ellie can appreciate better than most the difficulty JIA can bring to one's life and wants to utilise that experience for helping to improve the JIA services that NRAS offers. Ellie studied at Oxford University, receiving

a First-Class degree in Human Sciences. Part of her studies were focused on how various factors (such as gender, class, and race) cause massive inequities in the care that people receive. After leaving University, she joined the Civil Service Fast Stream, undertaking different roles across Government which have helped her to develop a suite of transferable skills that will be very beneficial to NRAS. Now in the Cabinet Office, she coordinates how digital technology can be used to improve people's lives.



Rich Flowerdew has been an NRAS Member and Volunteer Ambassador in Wales since 2014. Being a young father when first diagnosed with RA, he fully understands the impact that RA can have on family and working life. Rich works for the Scouts Association, ScoutsCymru, where his role is Head of Strategy.

Rich has now joined the Young Voices advisory panel which will be shaping NRAS services for JIA families and children as well as meeting the needs of young adults living with RA.

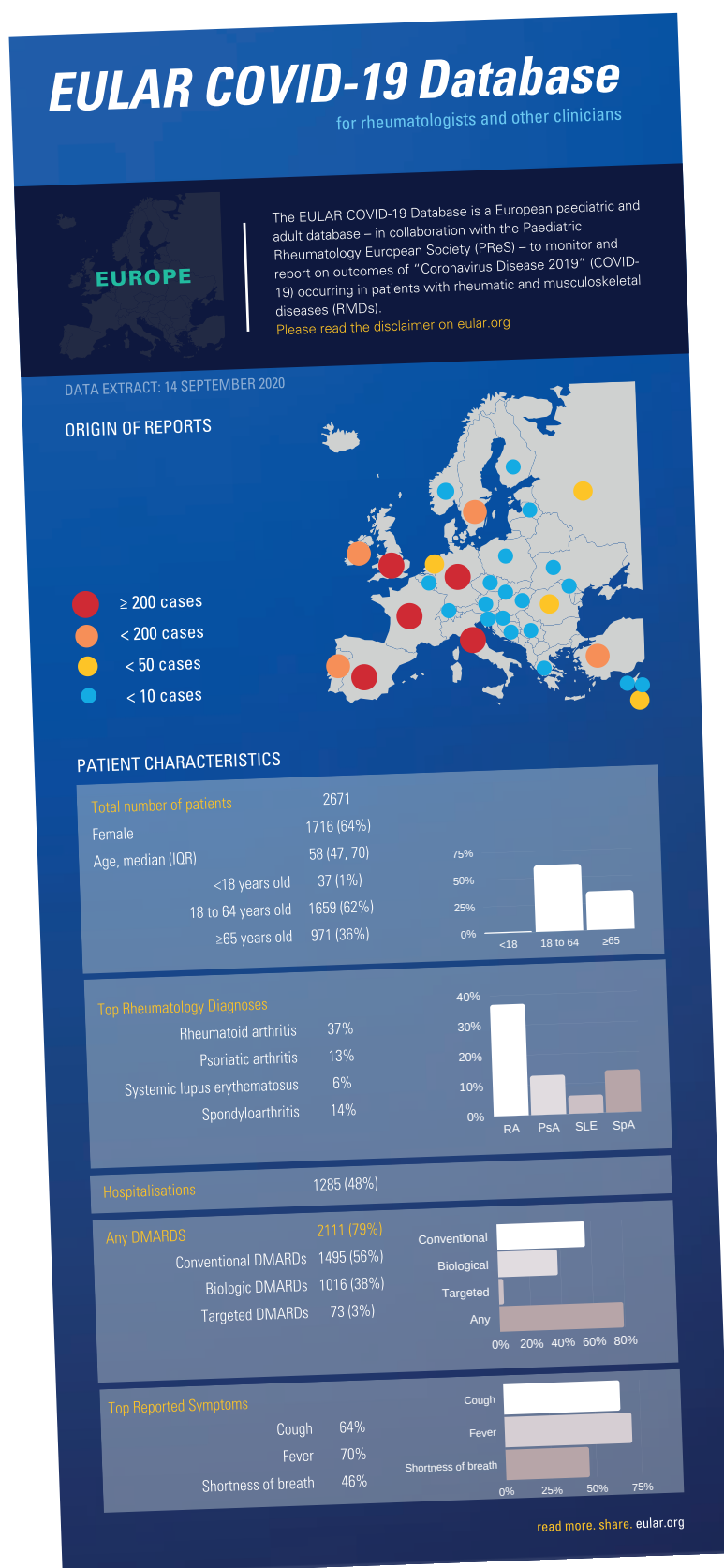


I hope you will all agree that these four new Trustees bring a wealth of extremely valuable experience and knowledge that will complement the excellent skill set already within the Board. It has been a particularly unusual time to join a charity's board as we have not been able to all meet in person, but Zoom is the next best option.

I'd like to say a huge thank you to not just our 4 new Trustees but also to Simon, Gordon, Zoe, Richard, Steve and Kirsten as well as Ellie Andrews (resigned in June), for all their support and guidance during what has been the most challenging of years for NRAS. I am confident that with such a strong and reliable Board of Trustees partnered with all the hard-working and dedicated NRAS colleagues, Volunteers and supporters that we will meet whatever challenges 2021 decides to throw at us with resilience and tenacity.

By Clare Jacklin, CEO

European paediatric and adult database update



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). There is an urgent need to understand outcomes of patients who acquire “severe acute respiratory syndrome coronavirus 2” (SARS-CoV-2) infection and are receiving steroids, synthetic or biologic disease-modifying anti-rheumatic drugs (DMARDs) and non-steroidal anti-inflammatory drugs (NSAIDs). This will help guide rheumatologists and other clinicians such as specialist nurses in advising and caring for their patients.

The infographic shows a snapshot of the data as of 14th September. As of that date 2671 patients have been included in the EULAR –COVID-19 registry from 32 countries. Out of which 1285 have required hospitalisation and there have been 294 deaths due to COVID-19. Comorbidities such as hypertension, lung disease and cardiovascular disease appear to significantly play a role in the severity of the virus in those with RMDs.

EULAR Disclaimer

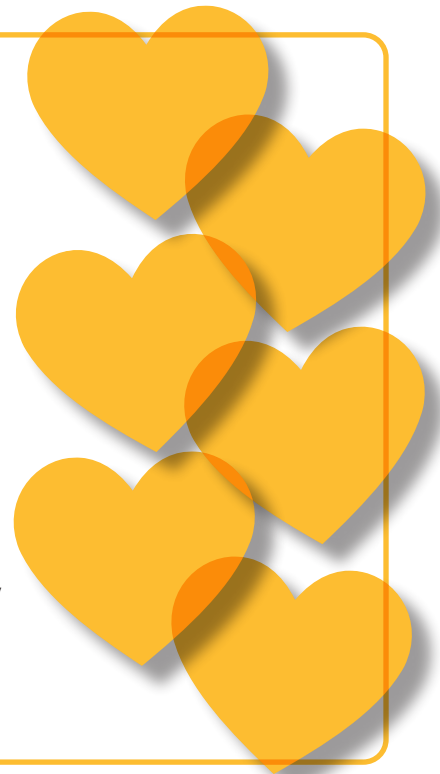
The EULAR COVID-19 Database is based on doctors voluntarily reporting cases, meaning that patients included do not necessarily represent the majority of patients with RMDs and COVID-19, but those who their doctors reported data to the database. Additionally, this database does not account for non-COVID-19 patients. Therefore, results cannot be directly extrapolated to the entire population of patients with RMDs and COVID-19 and should be interpreted cautiously. For research purposes and proper considerations, this data requires adequate analysis, further adjustments and stratifications.

Early treatment for RA lowers risk to heart

The risk of developing cardiovascular disease (CVD), in particular heart disease and atherosclerosis, are increased in patients with RA as equally as they are to people with better-known risk factors for CVD, including obesity and type 2 diabetes.

We know that signs of CVD are quite commonly seen in patients with well-established RA, but researchers in Leeds have been investigating whether or not signs of CVD were identifiable in early RA and if so, whether this could be modified by treatment with disease modifying drugs (DMARDs).

Eighty one patients in the study underwent a cardiovascular magnetic resonance (CMR) scan at baseline, 1 year and 2 years, set against 30 matched control subjects. Patients were also given either the biologic drug etanercept with methotrexate or methotrexate alone, to see if this helped to treat any signs of CVD. The study found not only were there signs of CVD in early RA patients, but that they improved on DMARD treatment, regardless which of the 2 treatments they received. This shows that early treatment with DMARDs can help to lower the risks of CVD, as well as giving a better outlook for the RA itself.



Which biologic works best with methotrexate?

Biologic DMARDs have been around for more than 2 decades now and the process has always been that patients first try standard, non-biological DMARDs, such as methotrexate (MTX), moving onto a biologic only if these options fail and the disease is considered active enough. This has been largely due to the additional cost of biologic drugs, but these drugs are also stronger, having a greater effect on the immune system.

Biologic drugs are mostly seen to work better when used in combination with MTX than when used alone. If MTX can be tolerated, it will therefore commonly be used in combination with the biologic. The question of which biologic should be added and how to know which option would work best for an individual patient is a really important question for physicians and patients alike.

A recent German Study published in the British Medical Journal (BMJ) has been looking for a clearer answer to this ongoing question. Within the study, 45 randomised controlled trials were investigated, each covering a minimum of 24 weeks (around 6 months), to assess the benefits of different methotrexate/biologic combinations, and also to assess the potential risks (e.g. side effects) with these combinations. The 8 biologics

identified as being used in combination with MTX in these trials were: abatacept, adalimumab, anakinra, certolizumab pegol, etanercept, golimumab, infliximab and tocilizumab.

Overall, very little difference was shown in either the level of success of these combinations or their potential harm. Anakinra was an exception, as it resulted in less remission and lower disease activity, but it is the least commonly used of these treatments. Certolizumab pegol in combination with methotrexate had slightly more adverse events and infections than the other combinations but overall any difference between the 8 combinations was minor.

In conclusion, though patients individually can certainly respond much better to one biologic than another, it is encouraging to know that overall there is little difference and therefore whichever biologic you are given, there is not likely to be a 'better' one they could have tried first. This allows clinicians to make decisions based on the cost of the drugs when they first prescribe a biologic, without negatively impacting on the effectiveness of the treatment option.





By Ailsa Bosworth, MBE

National Patient Champion
for NRAS

Meet our

Supporting our work on behalf of Global Majority communities

In 2016, we launched a new area on our website called 'Apni Jung' which means 'our fight' in Hindi, against RA. We did this in collaboration with Dr. Kanta Kumar, a lecturer at the University of Birmingham and Honorary Visiting Professor at PGI Hospital, Chandigarh, India. Dr. Kumar has a profile of work in ethnicity; her research interests are behavioural medicine and impact of ethnicity on rheumatology practice. With Dr. Kumar's enthusiastic support, and input from our Advisory Board, we are developing our Apni Jung web area in Hindi and other common Asian languages to support the South Asian communities in the UK. Over time, we wish to extend our work to support other global majority communities in the UK who, for reasons of culture and/or language, are less likely to seek support from organisations like NRAS and may also be disadvantaged in accessing healthcare as a consequence.

NRAS is committed to equality of access to treatment and healthcare, as well as support and information, for everyone living with rheumatoid arthritis (RA) or juvenile idiopathic arthritis (JIA) and their families and carers irrespective of race, disability, sexual orientation, age, gender, religion or belief. We are delighted to welcome the following health professionals and our lay expert to the NRAS family and thank them for giving their time, expertise, and commitment to our Advisory Board.



Dr. Kanta Kumar is a lecturer at the University of Birmingham and Honorary Visiting Professor at PGI Hospital, Chandigarh, India. She was the founder of the Apni Jung project with NRAS. Dr. Kumar has been awarded five national awards for her work in ethnicity in rheumatology. She is a member of a number of national bodies: BSR, South Asian Health Foundation.



Prof. Ade Adebajo is a Consultant Rheumatologist at Barnsley Hospital NHS Foundation Trust and a Professor of Rheumatology and Health Services Research at the University of Sheffield. He is a member of the NIHR Equality, Diversity and Inclusion Advisory Group and a Board member of the NIHR Centre for Engagement and Dissemination.

Dr. Monica Gupta is a Consultant Rheumatologist and physician at Gartnavel General and the Queen Elizabeth University Hospitals in Glasgow. Her MD was on the clinical and laboratory features of septic arthritis and she has co-authored The Textbook of Rheumatology chapter. She runs early RA clinics and a tertiary Sjogren's Clinic and sits on the British Sjogren's Syndrome Association's medical council.



Mrs. Joti Rehal is an NRAS patient Volunteer who has lived with RA for 21 years and worked with NRAS on a number of projects including appearing in a video with Dr. Dubey and Dr. Kumar about transitioning from DMARDs to Biologics on the Apni Jung web area. Since moving onto Biologics, her RA is under control and she is living now with fewer flares and less pain than used to be the case. Her RA started after the birth of her first son when she had a really difficult time. It subsequently caused her to leave her full-time job. She says it affected her not only physically, but in every way; emotionally, mentally, and financially. She didn't give up hope though and went on to have another baby nine and a half years later and is successfully running two businesses.



Advisory Board



Dr. Afshan Salim works as a GP at the Bellevue Medical Centre, Birmingham. She has a special interest in diabetes and is very keen on community education about chronic medical conditions and improving care. Dr. Salim said, "I am delighted to be joining this NRAS Advisory Board."



Dr. Vibhu Paudyal is a Senior Lecturer in Clinical Pharmacy at the University of Birmingham. His areas of research interests are community pharmacy service development, social and behavioural aspects of medicines' use and health inequality.



Dr. Arumugam Moorthy is a Consultant Rheumatologist at The University Hospitals of Leicester NHS Trust and Honorary Senior Lecturer at The University of Leicester. Dr. Moorthy is also a visiting professor of rheumatology at one of the prestigious medical universities in Chennai, India. Dr. Moorthy is actively involved in clinical research in rheumatology and medical education. He has presented his work in national and international conferences including the British Society for Rheumatology congress, EULAR and Indian Rheumatology Association meetings, and published in peer reviewed journals.



Dr. Shirish Dubey has been a Consultant Rheumatologist for 13 years, initially in West Midlands and now in Oxford (Oxford University Hospitals NHS Foundation Trust). His interests include vasculitis and connective tissue disorders, alongside ethnicity. He has previously helped improve resources for patients through videos which helped launch the Apni Jung website and has been contributing to research into influences of ethnicity on outcomes. He has presented a number of oral presentations at international meetings and continues to actively publish papers.

n.b The term 'People of the Global Majority' has been adopted by many people to describe the majority of the world who consider themselves non-white.

Interstitial lung disease not associated with methotrexate use

It had long been thought that methotrexate (MTX) increased the risks of RA patients developing interstitial lung disease (ILD). ILD is more common in patients with RA, so the question of whether or not methotrexate (which is the most commonly prescribed RA medication) definitely increased this risk has been disputed.

A recent study in the European Respiratory Journal looked at 410 patients with chronic ILD associated with RA and 673 patients with RA who did not have ILD.

What they discovered was that in fact the opposite appeared to be true. Patients who had ever been on MTX were found to have RA related ILD (RA-ILD) less frequently than those who had never been on MTX. Detection of RA-ILD was also delayed in the patients who had been on or were taking MTX.

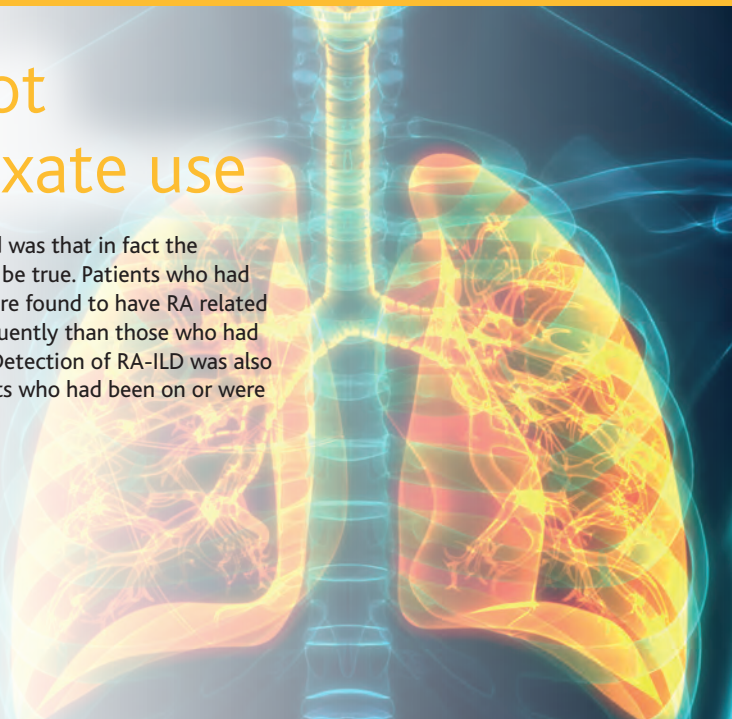




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Making Moves with Didy Veldman

Leading International Choreographer

Dutch born Didy Veldman trained as a ballet and contemporary dancer in Amsterdam. She danced professionally for 14 years and began choreographing in 1987. She has created new works nationally and internationally for the Birmingham Royal Ballet, Rambert Dance Company, Les Grands Ballets Canadiens de Montreal, the Royal New Zealand Ballet and the Royal Ballet School in London, to name but a few!

Didy has been teaching professional dancers and students internationally since 1994 and now runs her own dance company Humanoove. NRAS is delighted that Didy has now put together a dance and movement programme for those living with RA which she will pilot in November with NRAS members who signed up to participate. Didy was diagnosed with RA herself about 8 years ago, but despite having 2 hip replacements, she continues her work and is very much a believer in movement to keep you well and strong to help protect your joints.

If you would like to see some of Didy's work, she created a very timely piece "A Screen Apart" which premiered in July as part of the inaugural World Ballet School Day. This explored the theme of physical restriction and featured dancers from The Royal Ballet School and five other international ballet schools and can be viewed here: vimeo.com/442736678.

NRAS would like to thank Didy for her support and The Royal Ballet School who are kindly giving free use of their studio, sound and computer equipment for Didy's four classes.



Debbie Wilson

Young Persons' Project Coordinator

Debbie's Story

Young Persons' Project Coordinator

JIA has been a part of most of my life; I was diagnosed when I was eight-years-old. My ambition at the time was to be a gymnast but unfortunately I had to give this up, instead, I focused on playing the piano and managed to get to grade 8 standard (even though I had JIA in both my wrists). Throughout my teenage years, my JIA spread and all I was ever told from the doctors was just to get on with it.

It wasn't until I went to the University of Hertfordshire that I got the help and support I needed. It was also where I met my future husband, who was extremely supportive of my condition. I graduated with a 2:1 degree in statistics and economics and became a senior researcher/statistician in the Home Office.

After I had two daughters, I gave up my career to look after them. Any mother will tell you it is a hard but very rewarding role. As a family, we love going for long walks in the countryside, kayaking, and climbing mountains. When my girls were only eight and six, we climbed Mount Snowdon and last year we did the Pen y Fan. The plan at some point will be to do Ben Nevis!

My JIA has always been there in the background but during 2016 I was diagnosed with scleritis (inflammation on the white of the eye). It was a shock to me as I was never told that JIA could affect different parts of the body, especially the eyes. For the first time in my life, I then saw a rheumatologist who fully believed me and could see how much pain I was in. I went on methotrexate, which a year later I had to come off of due to side effects, and I am now taking Imraldi (biosimilar). This was a game-changer, and

my life was slowly getting back to normal. Just after this, my eldest daughter was diagnosed with JIA. It was heartbreaking to hear this as I didn't want her to go through what I went through as a child. Thankfully, medical advances meant that it could be managed, and her healthcare team were extremely supportive. It was at this point I received information about JIA@NRAS and the publications on JIA were a 'godsend'. I sent the 'Managing JIA at School' publication to the school who sat down with us to discuss how they could help and support us. Even the publication 'JIA Explained' was given out to family members so that they could understand a lot more about the condition.

Lockdown and shielding were a pivotal time for me; it really made me think about what I wanted to do in my life. I want to make a difference to young people's lives and I was over the moon when I was offered the role of Young Persons' Project Coordinator at NRAS. I have always made sure that JIA will not define me, but we have to learn how to manage it and deal with the ups and downs that this condition brings. There still needs to be more awareness and understanding about this disease and now working for NRAS I truly hope I can do this.

Unfortunately, I have seen that some things have not changed throughout the years. The stigma of having arthritis is still there as well as the comments 'you are too young for arthritis' or 'my granny has that'. It is not an old person's disease and, yes, inflammatory arthritis can happen at any age.



Diet and RA

The helpline regularly receives calls from people who want to try a specific diet for their RA. Well-meaning friends and relatives tell them that someone they know cured their arthritis by eating specific foods or eliminating something from their diet. Also, people want to be involved in their health management rather than handing everything over to the medical experts.

Unfortunately, there is no cure for RA, whether it be through medical intervention, diet, complementary or alternative therapies. The best outcomes we can expect are disease remission and symptom management.

Diet has been trialled to treat the symptoms of pain, fatigue, and inflammation, but most studies are too small to show consistency. This is not to say that individuals, or groups of people, have not had good outcomes with diet, but there are usually so many variables that a consistent result is not possible. Speaking with a dietitian or registered nutritional therapist is the best way to find out what works. Many people believe that the medical professionals will not be open to discussing anything other than medication, however, they will know if any foods or supplements which interfere and interact with medications and your team are open to helping you to stay as healthy as possible. For this reason, it is important that you tell your medical team if you are taking supplements or on a specific diet.

What we do know is that the Mediterranean diet is a good healthy balanced diet that can help reduce inflammation. Eating more oily fish that are high in Omega 3 fats such as salmon, mackerel and herring has been shown to reduce inflammation. If you are taking it as a supplement, be sure to use fish oils rather than fish liver (like cod liver) oils. Cod liver oil is high in vitamin A which can be dangerous in high doses. Dietitians agree that vitamins and minerals are best gained through food rather than a tablet, which is why speaking to a professional helps a great deal as they have a better

understanding of the nutrients in foods. Some vitamins are difficult to gain naturally, such as vitamin D, which we need to allow our body to process calcium that we need for healthy, strong bones, so in these cases a supplement is recommended. It can be tempting to speak to the 'experts' in health food shops about this, as they are there on hand and don't charge for their advice, however, just remember, their job is to sell you products.

Weight management is very important in RA, carrying extra weight puts pressure on joints and leads to increased pain. People who take steroids, such as prednisolone, report that they have an increased appetite so eat a lot more or snack more often. They can put on weight, which means they move less and feel worse about themselves, and then comfort eat. It's a dangerous cycle that is difficult to break on your own, another reason to speak with a dietitian as they have done all the research and understand how each diet can impact each individual.

Fasting has also been shown to reduce pain; however, some methods such as the 5:2 diet might be unsustainable and potentially lead to binge eating which is not beneficial to health or weight management. The 14:10 or 16:8 may be more beneficial to trial under supervision. Some people with RA find that they actually lose weight, particularly early on, although it's not known why this is. One theory is that your body is busy attacking itself, which needs fuel. Therefore, it is very important that you think about putting in good quality fuel to our most important machine.

Thinking of Getting a Flu Vaccine?

EULAR (European League against Rheumatism) states that people with autoimmune inflammatory rheumatic diseases (AIRD), such as RA, have an increased risk of contracting infections, for example, influenza (the flu) and these infections can lead to more serious symptoms. This can be because of the medications they take which alter immune responses or it can be the disease itself, the body is distracted by fighting itself, so other infections can slip past.

All decisions regarding vaccinations need to be made in collaboration between the individual person with RA and their rheumatology team and it's suggested that an individual plan is put in place which is reviewed each year. Vaccines are classified generally as "live" or "inactive"; it is not recommended that people taking immunosuppressive drugs be given live vaccines. The flu vaccine is an inactive vaccine therefore is safe to use whilst taking DMARDs and most Biologics, however it is worth speaking to your rheumatologist about if you need to have your flu vaccine on a different day to your medications.

The gov.uk website has guidelines for the 2020/2021 winter in line with COVID-19. It states that anyone who was on the NHS Shielded Patient list for COVID-19 is eligible for a free flu vaccine. It also states that more people will be offered free vaccines, so you should check with your GP.



Just a quick word on COVID-19 vaccines, there is a lot of research being done both nationally and internationally to find a vaccine. They will not be released until they have been tested on those classified as vulnerable, however, this will not occur until they get consistent positive results in the healthy community. The advantage of so many people searching for a vaccine is that there should be both live and inactive versions available.

The Success of RAAW 2020!

Physical and Mental Wellbeing



The purpose of RA Awareness Week has always been about spreading knowledge of these auto-immune conditions across communities and how they impact the daily lives of people living with them. This year, especially considering recent events, the focus for NRAS RAAW was on physical and mental wellbeing.

We are very excited to say that we had 1,364 people registered for RAAW which then led to

1,822 people booked to attend the online Wellbeing sessions throughout the week.

The feedback we have received has been excellent:

'I would like to say a huge thank you to you all at NRAS. This is my first year as a member and the past week has been terrific'

'Everything was well thought out and interesting across so many platforms and I feel you have set a precedent for next year. Thank you just does not seem enough.'

'Thank you so much! Fantastic and great work'

'I'm thoroughly enjoying this week, thank you'

'That was the best hour I've taken for myself in a long while, Carlyne Bennett is amazing! What a find! Well done'

'Best wishes to you all and another thank you!'

We would like to say a huge thank you to all our experts who gave us their time to run the wellbeing sessions:

- Kate Hughes – Mindfulness**
- Deniz Paradot – Qigong**
- Sara MacDonnell – Fitness/Exercise**
- Jessie Eloise – Chair Yoga**
- Janet Padfield – Diet/Nutrition/Sleep**
- Carolyne Bennett – Mindfulness/Meditation/Positive Thinking**
- Denise Balyoz – Yoga/Breathing/Posture/Stretching**

We will be looking to arrange some follow-on sessions going forward as we have found that this is a great way of sharing information and getting people in similar situations together online. Feelings of wellbeing are fundamental to the overall health of a person, enabling them to successfully overcome their difficulties and achieve what they want out of life.

Thank you

from the fundraising team



From everyone in the NRAS Fundraising and Marketing Team, please accept our sincere gratitude for everything you have contributed and achieved in 2020.

You have donated, taken part in virtual events, run, walked, cycled, baked, let us share in your important celebrations, climbed and collected all to do a wonderful thing and make a difference.

NRAS are also truly grateful to all the individuals, friends and family members, who lost a loved one in 2020 and chose to honour their memory with a donation to the charity.

Thank you for supporting NRAS, without you we wouldn't be able to help the 400,000 people living with rheumatoid arthritis (RA) and 12,000 children and young people living with juvenile idiopathic arthritis (JIA) across the UK, as well as their families, carers and the healthcare professionals who treat them.

NRAS would like to give special thanks to the following funding organisations and companies who, so far, have supported us in 2020:

In 2020, so far, you have helped NRAS

Manage over **3,200** helpline enquiries

Reach more than **730** individuals through informative webinars

Send over **8,700** copies of publications

Achieve over **120,000** views on our Facebook Lives

- | | | |
|---|---|--|
| The National Community Lottery Fund | Charitable Trust | The C M Lowe Charitable Foundation |
| The Schroder Foundation | Pilkington Charities Fund | Tesco Bags of Help COVID-19 Communities Fund |
| The David Brownlow Charitable Foundation | The Buckinghamshire Community Foundation | St John's Beaumont School |
| James Tudor Foundation | The Roger and Jean Jefcoate Trust | Healthcare at Home |
| The Leatherseller's Company Charitable Fund | The William & Mabel Morris Charitable Trust | Royal Institute of Chartered Surveyors |
| Berkshire Community Foundation | The Hospital Saturday Fund | Unity Lottery |
| The Peter Harrison Foundation | The Eveson Charitable Trust | Gilead |
| Scotland Alliance | John Swire 1989 Charitable Trust | Sanofi |
| Children's Arthritis Trust | Doris Field Charitable Trust | Amgen |
| The P F Charitable Trust | The Marsh Christian Trust | Roche / Chughai |
| Edith Florence Spencer Memorial Trust | Neighbourly Community Fund | UCB |
| The John Coates | Michael and Anna Wix Charitable Trust | Lilly |
| | | Janssen |
| | | Pfizer |

NRAS Shop

buy now while stocks last!

NRAS Masks

NRAS fluid resistant fabric face masks - fluid repellent outer layer, washable and reusable. Our masks have been very popular and those of you who wear glasses will be pleased to know that with our masks your glasses won't get steamed up! (as tested by our CEO!)

Special Member's Price for 1: £8.99
Special Member's Price for 2: £16.99



NRAS Tote Bags

5 oz standard cotton Shopper with gusset and long handles, ideal to keep in your car for your shopping trips and give a clear message to anyone not observing the 2-metre social distance rule.

Special Member's Price: £ 4.50



NRAS Hygiene Hook Keyring

A unique and new product that features a flat stylus tip, finger hole, keyring loop and a handy door hook, all of which help the user minimise contact with commonly touched areas when out and about. The keyring is made from 100% recycled plastics which are inherently antimicrobial, helping to prevent the spread of germs.



Special Member's Price: £3.00

You can find all NRAS Merchandise at our shop at www.nras.org.uk/shop

My Story - Mark Lowry

My name is Mark Lowry; I'm 67-years-old, married with no children, retired and living near Malton in North Yorkshire. This is my RA story.

Horses and horse racing have always been my passion and obsession. In the late 1970s and early 80s I had an enjoyable, if not particularly successful, career as a professional National Hunt jockey. When I retired, mostly in one piece, and left racing to do something more sensible I continued riding out for local racing stables at weekends and during holidays. I've always tried to keep fit, so I was also a keen runner and tennis player, therefore, for many years I had a healthy active life. As my retirement approached in 2018, I had it all planned out that when I retired, I would ride out three or four mornings a week, run and play tennis on other mornings and treat myself to a kayak, which had been a childhood activity.

In 2016, I started to get swollen and painful joints in my fingers and knuckles as well as pain in my wrists and other joints. It wasn't too bad and, as my mother has severe osteoarthritis, I assumed it was the onset of that or possibly the after-effects of riding injuries, so I ignored the symptoms and tried to carry on as normal. I also started to suffer greatly from fatigue which surprised me as I prided myself on my fitness and energy. I was one of those annoying people who always took the stairs two-at-a-time and I gradually found I was struggling to get upstairs at all. My tennis deteriorated as I became slower around the court, running became something I dreaded rather than looked forward to, and the joy of riding horses began to wane.

The symptoms got progressively worse, so I went to see my GP early in 2018. He was sure it was osteoarthritis. I had my hands, wrists and feet x-rayed and that appeared to confirm the diagnosis. Various drugs were tried but nothing made any difference and meanwhile the joints got sorer, and the fatigue got worse. At the beginning of 2019, and by now I had retired, everything was going rapidly downhill. I had virtually stopped running and playing tennis and I began to lose confidence riding as it became increasingly painful holding hard-pulling horses. I went to see my GP again who, although was still sure it was osteoarthritis, referred me to a Rheumatology Consultant. I had 5 months to wait before the appointment so I struggled on as best I could. In August 2019, after more than 50 years of riding racehorses, it became too painful to continue and I finally had to call it a day. I also stopped running as I could barely put one leg in front of the other and my tennis fell by the wayside too, so life felt pretty dismal.

In September 2019, I saw a Rheumatology Consultant at Scarborough Hospital who took one look at my hands and said "Rheumatoid Arthritis" which she confirmed with x-rays and blood tests. Oddly, despite RA being a "life-changing" condition, I was relieved at her diagnosis as I at least knew then what was causing all my problems. She passed me on to a clinical nurse (Michelle – top lady!) who started me on Methotrexate, initially 15mg and now 20mg per week.

Nothing happened for a couple of months and then quite suddenly my hands started to improve. By December, I was back riding out one or two days a week and now I ride out four days a week, anywhere from two to five horses each morning and I'm able to hold all but the hardest

pullers. The most difficult parts of riding now are getting up on a horse (no spring in my legs) and getting off again (arthritic toes aren't good when jumping on to a hard surface). I do need someone strong to heave me into the saddle these days. I still can't run, and I can't move very well playing tennis, but I can ride.



It has now been a year since I was diagnosed and started on Methotrexate and I really appreciate how fortunate I have been to have responded so well to it and be able to get a large part of my life back. Racing stables like to start very early, so I do take a couple of "over the counter" Ibuprofen tablets on riding out mornings as they quickly help to ease the morning stiffness in my hands. I would be lying if I said I never got any pain now, but it is manageable and bearable. I have been lucky to escape some of the dreadful effects of the condition that many other people have suffered, and I am very lucky that I didn't get RA until later on in life. I have read the stories of so many people who got it in their youth or early middle age and I really feel for them as it can be so debilitating.

Fatigue is now the worst part of my condition and mornings can be a struggle. I do need to limit my exercise and take days off to prevent flare-ups. It can be difficult occasionally as other people can see swollen fingers and knuckles, but they can't see fatigue and it can be hard to get people to understand that someone who looks fit and healthy can also get very fatigued very quickly.

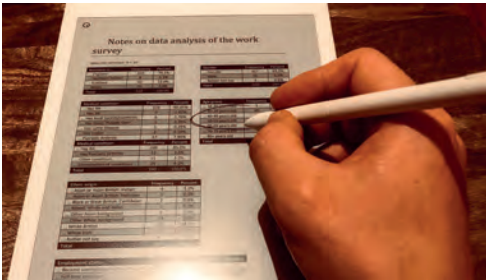
Twelve months ago, I thought my life had ground to a halt and had lost all hope of getting back to the active life I had before RA. Now, well, I've pretty much got my life back. Apart from riding, I go for walks instead of running. I'm not much good at tennis now but I still play a bit and I play a bit of golf too. Oh yes, and I got the kayak I promised myself and have had many happy hours on the river that flows past my home...

What can I say that will help others with RA? I guess, "never give up hope".



A closer look at the impact of COVID-19 and work

NRAS Policy & Communications Manager, Samuel Lawes, takes a closer look at the impact of the COVID-19 pandemic on the working lives of people living with inflammatory arthritis.



He reports on a recent work survey, 2019 NRAS interviews with Rain Newton-Smith, Chief Economist at the Confederation of British Industry, and Neil Carberry, Chief Executive of the Recruitment and Employment Confederation, and shares details of a new push to persuade more employers to support staff with their arthritis at work.

NRAS summer work survey

In July and August NRAS ran a survey on work and wellbeing in the context of COVID-19. We were keen to learn more about the impact of the lockdown on the working lives of people living with inflammatory arthritis.

We also asked respondents about the impact of the pandemic on their finances and career opportunities, about working from home, about how they feel about going into the workplace, and about what support they may need in the coming months. Respondents were also asked what support they felt they received from colleagues and employers. My sincere thanks to the 348 people who completed our survey.



Asking an employer for adjustments

Respondents who asked their employers for workplace adjustments, for the most part, got those adjustments. Employers agreed to almost all requests for flexible working hours, the option of working from home, reduced working hours, and changes in duties. If

The main findings

Your responses taught us some important things. Encouragingly, nine out of ten respondents told us they were still working or on furlough. However, more worryingly, we heard that support, flexibility and the understanding of colleagues and employers have been eroded, not strengthened, by the lockdown. We want to see the opposite: employers learning new adaptability from this difficult year, with new possibilities of flexible and digital working.

Many who switched to working from home feel they will not be able to work from home in future if they need to due to their inflammatory arthritis. If they were sustainably and productively doing so during the lockdown, I cannot see why this should be the case. Offering this option to employees living with inflammatory arthritis makes good business sense; employees are likely to be more motivated, more loyal, and when their own wellbeing is well supported, more productive.

A final message was that two in three respondents received a shielding letter and were fully or mostly shielding. When we asked about the support they received, nine in ten told us their employer had been supportive and would be supportive if they needed to shield again. But only one in ten said they felt ready to return to their workplace without further safety measures being implemented there.

you are wondering about asking your employer for an adjustment that would help you to carry out your role, you should!



By Samuel Lawes

Policy and Communications Manager

Encouragingly, nine out of ten respondents told us they were still working or on furlough. However, more worryingly, we heard that support, flexibility and the understanding of colleagues and employers have been eroded, not strengthened, by the lockdown.

	Frequency	Percent
	340	100.0%
	84	24.7%
	83	24.4%
	49	14.4%
	38	11.2%
	9	2.6%
	33	9.7%
	35	11.5%
	5	1.5%
	340	100.0%

Some requests for specialist equipment were turned down, though most were accepted. We are sending employers information on providing such support, in particular, signposting to the Access to Work scheme. Access to Work provides support to disabled people, those with long-term health conditions and their employers to help overcome work-related obstacles resulting from a disability or health condition. Financial assistance is available to help employers recruit, retrain or make necessary workplace adjustments.

One request that was turned down (five of the ten times it was made) was to undertake retraining for an alternative role at the same organisation.

Of the respondents who felt at increased risk from COVID-19, many of whom were shielding, 93% had told their manager, while 7% had not. Nine in ten of both those who were shielding and those practicing enhanced social distancing told us their employers were supportive regarding this.

Concerns about the future

Two thirds of respondents expected their arthritis to reduce future career opportunities, up from a half before lockdown. Only a third expected their colleagues and employers to be more understanding and supportive because of the pandemic, and only a third expected any improvement in measures taken to support them with their arthritis. A fifth worried they may lose their job, and a similar number told us it would be more difficult for them to do their job.

Support from your team

57% of respondents told us their colleagues and employer were 'understanding of my inflammatory arthritis and how it may impact on my work' before the pandemic. That figure fell to 53% when we asked if this understanding had continued during the lockdown.

This suggests positive change since our 2017 Work Matter survey, in which just under half of respondents told us their immediate supervisors and colleagues were 'always or often willing to listen to work-related problems' and 40% told us their colleagues 'always or often were helpful and supportive'.

Many also reported more flexibility from their employers – 66% were supportive or very supportive of employees who were shielding; a further 23% were 'as supportive as necessary'.

At the time of writing, the Chancellor had just extended furlough to March 2021, and three of the four UK nations were under lockdown. To help employers to support employees living with inflammatory arthritis in the months ahead, NRAS has produced new resources which can be accessed at www.nras.org.uk/resources-for-employers

These include video messages from Rain Newton-Smith and Neil Carberry, details about relevant schemes and support for employers, such as Access to Work and ACAS, and free use of *An Employer's Guide to Rheumatoid Arthritis*. We encourage employers to make use of these resources.

Two thirds of respondents expected their arthritis to reduce future career opportunities, up from a half before lockdown



image © pch.vector

CBI: a case in point



image © ArthurHidden

Last year our Patient Champion, Ailsa Bosworth MBE, interviewed the Chief Economist of the Confederation of British Industry (CBI), Rain Newton-Smith.

Ms Newton-Smith told us the CBI had 'recently surveyed over 350 businesses, and over 80% felt that health and wellbeing was important to their overall business.'

Asked about the incentive for employers to support staff living with long-term conditions, Ms Newton-Smith said, 'When we surveyed businesses around mental health, we found that half of businesses were providing support for line managers in how to have conversations with their employees around mental health.'

Reflecting on her own experience, the top economist, whose daughter was diagnosed with

juvenile idiopathic arthritis (JIA) aged three, added, 'I'm very lucky that my employer has always made it very easy for me... it makes me very loyal to the organisation that I work for.'

'I need the flexibility with my hours, and I think that's really what the modern world of work is about.'

Back to work support

We asked respondents who had been away from their place of work what support they would value on returning. 47% told us they would value a back-to-work interview with their line manager, 38% said they would value access to an occupational health adviser, 27% said they would value help with stress, and 28% said 'other mental wellbeing support'.

Occupational therapists, counselling sessions and a gradual return from furlough were also listed by 20% of respondents.



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Westminster and Holyrood

We are working with other patient organisations to put pressure on ministers for measures to support people living with inflammatory arthritis – in particular, those who have been shielding – in continuing to work, and to work from home, if that is the best option (a quarter of respondents told us their work could not be done from home). We have also presented preliminary findings from this survey to a Cross-Party Group in the Scottish Parliament in Holyrood, chaired by Brian Whittle MSP.

In all this work, we are pressing for flexibility, understanding and adjustments that are usually inexpensive to provide and which will enable people living with inflammatory arthritis to continue to play their full part in helping the country through these choppy waters; let's hope for calmer seas ahead.

A full survey report will be published in due course on the NRAS website. In the meantime, we will never tire of restating the payoff for employers of providing flexibility and support – retaining the best people for the job, fuelling productivity and building up a more motivated and fiercely loyal workforce.



We are working with other patient organisations to put pressure on ministers for measures to support people living with inflammatory arthritis – in particular, those who have been shielding – in continuing to work, and to work from home



Help us to Help you

This has been a year of uncertainty for all of us, and we have been so grateful for all the support for NRAS during this time. However, it does not look like COVID-19 is going anywhere anytime soon, and 2021 is full of unknowns for many charities like us. NRAS has supported the RA and JIA community for nearly 20 years and we want to be here for future generations.

We still need all the help we can get

With the Helpline costing around £1,657.60 a week, could you be one of the 89 people donating just £18.74 today to keep it running for a week? Any donation you can make will ensure the Helpline and our other vital services can continue during this period of insecurity.

Please visit

www.nras.org.uk/donate

or call the Fundraising team at 01628 823524 if you can help

Thank you

BeGambleAware.org



Could you be our next

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/nras-lottery. T&C's are on the website and the lottery is for players over 18 or over.

UK ONLY

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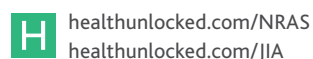
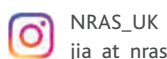
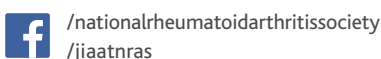
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