

YOUR *Members' Magazine!*

# NEWSRHEUM



nras

National Rheumatoid  
Arthritis Society

2001-2021  
ANNIVERSARY  
SPECIAL EDITION

# 20 YEARS Anniversary

STRIVING FOR A WORLD  
UNBURDENED BY RA AND JIA



By Clare Jacklin

NRAS CEO

# Dear Members

By the time you are reading this magazine, we will have been living with COVID-19 in the UK for almost 20 months. I often think, thank heavens we cannot predict or foresee what the future holds in store for us. Can you imagine if 20 months ago we would have known what we were about to go through and are still dealing with now? I'm not sure about you, but I think I may well have run to the hills and become a hermit! When faced with a crisis, it can be difficult in the moment to imagine that the experience will eventually lead to some type of growth. Resilience is a person's ability to bounce back from adversity and grow from the challenge, and research now shows that past adversity can help you persevere in the face of current stress. This has certainly been the case for NRAS and for many of you, I'm sure.

Life's experiences, both good and bad, can teach us important lessons. Often it is the difficult circumstances we all encounter at times in which we learn the most. I frustrate my family regularly when something goes wrong, and I say, 'we learn more from our mistakes than we do from our successes.' This is hard to see when you are in the middle of a crisis; but as time goes on, you might realise that each difficult moment was preparation for the next step or stage in your life. I am realising that now as we are planning our next three-year strategy for NRAS, the next chapter in our history will be different due to COVID-19 and that might not be a bad thing. This past 20 months has tested us all on so many levels, but also opened many new opportunities and forced us to do things differently. It is perhaps serendipity that as we celebrate NRAS' 20th birthday in October, that we not only draw on what we have learnt in those 20 years, but also in the past 20 months.

I already shared with you in previous magazines, my 'pandemic mantra' of '**not back to normal but forward to better**' and this, I trust, will be evident in every aspect of our three-year strategy. Always striving to move forward, improving our services and supporting the NHS in rebuilding and recovering. One key theme that will run throughout the strategy will be working in partnership with NHS colleagues in embedding self-management into treatment pathways. You will read later [page 4] about the EULAR recommendations and implementation plans for patient education to be given greater priority.

Another major NRAS achievement this year has been the news from NICE on improved access to advanced therapies for those with 'moderate RA'. See page 7 for full details.

This magazine is our 20th Birthday bumper bonanza edition and I hope that many of you will enjoy taking a trip down memory lane as we acknowledge what NRAS – YOUR patient organisation, has achieved since a certain Ailsa Bosworth MBE, had a notion to make a difference for those living with RA and JIA way back in 2001!

NRAS would not be able to do any of the amazing work we do without the ongoing support of YOU – NRAS Members, Volunteers, fundraisers, Trustees, industry partners and donors. Whilst we are unable to raise a glass with you all in celebration this year, please do think about how you can mark the occasion by participating in the '**#DoThe20Challenge**' ([nras.org.uk/dothe20](https://nras.org.uk/dothe20)). And with luck and a fair wind, we hope that in 2022 we can really pull out all the stops and celebrate with as many of you as possible in person, our coming of age and being 21!

Happy Birthday NRAS. Thank you for being part of our collective story.

Warmest regards to you all,

Clare  
Chief Executive

P.S Christmas is not too far away, you can support NRAS by taking a look at our fabulous Christmas Card leaflet enclosed!

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

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## 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](mailto:membership@nras.org.uk) to check we have your up to date email address and contact preferences.



**Ailsa Bosworth MBE**  
National Patient Champion

# Get ready to SMILE!

NRAS is proud to announce the launch of the first programme on our new e-learning platform – SMILE-RA – during RA Awareness Week 2021 on 17th September. SMILE-RA stands for Self-Management Individualised Learning Environment in Rheumatoid Arthritis. SMILE is a unique and engaging e-learning experience for people with RA, their families who want to understand more about RA, its treatments and how to support their loved one. It will also be a useful resource for health professionals, new into rheumatology, who want to learn more about this complex autoimmune disease, how it is managed and the importance of self-management for their patients.

SMILE has a modular approach to learning, so each module is on a particular theme or subject and takes between 20 mins and half an hour to complete. There is an intuitive interface which makes it easy to use and navigate your way round. After registering and completing the Foundation module which includes baseline evaluation questions, you can then direct your own learning experience and choose whichever modules are of interest to explore next. The data we are collecting through the programme is extremely important to us and will help us to understand the impact the programme is having on those participating over time. Data collection is fully GDPR compliant and will only ever be used in an anonymised

SMILE is a unique and engaging e-learning experience for people with RA and their families



and aggregated form to report back to our funders, the users themselves and the rheumatology community. Each module has learning objectives at the start and a few questions at the end to gauge how well these are being met for participants and this will help us to understand in broad terms that the structure of the modules is working optimally.

The modules are interactive, contain short quizzes and lots of video and voice-over contributions from rheumatology health professionals, NRAS staff and people with RA. We've worked very hard to make the programme attractive and engaging to work with and the content has been written with input at every stage from our E-Learning Advisory Board and the professionals and individuals with RA who have contributed to each module.

NRAS has invested a significant amount in developing this unique resource. The reason we have prioritised SMILE in this way is because supported self-management is critically important to everyone with RA (or any other long-term condition) if they want to live their best life with RA, have the best long-term outcomes and also feel in control of their disease rather than the RA controlling their life. Self-management sounds as though this is something you do on your own which is not the case, and why we always refer to it as 'supported self-management' (SSM). To learn how to self-manage well, you need the right support at the right time from a variety of sources including your rheumatology team, your family, friends and colleagues and your relevant patient organisation – in the case of RA, NRAS! As part of the Foundation module, we address why SSM should be as important to you as taking your methotrexate, or other medications you are on.



The modules available to be selected at launch are the following:

- **Foundation**
- **Newly Diagnosed**
- **Meet the Team**
- **Managing Pain and Flares**

The Medicines and Treatment module will be launched later in the autumn. More modules will be added as they are developed going forward and we anticipate that in time, we will have the most comprehensive resource spanning all aspects of living with RA. It takes time and significant cost to develop each module and we will progress as rapidly as we are able.



**“As a rheumatology nursing community, we value any reliable evidence-based resources that we can signpost our patients to in order to provide additional support on understanding their rheumatoid arthritis diagnosis, and welcome the launch of SMILE-RA”**

Julie Begum – Lead Rheumatology Nurse Specialist at Luton & Dunstable University Hospital NHS Foundation Trust and current Chair, Rheumatology Nurse Forum at the Royal College of Nursing



Rheumatology services have been impacted in a major way by the pandemic as so many rheumatology professionals were re-deployed to the COVID-19 frontline. However, this has created a backlog as all of you reading this article will be only too aware, which teams are tackling now. The recent publication by the British Society for Rheumatology (BSR) of their report on the state of the rheumatology workforce “A Crisis in Numbers,” said that numbers of consultants and nurses as well as allied health professionals have to increase in order to “ensure the sustainability of the workforce.” The rheumatology community has been aware of the critical state of the rheumatology workforce for a long time,

and therefore in recent times, NRAS have developed services and resources which not only benefit people with RA but also provide health professionals with easy and reliable, evidence-based services to which they can refer their patients. SMILE helps health professionals to meet NICE Quality Standard 3 which says: “Adults with rheumatoid arthritis are given opportunities throughout the course of their disease to take part in educational activities that support self-management”. This is a quality standard against which rheumatology units are audited by the National Early Inflammatory Arthritis Audit run by the BSR. SMILE-RA also complements our referral services ‘Right Start’ and ‘Living with RA’ - see the website for more details: [nras.org.uk/refer-a-patient/](http://nras.org.uk/refer-a-patient/)

**“As a result of amazing advances in the understanding of the causes of RA over the last few decades, we now have a greater variety of effective therapies than ever before and, consequently, the outlook for people living with RA is better than ever. However, adjusting to life with RA, learning to get the best out of treatment and navigating the healthcare system (which is invariably overstretched!), can be extremely daunting! It is therefore wonderful that NRAS have created this SMILE-RA resource which will be a boon to patients, their friends, family, and health professionals. It is a resource to take the user by the hand and guide them on the journey to wellbeing.”**

Peter C. Taylor,  
Professor of Musculoskeletal Sciences,  
University of Oxford

Recently, EULAR published “Recommendations for the implementation of self-management strategies in patients with inflammatory arthritis” and a second paper associated with this work entitled “Effectiveness of self-management interventions in inflammatory arthritis: a systematic review informing the 2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis”. The Taskforce which produced these recommendations was led by Joint Convenors Ailsa Bosworth and Dr. Elena Nikiphorou and you can read more about this work on page 14. The timing of these two publications is relevant to the launch of SMILE as they reinforce the importance of health professionals incorporating self-management strategies into routine clinical care to provide a more tailored and holistic approach to care than the more widespread clinical medical management model of care.

NRAS have developed services and resources which not only benefit people with RA, but also provide health professionals with easy and reliable, evidence-based services to which they can refer their patients



**For more information on how to get started, please see the enclosed leaflet**



**“Even though my RA diagnosis was many years ago, my involvement as a Volunteer with NRAS has taught me that there is always more to learn. The research, development and information in the world of RA is constantly evolving. I am a strong believer in ‘knowledge is power’ when it comes to managing your own condition. Therefore, SMILE is a great resource whether you are newly diagnosed or have been living with RA for many years.”**

Donna Saunders, living with RA

# NRAS JoinTogether Digital Groups

## Introduction

It can be hard to find someone who understands the issues faced when living with Rheumatoid Arthritis (RA) and being able to connect with others living with RA can be of great benefit and comfort. Our new NRAS 'JoinTogether' digital groups are a great way to interact with others who have busy day-to-day lives and are trying to manage the difficulties of their disease. These new groups enable you to regularly meet online to discuss your issues and learn to live better with your disease. Read more about the groups and their co-ordinators below!



*Katy Pieris,  
JoinTogether  
Digital Groups  
Volunteer Lead*



## JoinTogether Exercise & Back to Sport Group

### Co-Ordinators: Ian James and Katy Pieris

Having spent many happy times enjoying the more active side of the outdoors: in activities that range from mountaineering and fell-walking to running and cycling; I was not prepared to give up such sports when I was diagnosed with RA in September 2020 (particularly when I had decided to take early retirement at the same time to enjoy the outdoors!).

There have been many ups and downs since diagnosis, and many times when swollen joints or the dreaded fatigue has

stopped me from getting out and enjoying sport. At the same time, it has been difficult to get clear advice on what 'exercise' means when you want to get back out running and back onto the hills.

It has been difficult to find and engage with like-minded active people who can support you in an open forum when the need arises. So, setting up an 'NRAS Exercise & Back to Sport' JoinTogether digital group will hopefully open the pathway back to more intense exercise for myself and others in similar positions.



## JoinTogether Parenting with IA Group

### Co-Ordinators: Hansa Morar and Hafsah Amanji

I am very keen to help parents with Inflammatory Arthritis (IA). I feel it is important for parents to know that they can be a part of a wider digital group and to know that someone else is going through

a similar experience to them. It is a great way to be able to share helpful tips and give advice that can make parenting with IA more manageable.



## JoinTogether Working with IA Group

### Co-Ordinator: John Brooker

I was diagnosed with RA 3 years ago at the age of 23, just as I started a job in finance straight out of university. I didn't know anyone else with the condition and struggled significantly with managing a time intensive job and RA when I was first diagnosed. I am

the co-ordinator for the 'Working with IA' JoinTogether group, focused on connecting those who work with RA with an aim to help others have both a fulfilling work and personal life - something I am very passionate about.



## JoinTogether JIA Parents Group

### Co-Ordinator: Victoria Neale

It can be very overwhelming and lonely having a child with Juvenile Idiopathic Arthritis (JIA) - not many people understand what we go through as parents everyday: juggling appointments, school, work and a

world that still thinks arthritis is for old people. 'JIA Parents' JoinTogether group gives parents and carers the opportunity to talk to others in a similar position and understand how different each day can be.



## JoinTogether 18-35 Group

### Co-Ordinators: Francesca Hopkins and Chloe Walker

I was diagnosed with Rheumatoid Arthritis just after my 30th Birthday and during the pandemic. I found googling the disease terrifying and struggled to find any positive stories from people my age who were living well with RA.

comfort to me as a place where I could freely discuss ups, downs, treatments and coping mechanisms with other people in the same situation.

When the opportunity came up to start an '18-35' JoinTogether group through NRAS, I jumped at the chance as I believe it is so important for people to have a safe space to talk freely with people who understand what it's like to live with a chronic illness.

Eventually, I started an Instagram account (@journey\_through\_ra) and met an amazing, supportive community of young people with IA and other autoimmune diseases. This resource was such a huge

**If you would like to join any of the JoinTogether groups, or are interested in setting up a new group, please email [jointogether@nras.org.uk](mailto:jointogether@nras.org.uk)**

# Biggest change to treatment of RA since the introduction of biologics in the early 2000s

**NICE** National Institute for Health and Care Excellence

On 10th June 2021, the National Institute for Health and Care Excellence (NICE) issued draft guidance that gives approval for certain anti-TNF therapies to be prescribed for people with so-called 'moderate' rheumatoid arthritis and on 14th July 2021, this guidance was finalised.

## Background

Until now only those people with severe disease i.e. having a disease activity score (DAS28) of greater than 5.1, have been able to be treated with advanced biologic and targeted synthetic disease modifying therapies prescribed for them as part of their NHS treatment. There are many thousands of people living with active RA, but not quite reaching that 5.1 score, meaning they have not been able to access these medicines.

Since the advent of NICE in the early 2000s, the UK has had to live with the highest barriers within Western Europe to accessing such therapies. There are no such eligibility restrictions in Ireland and many other European countries where choice of treatment is determined by the prescribing clinician being able to use the most appropriate treatment in collaboration with the patient, free from cost restrictions.

## NRAS & BSR campaign for change

The inequity of access to proven, effective medications throughout the last two decades for the many thousands of people living with active, destructive and debilitating disease was the driving force behind NRAS' campaign over the last 3 years, to challenge NICE's eligibility criteria to access advanced therapies for those with 'moderate' disease. It also ends the dichotomy between the NICE RA Guideline and NICE Guidance. NRAS partnered with the British Society for Rheumatology (BSR) in the campaign with our first formal discussions on the topic with NICE and NHS England taking place at BSR's offices in February 2019.

## So, what difference does that mean for people with 'moderately active' RA?

These drug options, now accessible at an earlier stage than has ever been possible previously, will give thousands of people living with moderate active disease hope of

a significantly better quality of life, potentially ending years of living with disease that is not optimally controlled. The impact that this news will have on an estimated 25,000 people's lives, living with RA, cannot be underestimated.

## Managing Expectations

Given the pressure the NHS is currently under and the impact that COVID-19 has had on rheumatology services, it will take time, potentially months, to reflect these changes in clinical practice. If you believe you fall into the category of 'moderate' disease, you need to be aware that you will not necessarily be called in for assessment or moved onto one of these advanced therapies. Rheumatology units are working flat out to address backlogs in seeing new referrals as well as follow ups, so getting a face-to-face clinic appointment may not be that easy. Your rheumatology team will be very keen to implement these changes as swiftly as possible. They are delighted, as are NRAS to, at last, have these options available to improve the lives of many of their patients. NRAS asks for understanding and support of the rheumatology health professionals and commissioners who will be handling the guidance and implementation alongside the backlog of the pandemic.

This decision by NICE to allow access to a limited number of the available and approved biologics is a significant step forward. It will not only make a massive difference to individuals but will improve the experience of rheumatology health professionals who have felt, until now, constrained and restricted in their autonomy to prescribe what they believe will make a real difference to their patients.

NRAS would like to acknowledge the important contribution to this campaign that Professor Peter Taylor (NRAS Chief Medical Advisor), Dr Frank McKenna, and Dr James Galloway have made. Their commitment and unwavering support in so many ways, has been instrumental in helping us and the BSR to achieve our goal of getting access to advanced therapies for people with moderate and sustained active disease.

A recent published NRAS study (Nikiphorou et al, Rheumatology Advances in Practice, Volume 5, Issue 1, 2021, rkaa080) looking at the level of suffering of people with 'moderate' disease, highlighted that people not currently treated with advanced therapies experience profound difficulties in everyday living with rheumatoid arthritis, across a broad range of measures. The NRAS study surveyed over 600 people with RA in the UK who have active disease but, until now, have been unable to access these advanced therapies. 90% had experienced flares of their disease in the previous 12 months with almost a quarter experiencing 6 or more flares.



**Ailsa Bosworth MBE**  
National Patient Champion

"I need some help! I have been asked to start an Association for Rheumatoid Arthritis in the UK..."

## An interview with our first Volunteer: **Gloria Lawson**

When I decided to start an organisation for people with Rheumatoid Arthritis back in 2001, I put a very small ad into our local Maidenhead Advertiser in January, 2001. It said: "I need some help! I have been asked to start an Association for Rheumatoid Arthritis in the UK (I have lived with RA for 20 years). I need a fellow sufferer who also has professional business skills ..."

Gloria was the only person who replied, and she helped me to prepare NRAS for launch which took us 10 months. She said "I was so excited when I saw this, first of all because I thought there's someone else like me, but then I was worried about presenting myself as someone with RA, I didn't want that to define me. I agonised over the weekend, but Steve (Gloria's husband) kept saying 'do it, do it'."

As soon as we met, Gloria said "I felt as if we knew each other already" and my husband, Brian, said he always knew when Gloria was in the house because all he could hear was the pair of us laughing! Gloria was diagnosed with RA when she was 19 in 1985, just 4 years after I was diagnosed at age 31. At the time Gloria started to help me set up NRAS she was working in Steve's business, Freedom to Outsourcing, and she had some flexibility in her working week, so was able to give us some of her valuable time. They had

recently moved to Maidenhead with their 7-year-old daughter Michaela, and Gloria regularly got the Maidenhead Advertiser to find out about what was going on in the local area and build a social network (before the internet!) which of course was lucky for us!

Within 3 years of diagnosis, Gloria had had her right hip replaced then while recovering from that operation slipped and broke her femur which led to 3 months in hospital and the other hip being replaced! All this was swiftly followed by a revision of the first hip as her legs then didn't align! What a rotten beginning to her journey with RA. To date she and I are even on our tally of operations at 16 operations each to replace joints, repair joints, repair tendons etc.

Once NRAS had launched and we had recruited our first 2 or 3 staff, (working from my home), Gloria became Chair of the fledging board of trustees.

Gloria said "I don't know how that happened! I don't remember any voting, we used to sit round your dining table at Briarwood and the cats would jump up onto the table! ... but I



## #DoThe20Challenge!

### NRAS is celebrating its 20th Anniversary!

This year we will have a new fundraising challenge to help raise funds to keep the much-needed resources and services we provide running.

All you need to do to get involved is decide on a sporty, wacky, creative or foody challenge all focused on the number 20, set up your fundraising page, claim your free t-shirt and have some fun!

On completion of your challenge, you will receive a limited edition 'I did the 20 challenge' medal which you can wear with pride!

Here's Ellie Fleming, the first person to register. She took on the #DoThe20Challenge by doing a tandem skydive.... what a fantastic challenge!

Ellie managed to raise an amazing **£1,034** - a great start to our #DoThe20Challenge fundraising.

More information and details are on our website from "How to set up a fundraising page" to how to contact the fundraising team for help and guidance.





First Board of Trustees:  
Wendy Garwood (deceased),  
Mike Singh,  
Alice Peterson,  
Mark Liddell,  
Gloria Lawson,  
Sue Ball

do recall there was a lot of form filling for the Charities Commission. The important thing for me was that you had a clear goal to raise awareness. We both knew that the voice of people with RA wasn't being heard or represented, and you were also going to be national so the tentacles would spread across the country. Also, being online would give wider access to younger people. When I was diagnosed, I had to go to the library and get books!"

Things were very different when we were diagnosed in the early 80's. Gloria commented, "it was like 'take an aspirin and go and lie down till it, whatever 'it' was, passed!". The biggest change was with the launch of the biologics because before that it was steroids or bust! Having someone you could call and say, 'I'm having problems with X, Y or Z, was just the best thing ever."

What are some of the stand-out moments for you, I asked? "There are lots of them" Gloria replied. "The Berkshire Business Awards that we won in the early days, the British Society for Rheumatology conferences, the birthday celebrations with Theresa May ... Also HealthUnlocked is a fantastic resource, a whole community of friends – just incredible. That's what I needed when I was diagnosed, a platform like this which makes you feel like you're not on your own."

During her time as Chair of the Trustees, Gloria started to take on more and more, in spite of her debilitating RA and on-going bouts of surgery. She and Steve wanted to increase their family and were going through an adoption assessment process. Whilst this was happening, she underwent a partial nephrectomy (partial removal of one of her kidneys, not related to her RA), and on top of this, she was training to become a solicitor and approaching her finals. This 'super woman', understandably needed to step down as Chair of the Trustees and focus on these monumental changes in her life. She had already given NRAS so much of her time, support and infectious enthusiasm and we were just so grateful to have had her input over the first years, getting NRAS established as the voice for RA in the UK.

I asked Gloria if she had any idea, at the time she was first involved with NRAS, where we would be 20 years on? "OMG, no" she said, "But now, if you say 'rheumatoid' NRAS flies to the top of the list. When you think about how far we've come and how much NRAS is known and respected, not just in the UK but right across Europe, ... and then there's all the JIA side, and during the pandemic those Facebook Lives, every Thursday – just incredible!"

It's been so lovely to have the opportunity to reflect on the start of NRAS and those early years with Gloria. Thank you, Gloria, for being such an important part of our NRAS journey! Here's to the next 20 years!



# Remember a Charity Week

Remember A Charity Week is the perfect opportunity to take a moment and consider leaving a gift to charity in your Will, after taking care of your loved ones.

This year Remember A Charity Week is 6th to 12th September.

Join us and celebrate the generosity of Gifts in Wills and the work they make possible at NRAS.

**HELP PEOPLE WITH INFLAMMATORY ARTHRITIS**

Find out how to leave NRAS a gift in your Will

**WILL YOU**

nras  
National Rheumatoid Arthritis Society

REMEMBER A CHARITY IN YOUR WILL. Help the work that matters.

## 2 in 5



**Lonely or desperate calls to our helpline would go unanswered without Gifts in Wills**

A gift in your Will to NRAS ensures we can provide vital services now and long into the future, to all those living with RA and JIA across the UK.

Did you know that as little as 1% of your estate can help NRAS do amazing things. Leaving a Will lets you take care of your assets, your loved ones and the causes you care about.

**To find out more about leaving a charitable gift in your Will, see our website here:**

[nras.org.uk/  
gifts-in-wills](https://nras.org.uk/gifts-in-wills)

Or contact Emma Spicer  
Telephone: 01628 501 548  
Email: [espicer@nras.org.uk](mailto:espicer@nras.org.uk)



# Sitting down with NRAS' first member of staff



Lorraine taking a helpline call

Victoria Butler, NRAS' Information Manager, sat down with Lorraine Tanner, her former manager and the first member of staff hired by Ailsa Bosworth MBE when she set up NRAS. Lorraine started in 2002 and worked here for 14 years before continuing to engage in voluntary work since retiring.

## What made you apply for the job at NRAS?

I needed a different challenge after teaching for many years and after recently recovering from cancer, I had some insight into what it is like dealing with new treatments, hospitals and the psychological impact of a health condition. I had some knowledge from having a family member with RA and my parents worked in healthcare, so I felt that this looked like an interesting role for me. I was not wrong!

## What was your job role back then?

My biggest role initially was administration and answering phones, gradually doing more Helpline work. I also worked on developing the website, database, newsletter, fundraising - in fact, a bit of everything.

## What was it like in those early days, working out of Ailsa's house?

Challenging! The days were very busy and juggling everything was difficult. There was so much that Ailsa wanted to do but we had very limited resources. Ailsa and her husband Brian were very generous hosts and I felt very comfortable in their home and for the first few years it worked very well, until we outgrew it and had to move into office space.

## How did you go about setting up a helpline service?

I learned a lot working alongside Ailsa; initially she dealt with calls and emails, and I listened and gradually started taking calls myself when I felt more confident. I read and researched and with the support and counsel of the medical advisors that had been recruited to help by Gabriel Panayi (then chief medical advisor and now, a NRAS patron), we developed a range of information for the website. I also undertook several helpline training courses.

As the charity became better known we needed help to cope with the increasing demand for support. It was then that we were able to look at a more defined Helpline service and my gratitude goes to Helen Bunyan, who worked as Membership manager and the Helpline for several years, and Victoria, who worked on the Helpline for over 10 years, latterly as manager, who very much helped develop this part of our work. Also, throughout the years my gratitude goes to the other fantastic members of the Helpline team who also helped to refine and improve this service.



Lorraine with Membership manager Helen Bunyan.

## What did you enjoy most at NRAS

Making some very good friends, and meeting Ailsa has been an inspiration, as were the people I spoke to on the Helpline. I met and spoke to some lovely people, and it was good to feel I could make a difference and to work somewhere so dynamic.

.....  
 "I see my years at NRAS as an incredibly exciting, positive, very valuable part of my life."

**What is your message to NRAS for the future?**

Keep innovating in the way that you have for the last 20 years. My life would have been very different if I'd not worked for NRAS and I don't think I would have met such wonderful people, learnt so much and had such opportunities.

*"Lorraine was the nicest manager I ever had and remains a good friend. Her level of knowledge was astounding, and her management style was a breath of fresh air to me. When you have a manager who is that kind and thoughtful, you would never want to disappoint them. I learned a lot from Lorraine and would not be where I am today without her guidance and support."*

Victoria Butler



Lorraine and Victoria

*"Lorraine was the first 'long term' employee I took on in February 2002. Little did I realise what a fantastic asset she would turn out to be. She led our Helpline team over a period of 10 years and made an enormous contribution to the growth and development of our Helpline, information and support systems and resources and subsequently became and still is, a valued Volunteer for NRAS. She remains one of the 'NRAS Ronettes', singing at the NRAS Christmas shows. Thank you, Lorraine, for all your passionate hard work – you made a positive difference to many lives!"*

Ailsa Bosworth, NRAS Founder



Lorraine and Ailsa

*"My gratitude goes to the other fantastic members of the Helpline team who also helped to refine and improve this service."*

## The Benefits System, post-COVID-19

Many people who have contacted NRAS in the last year asked about what is available for people who have been shielding or classed as clinically extremely vulnerable and who may need to re-evaluate their work situation. The Coronavirus Job Retention Scheme and Self-employed Income Support (SEISS) have been extended until 30th September 2021. From 1st July 2021, the government will only pay 70% of wages up to a maximum cap of £2187.50 for the hours the employee is on furlough and employers will have to top this up, so that it meets a minimum of 80% of usual wages.

If you have lost your job or been made redundant because of COVID-19, or if you are earning less, you may be entitled to benefits or an increase in the amount you receive if you are already on benefits.

Universal Credit is a payment to help with your living costs. You might be eligible for Universal Credit if you are on a low income, you are not working, you have a disability or illness, or you are caring for someone that does. The amount you get will be dependent on your needs, your earnings and amount you have in savings.

If you are not able to return to work or must reduce the hours you work, you may be eligible for Personal Independence Payment (PIP). This is one of the benefits most often claimed by people with RA. It is not means tested and covers two areas – daily living and mobility.

Try these online benefits and grants calculators to work out if you may be eligible:

[citizensadvice.org.uk/benefits/benefits-introduction/what-benefits-can-i-get/](https://citizensadvice.org.uk/benefits/benefits-introduction/what-benefits-can-i-get/)

[turn2us.org.uk/Get-Support](https://turn2us.org.uk/Get-Support)

NRAS has two publications- Benefits and Rheumatoid Arthritis and How to claim Personal Independence Payment (PIP). Our PIP guide has recently been updated to reflect changes in the benefits system, with our Benefits Guide due to follow soon (at time of writing). Both can be downloaded and ordered on the NRAS website through the shop section - [nras.org.uk/shop](https://nras.org.uk/shop)

### ASK THE HELPLINE

**Nadine Garland**

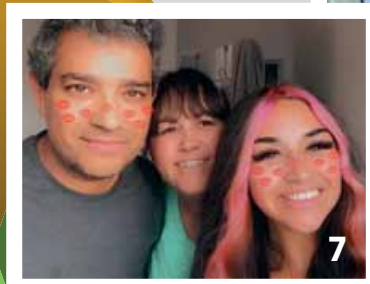
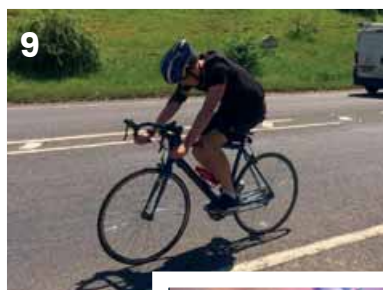
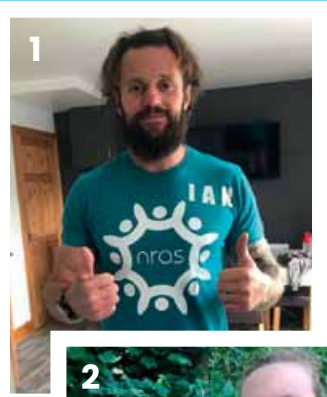
Information and support services manager



# Fundraising in the Community

We would like to celebrate some of our amazing fundraisers who set themselves a variety of personal challenges and even though we were still experiencing lockdown this did not prevent them reaching their end goals. We have had some amazing support to kick start 2021 and our 20th Anniversary year, bringing in over £9000 between them! Here is a quick name check and round up of what some of them got up to from March to the end of July...

1. Ian Burkitt did an amazing 100 miles in 24 hours this was his second year in this challenging event and raised a phenomenal **£1185**
2. Mum and son duo Jack and Jaime Sim walked an incredible 200 miles in the month of June and raised a fantastic **£300**
3. Suzanne Miller from Bolton took on the Great North Swim in Lake Windermere and was sponsored **£395**
4. The girls and staff from Wendreda House at Kings Ely School in Cambridgeshire organised a team challenge to celebrate the life of Wendreda House Matron, Liz Firek. They walked the Lands End /John O' Groats distance and raised **£1482**
5. Paula Wilkie banished alcohol for 8 weeks in Feb and raised **£509**
6. Lucy Stephenson was showing support for her fiancée who has RA and walked 500,000 steps in May and was able to donate **£320**
7. Walking 100 miles in March was Nadia Davari and she raised a wonderful **£155**
8. Dan Halls was one of our younger fundraisers, cycling 100 miles in March to support his Mum who has RA and his challenged bought in an amazing **£720**
9. Another young fundraiser was Frankie Knight from Worcester who completed an Olympic distance Triathlon! We were delighted he raised over **£700**
10. Kayleigh Jackson took on a more unusual challenge of a 'Head Shave' in honour of her Mum who has RA but continued to work for the NHS during the Pandemic. She generously donated **£259**
11. Mum and daughter Lucy and Demi Drury shared the distance of 22km (half marathon) between them as Lucy has RA along with other health conditions but wanted to push herself to walk 7km. They raised a wonderful amount of **£418**
12. Walking was very popular in March with Lyndsey Scarisbrick walking 300 miles and raising **£1020** and Lesly Moir walked 100km and raised **£1426**
13. Anna Reed took on a rugged Coastal path challenge of 10K and was sponsored to the tune of **£244**



# Rheum for Inclusion

'Rheum for Inclusion' is a new NRAS Advisory Board that has been set up to drive strategies and interventions to improve NRAS' inclusivity and diversity.

The group is in the process of welcoming five new members, but here is an introduction to the five founding members - Simone, Haffy Sukhjeen, Suruthi and Karin.

At NRAS we have no doubt that this group will continue to flourish and grow and make positive changes for those in diverse communities who live with RA or JIA. If you would like to find out more or get involved with the 'Rheum for Inclusion' Advisory Board, please contact [Janet@nras.org.uk](mailto:Janet@nras.org.uk).

## Simone (Founding Chair)

After being diagnosed with Rheumatoid Arthritis (RA) as a biology undergraduate in 2018, I chose to focus my academic research on the immune system and what constitutes a 'normal' immune system.

I have 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. I am keen to bring my knowledge of science, diversity and inclusion and RA diagnosis in young people to the future work of NRAS.



## Suruthi

I'm 23 years old and currently working as a research assistant before starting my PhD. I was diagnosed with Juvenile Idiopathic Arthritis (JIA) at the age of 3 and have learnt a lot about my condition along the way, but also realised that there is sometimes a lack of support for people like me, and that's what made me decide to join Rheum for Inclusion!



## Karin

I am a South London resident, born in Sierra Leone. I have completed my education in Sierra Leone, the UK and the USA: where I obtained my PhD. in Educational Administration and Policy Analysis from the University of Chicago.

In my professional life, I focused on increasing the educational participation of girls and women, particularly in sub-Saharan Africa. The symptoms of Rheumatoid Arthritis (RA) started in 2002 with extreme pain and stiffness in knees, progressing to the hands several years later. The RA diagnosis came in 2013 and despite several flare-ups, my quality of life gradually improved with treatment. My membership of NRAS was spurred by a desire to educate myself about developments in treatment and lifestyle choices that could reduce the likelihood of future flare-ups.



## Haffy

I was diagnosed with Rheumatoid Arthritis (RA) back in 2019. My journey thus far with RA is the reason why I joined 'Rheum for Inclusion'. When I was diagnosed, talking about my condition was taboo in my community and I was left feeling very alone to deal with a life changing experience. Being from a British-Indian background I want to help raise awareness and educate people from ethnic minorities about RA and the challenges we face, hopefully helping to show that it's not such a taboo thing to talk about.



## Sukhjeen

I have lived with Rheumatoid Arthritis (RA) since October 2018, whilst completing my university studies. Having grown up in a South Asian/Indian background and after noticing the intersection of health and ethnicity, I decided to join 'Rheum for Inclusion' to encourage those from a minority background to be included in the forefront. I also aim to use the role to increase representation from all communities.





Ailsa Bosworth MBE  
National Patient Champion

# 2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis

Over the last 2 years or so, I have had the privilege and pleasure of being Joint Convenor of a EULAR Taskforce with my friend and colleague Dr. Elena Nikiphorou, Consultant Rheumatologist, King's College Hospital and Adjunct Senior Lecturer at King's College, London. Our challenge was to create EULAR recommendations for the implementation of self-management strategies in inflammatory arthritis (IA). This was my first experience of working with a EULAR Taskforce and it was born out of a suggestion I made to a past President of EULAR when at a meeting in Amsterdam 3 years ago! I felt that the EULAR Recommendations on the management of rheumatoid arthritis did not sufficiently address the important element of supported self-management and were too medically focused. Prof. Bilsjma suggested that I apply to convene a Taskforce to provide the evidence base for such recommendations and before I knew it, I was starting to write the application. Being unfamiliar with the EULAR operating procedures for this, I was very relieved when Elena was proposed, and agreed to be my co-convenor. Elena has a lot of experience of working within such Taskforces, is a EULAR methodologist and is also a strong advocate for patients and shares the NRAS passion to get supported self-management into routine clinical care.

Our first task was to identify our Steering Group which required a methodologist, (Loreto Carmona, Scientific Director, Instituto de Salud Musculoesquelética, Madrid) and 2 Fellows who would conduct the systematic literature reviews, Andrea Marques, Professor at Nursing School of Coimbra, ESEnfC and Eduardo Santos, Professor at the Viseu Higher School of Health, Portugal. Our Taskforce numbered 18 health professionals (HCPs) in total from 11 different countries

and represented the whole rheumatology multi-disciplinary team, and of course also included input from people with lived experience of inflammatory arthritis (the Taskforce members are listed at the end of this article).

.....

"I was delighted to work with Ailsa, our patient research partners and health professional colleagues from the wider EULAR network on this important piece of work. I hope these recommendations will bring positive change and that they will improve the care and outcomes of people living with inflammatory arthritis."  
- Dr. Nikiphorou



Dr. Elena Nikiphorou

## Background

The ability to self-manage in inflammatory arthritis (IA) represents an essential component of care that goes beyond drug therapy, and which supports the individual in managing the practical, physical and psychological impacts of disease. Self-management is a multi-component, complex intervention that represents an unmet need in the care of people with IA.

The term 'self-management' makes it sound as though this is something you do yourself and alone. However, this is not the case and why NRAS prefers to call it '**supported** self-management' as you need help and support from a range of different sources to enable you to do it well. These sources of support include your rheumatology team, your close family and friends and the relevant patient organisation like NRAS. Also, comorbidities (other co-existing conditions) including cardiovascular disease and common mental health conditions represent important, yet often poorly addressed aspects of IA despite their impact on disease outcomes. Addressing physical as well as psychological comorbidities is therefore crucial, and more likely to be achieved if more holistic approaches to patient care are adopted, including referral to other members of the multi-disciplinary team (MDT).

All these important aspects of disease, which can place a high burden on the individual and their immediate family, necessitate the incorporation of supported self-management in the routine clinical care of people living with IA. For self-management to be effective however, it is imperative that health professionals are given adequate guidance and professional training. This has a significant positive impact on their engagement in clinical self-management support and patient-centredness, as well as on their overall confidence to support self-management.

As mentioned above, patient organisations also play a major role in the provision of supported self-management resources and if we want health professionals to routinely refer their patients to our resources, it is vital that we build in the necessary evaluation to evidence the impact of such services and resources. This can be hard and costly for patient organisations to do, but we must evidence impact for funders, so it is equally important to demonstrate effectiveness for the NHS.

Three overarching principles and nine recommendations were formulated.

### Overarching principles

- |          |                                                                                                                                                                                      |
|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>1</b> | Self-management implies taking an active role in learning about one's condition and in the shared decision-making process about one's health and care pathway.                       |
| <b>2</b> | Self-efficacy (personal confidence to carry out an activity with the aim of achieving a desired outcome) has a positive effect on various aspects of living with IA.                 |
| <b>3</b> | Patient organisations often provide valuable self-management resources and collaboration between healthcare professionals and patient organisations will therefore benefit patients. |

### Recommendations

- |          |                                                                                                                                                                                                                                           |
|----------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>1</b> | HCPs should encourage patients to become active partners of the team and make them aware of HCPs and patient organisations involved in all aspects of the care pathway.                                                                   |
| <b>2</b> | Patient education should be the start point and underpin all self-management interventions.                                                                                                                                               |
| <b>3</b> | Self-management interventions that include problem solving and goal setting and, where relevant to the individual and available, cognitive behavioural therapy should be incorporated into routine clinical practice to support patients. |
| <b>4</b> | HCPs should actively promote physical activity at diagnosis and throughout the disease course.                                                                                                                                            |
| <b>5</b> | Lifestyle advice based on evidence should be given to better manage common comorbidity and patients should be guided and encouraged by their healthcare team to adopt healthy behaviours.                                                 |
| <b>6</b> | Better emotional wellbeing leads to better self-management; therefore, mental health needs to be assessed periodically and appropriate intervention should be made if necessary.                                                          |
| <b>7</b> | HCPs should invite discussion with patients about work and signpost to sources of help where appropriate or where needed.                                                                                                                 |
| <b>8</b> | Digital healthcare can help patients to self-manage and should be considered for inclusion in supported self-management where appropriate and available.                                                                                  |
| <b>9</b> | HCPs should make themselves aware of available resources to signpost patients to, as part of optimising and supporting self-management.                                                                                                   |

These recommendations, based on evidence and expert opinion, confirm the beneficial effects of different components of self-management

These recommendations, based on evidence and expert opinion, confirm the beneficial effects of different components of self-management and provide guidance on embedding self-management interventions into the routine clinical care of people with IA. Importantly, this work also highlights the value of patient organisations in providing support and structured guidance for people with IA and emphasises the need to demonstrate and document the effectiveness of specific self-management interventions.

Elena and I are now working with EULAR to develop a framework around implementation to encourage health professionals and patient organisations to work collaboratively to incorporate these strategies into routine clinical care. We will start with strategies here in the UK to determine routes to implementation which are most effective and then share such practice with health professionals and patient organisations across Europe. Incorporating these recommendations into routine clinical practice will lead to improved patient care and outcomes in people living with IA and will encourage a more active patient role in the management of disease.

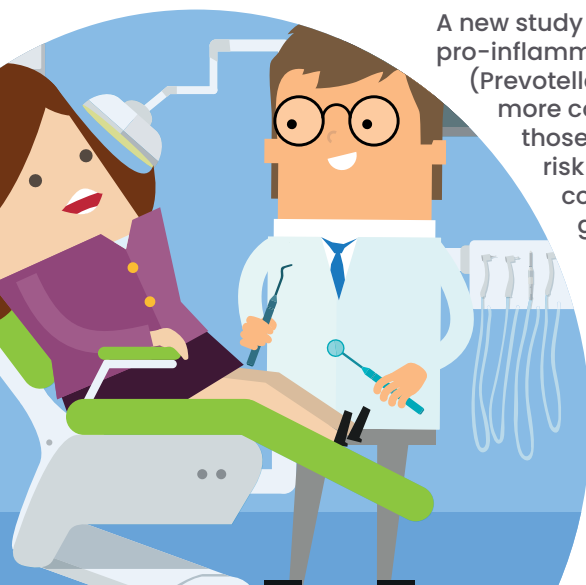
Anyone wishing to support the implementation of these recommendations can get in touch with us by email at [ailsa@nras.org.uk](mailto:ailsa@nras.org.uk) and [enikiphorou@gmail.com](mailto:enikiphorou@gmail.com)

You can find links to both papers on the NRAS website: "2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis" and the systematic review: "Effectiveness of self-management interventions in inflammatory arthritis: a systematic review informing the 2021 EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis."

### The Taskforce members:

Ailsa Bosworth	UK
Elena Nikiphorou	UK
Loreto Carmona	Spain
Hans Biljsma	Netherlands
Peter Bohm	Germany
Claire Daien	France
Annette de Thurah	Denmark
Bente Appel Esbensen	Denmark
Ricardo Ferreira	Portugal
George Fragoulis	Greece
Pat Holmes	UK
Andrea Marques	Portugal
Hayley McBain	UK
George Metsios	UK
Rikke Helene Moe	Norway
Eduardo Santos	Portugal
Tanja Stamm	Austria
Codruta Zabalan	Romania

## Inflammation, the mouth and early RA



A new study has found that two pro-inflammatory microbiomes (Prevotella and Veillonella) were more common in the mouths of those with early RA or those at risk of developing RA than compared to the control group. Microbiomes are the genetic material that makes up microbes in the body, such as bacteria, fungi and viruses.

Pro-inflammatory microbiomes indicate inflammation in the body, so it might not be surprising to see these present in a greater

quantity in people who have an inflammatory disease such as RA. However, researchers wanted to know if this is statistically significant in those who are only recently diagnosed (within the last year) or those who have been living with RA for a while and to look at those who do not have a diagnosis or symptoms of RA, but are considered to be at risk of RA, e.g. due to the presence of anti-bodies such as rheumatoid factor (RF) and antibodies against citrullinated proteins (ACPA).

The presence of these pro-inflammatory microbiomes could indicate a link between oral microbiome and the onset of RA and offers another possible early warning sign for RA.

To read more visit [bit.ly/3gNCOMT](https://bit.ly/3gNCOMT)



# Global Collaboration on JIA Research

The European Alliance of Associations for Rheumatology, EULAR, held its annual congress virtually this year in June. Eular represents people with arthritis/rheumatism, rheumatology health professionals and scientific societies of rheumatology of all the European nations. The congress attracts more than 18,000 delegates from more than 130 countries. For more information on Eular please visit their website: [eular.org](http://eular.org).

There were two main sessions on paediatric rheumatology and advances in paediatric rheumatology, which covered research that had been completed and secondly how the different societies across the globe were collaborating, which they feel is essential to achieve progress and share best practice.

A research project 'Predictive Value of Musculoskeletal Ultrasound in patients with JIA in clinical remission' by Marta Mazzoni, Silvia Merlo et al, investigated over a three-year period the use of ultrasound in patients with juvenile idiopathic arthritis (JIA) in clinical remission. Ultrasound is more sensitive than a physical examination and it is used in rheumatoid arthritis (RA) patients who are in clinical remission. Ultrasounds are used to detect persistent joint inflammation, which is used to predict disease flare and any structural damage. However, it is not routinely used in JIA. They concluded that like RA, inflammation of the tendons (tenosynovitis) was the strongest predictor of disease flare, so having the surrounding tendons of the wrist/hand and midfoot/ankle joints examined using ultrasound will be a good way to monitor clinically inactive JIA.

Prof Dr Gerd Horneff looked at the 'Comparative analysis of etanercept biosimilar and originator use in clinical practice; Data from the German BiKeR registry'. Using the Biologics in Paediatric Rheumatology registry (BiKeR) the treatment of two Etanercept biosimilars were compared to the originator Enbrel. They found that there was no difference in efficacy of biosimilars, therefore as biosimilars are less expensive they can be offered to more patients, with good outcomes for all.

In North America, the Childhood Arthritis and Rheumatology Research Alliance (CARRA) which was set up in 2002, is now collecting data from over 175 clinical sites. The CARRA Registry collects disease and patient-reported information on thousands of children, adolescents, and young adults with paediatric-onset rheumatic diseases. One of their projects they are looking to conduct is a long term follow up of ten thousand patients to evaluate adult outcomes of having been diagnosed of a rheumatic disease in childhood. CARRA have also developed and published treatment plans to be used in clinical practice.

CARRA have formed a working party with the Paediatric Rheumatology European Society (PReS) to promote research projects and award research grants. PReS is an international organisation based in Europe which is dedicated to the advancement of the care and improve the health and well-being of children and young people with rheumatic conditions.

Some of the research projects that PReS are working on are:

- Standardizing ultrasound examination to estimate disease activity;
- Developing Eye-Q which is the only uveitis specific paediatric questionnaire that measures visual functioning and visual related quality of life (VR QOL) in 5-18 year old children and adolescents with uveitis;
- Investigating the current treatment strategies in systemic JIA and Macrophage Activation Syndrome (that occurs in about 10% of children with SJIA).

These organisations are also developing ways to improve the quality of education, provide more clinical and research opportunities as well as enhancing global collaborations for trainees working in the field of paediatric rheumatology. Following a brainstorming session at the PReS Young Investigators Meeting in 2016, PReS developed a new group Emerging Rheumatologists and Researchers (EMERGE), and they are also working with the CARRA Early Investigators Committee to help with the development of new generations of professionals.



EUROPEAN ALLIANCE  
OF ASSOCIATIONS  
FOR RHEUMATOLOGY

eular



# Celebrating the U in Volunteers

Volunteers' Week takes place every year during the first week of June, and this year was the 37th time the celebratory campaign has been run. It is a chance for organisations like NRAS to say thank you to Volunteers for the invaluable contributions they make within the organisation and the support they provide to those who use our services.

As a special thank you we held a virtual coffee morning and we were joined by many of our Volunteers, NRAS staff and Clare Jacklin our CEO. The morning provided us all with a chance to put a face to a name, have a chat over a hot drink and to get to know each other.

It also gave us an opportunity to hear from some of our Volunteers themselves who

spoke about how volunteering for NRAS also benefits them. Robin, Ayesha and Katy shared their experiences, with Katy (and I hope she won't mind me saying this) even getting a little bit emotional.

It was great to see those who attended, and for those who couldn't make it, we will hopefully see you next year!

NRAS also created a thank you video highlighting some of the work our Volunteers do and the impact this has had on the work we can do as an organisation. These were posted on our social media channels, so if you didn't get a chance to watch, please visit [fb.watch/6DS0aIKu95/](https://www.facebook.com/watch/6DS0aIKu95/)

Certificates of appreciation were also designed and emailed out to all our registered active Volunteers.



**We always want our Volunteers to feel appreciated all the year round, not just in Volunteers Week, so a big THANK YOU again to all those who contribute their time, skills and knowledge to NRAS.**



## Remembering Joan

Joan Bennett worked at NRAS in 2009/10 in a joint role on the Helpline in Volunteer support. When she left she continued to support NRAS as a Volunteer for many years. After a period of ill health, Joan sadly passed away this summer, and will be missed dearly by her family and her NRAS family.

Joan was diagnosed with RA at a time when there were far fewer medications available than there are today and she had aggressive disease, which caused her a degree of disability, but she never let that stop her and she always thought of others before herself, even on her worst, most painful days.

NRAS colleagues who worked with Joan as well as the many people with RA she helped, will remember her for her calm voice and helpful nature. The following typical feedback was from one caller Joan spoke to who just had to call back to let us know how helpful Joan had been,

*"A young man who spoke to Joan called. He was full of praise for the information and support she gave him, which helped him cope with what was going on and he felt much better after the call."*

After her time at NRAS, Joan volunteered on the Samaritans helpline, where she no doubt helped countless more people in crisis with her calming and empathetic manner, often working late shifts to help those in need.

Joan loved to read, often finding herself so lost in a good book that she'd read right through the night! Purple was her favourite colour and she was an avid music lover, especially the rock band Queen!

Friends will remember a lady who bravely took on whatever life threw at her and she would never want anyone to feel sorry for her, or look back with sadness.

# Looking back at the first NRAS Group

The North East NRAS Group held its first committee meeting on 26th September 2005 following on from building relationships with members of the musculoskeletal department (MSU) and the hospital trust management. They gave their full support to the new group and agreed to host all future meetings in the hospital. The first open meeting took place on 9th November 2005 and since then we have held a meeting four times a year, apart from in 2020/2021 due to the pandemic.

The group has gone from strength to strength over the years and the support from the Freeman Hospital has been unwavering; with the strong relationship built on mutual respect bringing the MSU team, academics, and patients closer together.

I know that the medical team in the MSU have benefited from the group being in place as they know their patients will get tremendous support from us and help in managing their RA, which is something we feel we do very well. We have also helped in research studies over the years supporting the recruitment of patient volunteers via our group network.

I feel proud and honoured to be a part of this NRAS Group; what we have achieved over the years and the friends that I have made along the way is a great feeling.

Lots of social events are also organised and enjoyed by everyone. These events are so important to bring people together for support and understanding.

Over the years committee members have come and gone and now there are just four of us, but it works very well. My thanks to Judy Dobson, Gillian Bennett and Joe Burns for all their dedication and ongoing support.

I would also like to acknowledge and thank: Mr. Mark Liddell, who for a while was part of the committee, as well as a Trustee of NRAS; and others who were involved in the past - Pam Boyes, Jacquie Stokoe, Anne Scadeng and Debbie Bolton. I can't forget the late Alex Gipson

who was a great help and support, and Ann Murray, a founder member who is now living in Ireland.

A huge thank you also to all the patients and their families who come along to our meetings and events. I am sure they appreciate the group's good relationship with the health professionals at the MSU, which enables me to contact them with queries posed by group members.

I will continue to be the Coordinator of the North East NRAS Group for as long as I am able and continue to offer much needed support to our members.

Congratulations on the 20th Anniversary of NRAS and let us all work together to ensure that everyone living with RA has a voice and a safe place to find help and support.



**Eleanor Houlston**  
Group Coordinator



# NRAS turns 20!

## A look back at NRAS over the years

2001



It started with an ad.

2001



Launching NRAS

2002



Theresa May becomes a patron

2003



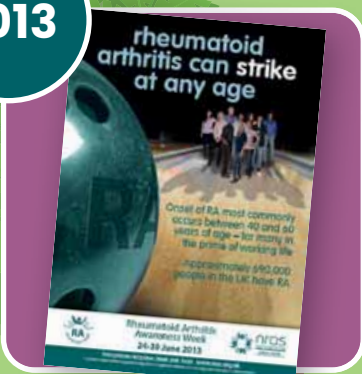
Sue Oliver appointed as Chief Nurse Advisor

2004



Communications Award

2013



NRAS launches RA Awareness Week

Emotions, relationships & sexuality resource landed

2013



Focus on JIA report



Welsh Assembly visit by Welsh Ambassadors



Family Matters re

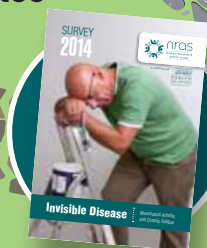


Mark Liddell, longest serving Trustee

2014



First JIA Family Day



Invisible Diseases Report



Professor Iain McInnes appointed as Scottish Patron

2021



Success in lowering barrier to treatment for people with moderate disease

2020



We RA Priority campaign



Clare takes over as CEO and Ailsa becomes NRAS Patient Champion

2019



Healthcare Award

2005



First NRAS Group Newcastle

2007



Great North Run Ailsa's first of 3

2008



First Healthcare Champions Awards

2009



Kings Fund Report



Current and previous Chief Medical Advisors

2010



Knocking on Number 10's Door

2011



S Factor Public Awareness Campaign

2012



Physiotherapy Report



Scottish Parliament Visit by Scottish NRAS Ambassadors

2016



Wear Purple for JIA-at-NRAS

2016



Ailsa receives MBE for services to people with rheumatoid arthritis

"It's hard to explain the pain that you're going through"

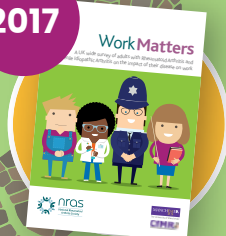
Behind the smile campaign

2015



Apni Jung resources launched online

2017

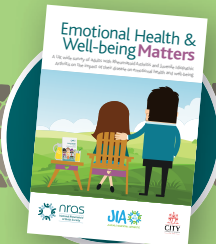
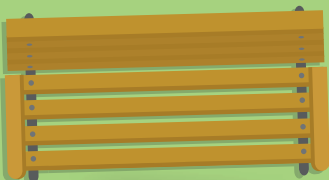


Work Matters report

2018



Diwali event



Mental Health Matters report



JIA children visit Westminster

Healthcare Champions Awards



Joel Nelson



# From Educated in Discomfort to Educating the World

## Why today's children with JIA are tomorrow's game changers.

As a child with arthritis, I was fearless. Stubborn, I had far more resilience back then than I do as an adult with JIA. As kids so often do, I made the pieces of the game handed to me my own. Some days, I revelled in the uniqueness of it all – other days, I sobbed alone in a bleak hospital ward in a bed that sadly became more familiar than my own.

Surrounded by children far younger than me, I resorted to friendships with my nurses as they welcomed me back with each stay – all whilst my friends seemed to mature at breakneck speed as I missed months of high school. My education was in pain, an apprenticeship beyond my years – discomfort rather than textbooks.

### A second life

I owned my arthritis as a teenager. I had little choice, given I was a wheelchair user. Still, when, via a lot of support and adjustments, I was able to go to university a week after my 18th birthday. I buried it all – reinvented me – and for the next fifteen years, I barely uttered the word arthritis.

Instead, I left the crutches and twisted knees of my youth behind for hockey sticks and an electric pace I discovered in my early 20s after a long period of remission, more from sheer determination to cover my flaws than any natural ability. I would spend my Sundays in agony, recovering in scolding hot baths for hours on end, and when I couldn't walk, I covered it up by saying I had a fever, locked my door and closed the curtains until it passed. Sometimes, I spent entire weeks in a room. And, for a time, it worked. It certainly felt easier than trying to explain how this confident young man had a condition that other students had only heard of from their grandparents.

### Game over

A nasty flare coincided with the arrival of my son, and with it, the house of cards fell. The game was up. I could not only no longer hide it, but at this moment, when upsettingly I couldn't carry him due to crutches, I realised I had to be a better role model. So, in 2019, I became an advocate almost by accident. One minute I was writing about

my experiences on the advice of my GP as my mental health faltered from the series of chapters I had tried to live; the next, I was an arthritis 'patient leader'.

Of course, none of this was by chance. I think I was destined to end up here. The experiences that turned that scrawny child into a stubborn, determined young man hellbent on proving people wrong, was always going to end up finding his voice. It just took the jolt of parenthood and discovering the gap between support as a child with JIA and the lack of it as an adult to light that fire. Once I started telling my story, I couldn't stop.

### The game changers

Cut through the unsavoury side of social media, and you will see a trend that rapidly escalated through the events of 2020. Young adults talking about their rheumatic conditions openly. Sharing pictures on Instagram and, for what feels like the first time, having candid conversations about previously taboo subjects such as fatigue, disability and the mental health impact of living with these challenges.

These game-changers have built a community of inspirational people that can genuinely change the perceptions of arthritis in younger people – smash down walls, rebuild attitudes and with it, the support systems barely afforded to adults with JIA.

I am proud to be a part of this movement, and my experiences of JIA, although unwelcome, gave me the strength and character to willingly be amongst the frontrunners for change. Despite pain, I wouldn't change a thing.

Once I started telling my story, I couldn't stop

Visit Joel's website:  
[joelvsarthritis.co.uk](http://joelvsarthritis.co.uk)

Twitter/Instagram  
[@joelvsarthritis](https://www.instagram.com/joelvsarthritis)



# New Medicines in JIA Resource Launched

We are pleased to announce the launch of our new JIA-at-NRAS booklet 'Medicines in Juvenile Idiopathic Arthritis'. The focus of this booklet is on the medicines that are used to treat juvenile idiopathic arthritis (JIA), but it also contains information about what parents and young people with JIA can expect at every stage from diagnosis onwards, showing that medicines are only one part of treatment.

Starting medication for the first time or starting a new medication can be daunting for young people and parents. Your healthcare team will support you through this process, and we wanted to create a booklet that will complement that support, helping to answer some common questions and concerns and talking you through how medication fits into the JIA journey.

This booklet was made in close partnership with parents, young people and healthcare professionals. In the booklet, you will find a directory containing detailed information on each of the JIA medicines, as well as information on how the immune system works, the support you can get from your healthcare team and other ways that you can help manage JIA alongside medication.

**Already we have had great feedback from hospitals and families:**

*"Amazing resource"*  
Children's community nurse

*"Thank you for the awesome books, they arrived this morning"*  
Nurse from Manchester Children's Hospital

*"Lots of useful information in addition to the medicines, and the team are using the new booklet already"*  
Consultant from Manchester Hospital

*"I found the medication landscape bewildering. This booklet helps make sense of it all. A very informative read"*  
Parent of daughter with JIA



If you would like to order a hardcopy or download a pdf version, please visit our website at:

[jia.org.uk/shop](http://jia.org.uk/shop)



**Victoria Neal**

JIA Parent Group Lead  
Volunteer

# JIA Parents Join Together

Part of the new JIA-at-NRAS service framework was to develop a parent/carer peer to peer online group and back in March this year we held a Zoom event for parents/ carers with children who have JIA, called 'Coping with JIA during COVID-19'. During this event we discussed starting up a new parent online peer to peer online group. We were asking for two Volunteers to take this forward, and we are delighted to have Victoria Neal as the lead Volunteer and Natalie Hunt who is supporting Victoria. The first meeting was held on Monday 7th June and the plan is to have them monthly on the first Monday of the month at 7 pm.



**Debbie Wilson**

Young Persons Project  
Co-ordinator

To tell you a bit more about herself and why she chose to lead the group, Victoria agreed to do an interview with Debbie our Young Persons Project Co-ordinator.

## Why did you decide to become a Volunteer for JIA-at-NRAS?

It can be very overwhelming and lonely having a child with JIA - not many people understand what we go through as parents everyday juggling appointments, school, work and a world that still thinks arthritis is for old people. JIA Parents Join Together group gives parents and carers the opportunity to talk to others in a similar position and understand how different each day can be.

## What are your plans for the meetings?

I have lots of ideas for the group - I would like to host some meetings for the whole family as well. Starting from September we will be discussing a different topic each month relating to different stages of JIA. There will be lots of other exciting activities coming up too.

## How can parents/carers join?

You can email [jiaparents@nras.org.uk](mailto:jiaparents@nras.org.uk). Our parent meetings are hosted through Zoom on the first Monday of the month at 7 pm. We will send out details of the family group meeting separately. I look forward to seeing you there.

## You have had the first meeting - how did it go?

The first meeting was a huge success! It was lovely to see and hear from parents and carers at all different stages from those with newly diagnosed children to those with children who had been living with JIA for years.





# NRAS Young Voices - One Year On

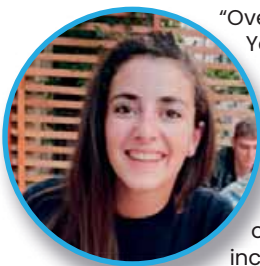
It has been over a year now since NRAS recruited the Young Voices Panel. Throughout the last 12 months the panel have developed and prioritised the service framework for young people with inflammatory arthritis and JIA-at-NRAS. One of the main priorities was peer to peer support and now having the JIA Parents online group we can offer this to parents, alongside our other new JoinTogether online groups as well e.g. 18 to 35 year olds, Working with inflammatory arthritis and Exercise and Back to Sport with inflammatory arthritis.

(Please email [jiaparents@nras.org.uk](mailto:jiaparents@nras.org.uk) for more information on the parent's online group)

In addition, the Young Voices have been involved in many other NRAS activities, including Facebook Live sessions during RAAW, Wear Purple for JIA in November last year and recently for the new #WearPurpleForJIA Wellbeing Week in June. Some of the Young Voices were also part of the focus group for the new Medicines in JIA booklet which has now been launched. They shared their stories and experiences at the event for parents Coping with JIA during COVID-19 in March and at the young person's event Navigating your future with inflammatory arthritis in April. They have also helped NRAS focus on what young people may want from the new JIA digital membership (launching soon) and participated in other ad hoc requests such as podcast and articles for Enable magazine.

They have achieved so much in the last year and we are working hard with them to continue developing services for young people and their families.

Here are the voices of the panel describing what being a part of the Young Voices group means to them:



"Over the last year, I have chaired NRAS' Young Voices Panel, working with a range of inspiring and influential young adults to enact real change for people suffering with JIA or RA. Often it can feel like arthritis isn't a disease for 'young people' (which is something I have been told many times!) and being part of this group has made me realise how incredible it is to have a community of people going through the same challenges. The Young Voices Panel is made up of completely different people (from students to fashion models!), we are united in our drive to raise awareness for NRAS. This last year has made me realise how much people can do when they set their minds to it, and I can't wait to see what the future holds for the Young Voices." - **Eleanor Potter**



"Being in the Young Voices group has been so amazing and allowed me to not only meet other young people with JIA/RA but work with them to help other young people also suffering with arthritis. Growing up I really struggled with my condition, and this group has allowed me to use my experiences to help others and hopefully make a difference. Everyone in the group has been so amazing and supportive and I couldn't be happier to be a part of such an amazing initiative." - **Suruthi Gnanenthiran**



"The founding of the Young Voices came at the perfect time. I am normally a worker bee who never stops but lockdown happened and turned my life on its head. I have a constant need to be busy, productive and make a difference so when the opportunity to contribute to changing the lives of young people with arthritis arose, it was like fate! Having been diagnosed with arthritis at 19 (although potentially living with it undiagnosed throughout my teen years), I know how it feels to be young and at the mercy of your own body attacking itself from the inside. I know how it feels to look around you and see other young people your age out enjoying their lives pain-free and wondering why you can't have what they do. To have people question your pain because it's 'invisible' and it's difficult for people to understand your suffering. Being able to put plans into action for a cause so close to my heart has been incredibly rewarding. But not only that, I feel that I have made a second family out of the members of the panel. When I have been struggling with my mental health, NRAS were fantastic at providing me support, an ear to listen and the knowledge that they were there for me if ever I needed them. It's lovely to be involved with a group of people who understand if I'm ever down because they've been there themselves." - **Ellie Farr**



"I'm so happy to be a part of NRAS Young Voices as it has given me a unique opportunity to use my own RA journey to help others through theirs. The feedback we received from a Facebook Live event was really heart-warming and it was a great feeling to know that talking about our experiences was helping other people. Living with RA is not always easy (and certainly for me has been very hard in the past) but this group of people are so positive and inspiring and I feel lucky to be involved." - **Catriona Boyd**



"The last year has been a tough one for everyone but one good thing that came out of it for me personally, was becoming a member of the NRAS Young Voices. Over the past 12 months we have helped shape the JIA-at-NRAS website, shared advice and our lived experience for new medication booklets and spoken to thousands of people on Facebook through our Live sessions. It feels positive to be surrounded by other young people motivated to use their experiences to help others. Before this group I had never spoken to another young person with JIA, despite living with the condition for over 14 years, and now I have a whole support network to turn to. We have achieved a lot in a year, and I am excited to see what we do next!" - **Annabel Longden**





**Debbie Wilson**

Young Persons Project  
Co-ordinator

# First Ever #WearPurpleForJIA Wellbeing Week

14th-18th June 2021

This year was the first time we held a #WearPurpleForJIA Wellbeing Week. We knew that the last year has been tough for everyone especially for children, so we decided to have a week of free online Wellbeing classes for children with juvenile idiopathic arthritis (JIA). All the classes were well attended, and some children came along to all of them. We have decided to continue this for next year as well, so please keep an eye out on our website and in e-newsletters for next year's classes.

Throughout the week we also held four Facebook Live Sessions in the evening, covering a number of areas relating to JIA. The first was a question-and-answer session with two specialist nurses, covering what symptoms a parent should look out for, how the healthcare team can support you, managing treatment and ended with them sharing a positive story of a child with JIA they had treated over the years.

A proportion of children also still have JIA in adulthood, and we had a session of five adults still living with JIA discussing and sharing their stories. Some of the experiences shared were very similar and everyone felt that it would have helped growing up knowing that someone else was going through similar situations. We are now so grateful that we can talk to others and there is support and more information out there.

Parents and families are also hugely impacted by a child in the family having JIA. It can feel very overwhelming as a parent/carer, so we had parents sharing their experiences of having a child diagnosed with JIA. In the discussions we covered how long it took for their child to get a diagnosis and how they felt about it, coping with flares, and generally managing with the ups and downs this condition has and what inspires them about their child. On the panel we had Lynette whose daughter Freya started the Wear Purple campaign 5 years ago and it was Freya's determination that helped make sure the campaign continues and succeeds.

The last Facebook live session was slightly different as we were joined by special co-hosts, children with JIA. Children need to be able to talk to their health care professionals to empower them and make them feel more in control of their JIA, so how better than to get them to ask questions to doctors and nurses. Only a few questions were on JIA, but others included: if you had Aladdin's lamp what would you wish for? If you could give one bit of advice to your 16-year-old self, what would it be? The best answer was from Kit Tranter on the question: what living person do you admire most? Her response was children living with JIA.



It can feel very overwhelming as a parent/carer, so we had parents sharing their experiences of having a child diagnosed with JIA

All the Facebook Live sessions are on the JIA.org.uk website and our Facebook page for you to watch back (you do not need a Facebook account to watch them)

[facebook.com/pg/jiaatnras/videos](https://facebook.com/pg/jiaatnras/videos)

# • DIARY OF THE WEEK •

## Monday 14th June:

Nancy Edwards, who was diagnosed with JIA last September, ran a portrait art class. She went through the different proportions and shapes of the face, and how even small changes can have a powerful impact on the picture. Feedback from this class showed it was one of the most popular of the week.



## Tuesday 15th June:

Our JIA Ambassador, Lynsey Knight, who has JIA herself and whose daughter has JIA, co-hosted the Yoga therapy class along with Sam Maguire, a qualified Yoga Therapy teacher. The aim of the class was to help relax the mind which in turn relaxes the body and to do exercises to strengthen the muscles that protect the joints. By the end I think everyone could have fallen asleep; it was very relaxing.



## Wednesday 16th June:

The Happy Human Project who specialise in children's mental health hosted a class about learning valuable skills and techniques for managing difficult feelings and building a positive mind set. We also covered how positive affirmations can really boost our feelings, breathing techniques to help us focus our mind and finished with a guided visualisation.



## Thursday 17th June:

Ellie Farr, a member of the Young Voices Panel and a professional photographer showed some of her favourite photos she has taken and covered useful hints and tips to create the best photo. Ellie discussed how she got into photography (even though she wanted to be a killer whale trainer when she was young) and shared how best to start out in a photography career.

*Photo taken by Emma after the class of her dog Whiskey*



## Friday 18th June:

Lastly, we had a dance class run by Amy Latchman of Rickmansworth Razzamataz. Amy has taught dance to children with JIA and put together two routines that they would be able to perform. The first one was to the song 'All in this together' from High School Musical and the very apt 'This is me' from The Greatest Showman. It was a fantastic class to end the week and the most well attended.



*"Loving this!! Fab idea for children to know that their medical team are just like everyone else".*

*"That was so inspirational".*

*"Thanks everyone for sharing and your great advice".*

*"This was great, really helpful".*

# Explaining the impact of RA

## Advice from the Helpline



Sarah Watford &  
Debbie Skinner

.....  
Helpline Team

*Hi there, I've recently been diagnosed with RA. How do I make people understand what I am going through?*

Having just been diagnosed with a long-term condition can elicit a range of emotions. Initially, some people may feel shocked, scared, apprehensive, depressed and very alone. It takes time to come to terms with your diagnosis as it can initially feel very life changing. Understanding and learning about the condition itself; the medications involved and how they work; and what this all means to you daily; all requires time to process. You might like to download our information pack for people newly diagnosed from our website and encourage your family and friends to read it too.



Once you feel more comfortable with your diagnosis, you might feel more confident about reaching out to close family and friends for their understanding and support. They will need to be educated about the condition, the medication, and how this all affects you. Don't be afraid to ask loved ones for help if you need it. Are there things they can help with around the house, or shopping they can do, just while you are getting started on the medication? Once you are established on the right medication, you should be feeling so much more back to your old self. It is important to reassure everybody, especially your children, that this is a temporary glitch until you are back on your feet. Learning the art of pacing and having patience are very important with RA. Be kind to yourself and focus on what you can do.

It is also important that your employer and your work colleagues are aware of your condition, and have an understanding of it, including how it may initially affect you. However, it is also about working with your

employer to let them know what they can do to help and support you. It isn't easy to explain that the medications may take time to be fully effective, and sometimes you may need to try a couple of different medications until you find what works for you to get you back on track. It can be very difficult to convey to another how debilitating the fatigue is, when they cannot see it. We have two booklets about work and RA which you may find helpful, one is for you and the other is to give to your employer:



Getting the support of family, friends and work colleagues and your employer is crucial to helping you navigate the next steps in your RA journey. If you are feeling down, this is a perfectly natural response to your diagnosis. Please do not sit alone in silence, reach out and let people know how you are feeling. Talking is good. You can call your GP, call our Helpline (0800 298 7650) or ask us to arrange a call with one of our trained Volunteers. We are here for you.

As a patient led organisation, we constantly strive to find new ways to support people in managing their condition better. To this end we have launched the Right Start programme where consultants can refer newly diagnosed patients directly to us. We have the time to spend with these individuals to give them ample opportunity to explore their new pathway and air their worries and concerns. It is also the ideal opportunity to introduce NRAS and all we have to offer. This is proving invaluable to patients, and we are hoping that in time this service will be taken up by RA consultants across the country.

.....  
It takes time to come to terms with your diagnosis as it can initially feel very life changing



**Social Media Expert**  
@miracle\_knowledge



# "I found a cure"

The Helpline gets numerous calls from people who have read or been told about the latest 'cure', or amazing treatment for RA. It is understandable that people with RA are keen to find things that will help them live their best life so this can make you vulnerable to exaggerated or false claims.

How do you know if these are based on scientific evidence and decide from someone who is misguided who genuinely wants to help or an unreliable salesperson? Also, how do you decide what is good for your health or will work for you? Be it the latest diet, supplement, exercise, or activity, you need to figure out if it is worth your time, money, and effort.

## Here are some things to look for when considering a new treatment:

**A cure is offered:** There is currently no cure for RA so be wary of products or treatments that promise this.

**Proof about the treatment relies only on personal stories:** What works for one may not work for all.

**You are told to give up your current effective treatments or discouraged from getting treatment from your doctor:** Your doctors are there to help you decide the most effective treatment methods and how to manage your RA.

**The information on this treatment comes from people selling it:** Regardless of whether they have complimentary reviews from users or are quoting studies, if they sell the product, their information is likely to be biased.

**Check for possible side effects or negative effects of these treatments:** The positive information is easy to find, however the negative can be harder to discover. Call the NRAS Helpline or check with other people living with RA, such as those on HealthUnlocked.



There is an exceptionally reliable website that helps you find out if the claims are supported called Ask for evidence - [askforevidence.org](http://askforevidence.org). Another good place to check claims, particularly regarding scientific evidence is [clinicaltrials.gov](http://clinicaltrials.gov). They have a summary of all the completed research which is the best way to check things like sample size and who has been included in the study, which will help you understand if it's related to your needs.

If there is evidence, from several good sources, then we can be more assured that the information is true. Remember always talk to your rheumatology team before starting any new treatments or making any changes to ensure it does not interfere with your current treatment plan. When you have considered all the above and decide you want to try a new treatment, try to approach this scientifically. Keep a diary to monitor any potential improvements, ensuring that you record other factors which could be contributing to this improvement, such as changes in medication and regularly re-assess to see if you want to continue with this treatment. Remember, if you have any questions the Helpline is here to help on 0800 298 7650.

**Nadine Garland**  
.....  
Information and support  
co-ordinator

.....  
If there is  
evidence,  
from several  
good sources,  
then we can  
be more  
assured  
that the  
information  
is true



# Celeste Kostopoulos

I have just become a grandmother! Hello, my name is Celeste and I'm mother to Marilena. She was diagnosed at nine months old with JIA back in South Africa. At first, it was in one joint then it moved into multiple joints; it took a long time to get a diagnosis and it was a worrying time.

When she was four years old, we made a life changing decision and moved to the UK to get the best treatment possible for Marilena, and back in 1994 that was Great Ormond Street Children's hospital in London. We had phenomenal care from Professor Woo and the team there. Marilena managed at school, but it was tough, as taking Methotrexate at the weekends meant she was sick all over the weekend. The mornings were challenging at school until she could gradually get her joints moving each day, but she has an exceptionally strong personality and a drive that kept her going through the flares, which were difficult for all of us to manage.

Things changed when Marilena transitioned from being treated as a child to being treated as an adolescent. Appointments with the rheumatology team were 15 or 20 minutes at most and as anyone with a teenage daughter will know, getting her to verbalise to the team how difficult simple tasks were, such as doing up a button or brushing her hair, was really hard. This was especially so at an age when they can start to attend appointments on their own if they wish, and so her disease didn't get the attention it needed. Eventually, through a friend who is a Professor at Oxford, we managed to get her transferred to the Nuffield Orthopaedic Centre, and things improved.

After she left school, she went on to St Mary's University to study sports medicine and physiotherapy. She soon realised that the vocation she had chosen was too physically demanding, and changed direction and went on to work as an Underwriter in the City.

Having Adult JIA means you never know what each day will bring; stiff and in pain one day and the next a little more agile. That means you just can't plan the day ahead or always keep up the pace with your friends and that takes an emotional toil. We are very close, and I have supported her as much as I can without it appearing that I am doing too much, but just helping with chores and

trying to make things as easy as possible for her.

I have always been in awe of her strength, positive outlook, and her ability to cope with constant pain.

Fast forward to 2020 and the COVID-19 pandemic meant that she could work from home, which was a great help with managing her disease. Last year, when she realised she was a couple of weeks pregnant, she contacted her consultant at the Nuffield in Oxford and they instructed her to come off her injections (Abatacept) with immediate effect. This unfortunately was a huge issue, as Marilena seized up overnight. She regressed rapidly and was in considerable pain and in a very dark place those first few months. It was frightening for me to see how she was battling to cope.

And then I found NRAS! With your support and intervention she got some very much needed help and consequently, some relief during her pregnancy. Once I reached out to you and you managed to get a dialogue going with her consultant, she was put on a low dosage of steroids and was told that it was safe to take some paracetamol for pain relief. She was still stiff and in pain, but in a significantly better place.

What was also of great help, with NRAS' assistance, she was transferred to Queen Charlotte hospital; the support and care was exceptional and they understood the issues she faced.

Marilena was very worried about not being able to have a natural birth because of the stiffness of her joints and she definitely could not have endured a prolonged labour. She had a C-section on the 5th July. Baby Nephelie (it's from the Greek word for cloud) is just perfect and suffered no side effects from the steroids; she was a healthy weight of 4kgs.

Marilena needs to get back on her medication so she can get some much needed pain relief and better mobility, this is the longest she has been without medication since she was 9 months old. She is worried about the effect on her breastfeeding, but mobility is paramount being a new mother.

Marilena, her husband and baby Nephelie are staying with us at the moment. I'm working stupid hours and at home and trying to help Marilena with the baby. Nephelie is just perfect, but Marilena has been battling with her arthritis since the birth.

We all can't thank you enough for the empathy, support and guidance you gave us.

I so wish I had found you before, but so grateful that we found you at this most important juncture in Marlena's life.

I have always been in awe of her strength, positive outlook, and her ability to cope with constant pain.

Marilena's daughter, Nephelie



# RA medication in expectant fathers not linked to poor birth outcomes

A recent study, published in *Gastroenterology*, has shown that the babies of men with inflammatory diseases such as RA who had RA medication within 3 months of their baby being conceived were not seen to have a higher risk of adverse birth outcomes.

The study looked at a total of 7453 expectant fathers with inflammatory autoimmune conditions. This included bowel diseases, RA and the subsequent outcomes of those births, followed up 3 months after their babies were born.

Within this group, 5607 participants did not take any immunosuppressant medication during the 3 months prior to conception, whilst 1846 (around 25%) did. The group who were on medication included 9% who were taking methotrexate and 59% who were on one of the anti-TNF biologic medications.

The primary outcome that the study focused on was the risk of major malformations, and secondary outcomes included the risk of premature birth and low birth weight. For all these outcomes, no significant increase in risk was observed for any of the medications

when compared to those not taking any of these medications just prior to conception.

The researchers did point out that their study had certain limitations. The study was 'retrospective', meaning that they looked at historic data and were therefore limited in the level of detail they were able to get on each of their subjects. Limitations to the study included not being able to determine the impact of paternal exposure to these medications on fertility, abortion and stillbirth, not being aware of smoking and/or alcohol intake in fathers and mothers of the babies and limited ethnic diversity (68.8% of the fathers were white).

Despite these limitations, this study shows some really encouraging signs that men taking immunosuppressant medication may not need to stop taking these drugs in order to father a child, allowing them to better maintain control of their RA. Hopefully other studies will continue to provide evidence in support of this.



# The RA risks of secondary smoke

It has long been established that 'ever-smokers' (people who have ever smoked, regardless of whether they smoke currently) are at increased risk of developing rheumatoid arthritis, and now studies show that exposure to secondary smoke also increases risk.

The exact reason that an individual develops RA is complex, as it involves many factors coming together at a specific point in time. Some of these factors are genetic. Even if you don't have a family member who has RA, you may be carrying genes that make you more susceptible. Other factors are environmental. The most well-established of these is smoking. There also appears to be an incident known as a 'trigger' that occurs shortly before onset of symptoms.

Some potential triggers have more evidence behind them than others. Some of the more common triggers appear to include giving birth and physical or emotional trauma.

A study presented at the annual European Congress of Rheumatology this year,

looked at the effect that secondary smoke inhalation has on the onset of RA in women. They found that not only did the likelihood of developing RA increase with exposure to secondary smoke, but that the age of onset occurred earlier in those exposed. This increase in risk was present whether the exposure occurred during childhood or adulthood. Overall, the risk for developing RA was shown to increase by around 20-40% if exposed to secondary smoke.

The findings of this study demonstrate further reasons that smoking should be avoided, both for personal health and for the health of those around you. People with RA who smoke have increased risks of more severe disease and medications have been shown to be less effective for smokers. This study adds to the importance of getting support to quit smoking if you have RA, particularly if you have children or other people who might be exposed to your secondary smoke and especially if they are already genetically more susceptible to RA.





**Ailsa Bosworth MBE**  
National Patient Champion

# Enhanced 'Right Start' Pilots

NRAS launched their New2RA Right Start service in April 2019 after working for a period of time with a group of UK rheumatologists to design a service which would demonstrate the value of the support that we provide to people with rheumatoid arthritis – in this instance, those who are newly or recently diagnosed. Our intention was not only to provide crucially important, tailored emotional, practical and educational support to people at this critical time in their lives, but to also support health professionals and create capacity, particularly for nurse specialists, enabling them to meet NICE quality standards at the same time, against which rheumatology units were being audited. The service was well received and during the rest of that year we collected qualitative and quantitative data which helped us to refine operating protocols and determine a strategy for expansion and sustainability of the service going forward.

*"... and suddenly, instead of seeing a dead future ahead, you see one where you are going to enjoy old age. A fantastic, very supportive, very sympathetic and knowledgeable organisation"*

Carol – Right Start referral

*"Whilst the medical team were extremely expert, they were also really busy. The Rheumatology Nurse Specialist referred me to NRAS, and they provided telephone support and a lot of information. They also put me in touch with a Volunteer to get experiences from others with RA. Overall they provide a useful service. They certainly helped me."*

Eddie – Right Start referral

COVID-19 then struck in the first quarter of 2020 and the world changed. NRAS had to adapt our services to deal with a huge increase in calls to the helpline, a massive drop in income, and suddenly all staff working from home. At the time, this was more than a

little challenging, but looking back now, 15 months later, everyone rolled their sleeves up and worked harder and we got through it and even managed to develop and deliver new digital services which we will retain as we come out of this pandemic. Right Start continued to grow and the hospitals which had incorporated referral to Right Start into their Early Inflammatory Arthritis patient pathway, were now referring numbers of people to us. We also started a similar service for people with existing disease called 'Living with RA' and we have now received over 300 referrals from over 50 rheumatology units across the UK. However, COVID-19 had interrupted our intention to evidence the impact of this important service more formally, and so, in early 2020 we brought internal discussions back to ways in which to best evidence the impact of these two services.





The standard service, outside of the Enhanced Pilots, is simple and can be described in 4 easy steps:

<b>Step 1</b>
Referrals by the treating health professional (HCP) will be made via a portal on the NRAS website with consent from the patient. NRAS ensures GDPR compliance at all stages.
<b>Step 2</b>
Within five working days of the referral being received by NRAS, a member of the Right Start support team will call the patient to arrange a pre-booked appointment with one of our trained Helpline team and complete a short baseline questionnaire.
<b>Step 3</b>
On conclusion of the call, a tailored pack of resources will be shared with the person covering the specific issues discussed. These will be in a combination of formats comprising hard copy, digital and referral links, maximising the level of support at this crucial stage in their journey, but without overwhelming them with information that may not be of interest or relevant at this time.
<b>Step 4</b>
A call with a trained NRAS support Volunteer who has RA is also offered. This provides an opportunity to talk with a peer who has lived experience which can be very powerful. If desired, a further follow-up call will be offered with the same member of our Helpline team and the support Volunteer. If the patient wants to take advantage of the second call/s, this will be arranged to take place within the following 6-8 weeks, or sooner if possible. This allows the referred patient time to further process their diagnosis and formulate any supplementary questions.



The goal for the engagement period for each referral is to conclude the intervention within an 8-12 week timeframe.

To conduct the enhanced pilots, we wanted to work with a small number of rheumatology units with the following aims:

- to evidence the patient benefit of being able to access Right Start
- measure any benefits accruing to the team in terms of building capacity, particularly for the nurses
- explore the perceived impact of the service and compare expectations of the service with practice

The pilot sites include:

- University Hospitals of Morecambe Bay NHS Foundation Trust**
- Lancashire & South Cumbria NHS Foundation Trust, Preston**
- Manchester University NHS Foundation Trust**

Five rheumatology units were keen to be part of an 'Enhanced Right Start pilot'. We refer to them as 'Enhanced' because in addition to the above steps, we plan to use a number of validated questionnaires including the MSKHQ and others, at baseline, post intervention and at 12 months. The team at University of Manchester will also undertake surveys of and qualitative interviews with the health professionals at each participating unit, to evaluate impact of the service..

- King's College Hospital NHS Foundation Trust**
- Royal Devon and Exeter NHS Foundation Trust**



The University of Manchester

We are very pleased to be working with professionals from Manchester University who will be analysing the data from the pilot sites, including data from patient reported outcome measures and also conducting surveys with staff and a limited number of qualitative interviews with a member of staff from each of the pilot sites.

*“My patients have given really positive feedback. They said the phone call was extremely useful and have come away with new ideas and no longer feel as alone. In their own time they can read the follow up pack and follow the online links to further information. It helps guide them in an appropriate direction. I don't know where we would be without the wonderful support of NRAS, helping us to help our patients to become better at self-managing their rheumatoid arthritis.”*

Christina MacLeod,  
Occupational Therapist

**OBJECTIVES**

- To explore the barriers and challenges to implementation within the EIA pathway
- To explore enablers to implementation
- To compare expectations and plans for the programme with practice (fidelity)
- To explore perceived impact of the programme

By the time you are reading this article, recruitment will have started at each of the pilot sites and our intention is to recruit a total of between 60 – 120 patients. Through the Enhanced Right Start pilots, we hope to demonstrate that in providing the right evidence-based support to people with RA at the right time, in line with NICE NG100 and QS33, we can improve patients' self-efficacy and outcomes and reduce feelings of anxiety and isolation, enhancing the 'usual' care pathway provided by rheumatology units in the UK.

In the meantime, it's business as usual for 'Right Start' and 'Living with RA' and a patient can be referred to either of these services by going to the website ([www.nras.org.uk](http://www.nras.org.uk)) and clicking on 'refer a patient' in the top left-hand side of the screen next to the Helpline number. People can also refer themselves in the same way.

For more information about Right Start or Living with RA or if you would like to arrange for a presentation on these services at your next MDT meeting, please contact Iain McNicol, Director of Services, [Iain@nras.org.uk](mailto:Iain@nras.org.uk)

# Our Commitment to your Wellbeing

This summer saw the launch of the new NRAS Wellbeing programme, with courses available to purchase via the NRAS website. The programme was developed following positive feedback from the 2020 RA Awareness Week Wellbeing sessions as well as input from the NRAS community. Many of them got in touch to express how their overall health and wellbeing – in terms of exercise, nutrition, lifestyle and mental wellbeing – had a significant impact on the self-management of their condition.

NRAS approached 5 experts in their field (who all live with RA or JIA themselves or have close family members with Inflammatory Arthritis) and asked them to design short courses targeted at those living with RA and JIA. Read more about the Experts and the courses they offer below:

## Meet the Experts:

### Carolynne Bennett



Carolynne is an advanced 'Law of Attraction' teacher and speaker as well as a member of the Association for Coaching. She has run several mindfulness and meditation sessions for NRAS, all of which have been universally praised.

#### Mindfulness & Meditation

Meditation and mindfulness provide a set of simple yet powerful practices that can easily be incorporated into everyday life to help break the negative cycle and relieve many modern-day symptoms of stress, anxiety and depression. The practice may also help with pain and inflammation and relief from exhaustion and irritability.

### Ayesha Ahmad



Ayesha is a fully qualified personal trainer: REPS/eReps Level 3 GP referrals, Level 3 PT, Level 2 Fitness Instructor,

Functional Fitness. (Level 4 Nutrition and Obesity, coursework passed, practical to film for official certification)

#### Resistance based personal training

Resistance training for strength uses resistance bands and weights (or a pair of cans and a rucksack loaded with books for those without the appropriate equipment). During the course, participants learn "the big 5" which are compound lifts that work multiple muscle groups. Isolation work (using single muscle groups) and bodyweight only exercises also feature in the sessions. (At time of print Ayesha's course had started, please keep an eye out for further courses)

### Daisy Ilchovska



Daisy is an MSc level educated, qualified and registered Nutritional Therapist and a published researcher on the topic of autoimmune diseases. She runs her own virtual nutritional therapy clinic 'Optimal Health Nutrition'.

#### Nutritional Therapy & RA – Diet, Supplements and Lifestyle Changes

Using up to date evidence, Daisy specialises in explaining the reasons behind adopting different diets, supplement use and general lifestyle changes for the management of autoimmune conditions. Her passion for cooking, healthy eating and helping people to implement lifestyle changes also features in the sessions.

**Jessie Eloise**

Jessie is a qualified yoga and qigong instructor. She is incredibly passionate about sharing the transformative ways in which yoga can support in daily life.



**Chair Yoga**

Sessions focus on a specific joint and go through stretches to help create space in the joint; releasing tension and tightness, to allow blood to flow through the joints. Jessie’s mother, grandmother and mother-in-law have RA and therefore she understands and takes a vested interest into how yoga can help those living with the condition. Jessie’s classes take a mindful approach whereby participants are invited to take the time to tune into themselves, to get out of chattering minds and focus into the physical sensations and states of their bodies.

**Louisa Roberts**



Louisa sings in several acapella vocal groups including ‘Sine Nomine International Touring Choir’ and ‘The Joyful Company of Singers’. Her own student choirs have performed on Capital Radio and BBC Music Live, at the O2, the Birmingham Symphony Hall, The Sage Gateshead and The Royal Albert Hall. She is Head of Education and Learning for Stagecoach Performing Arts and regularly facilitates singing workshops within this role. She has supported performers and teachers throughout the world in teaching music for over 25 years. Louisa has sero-positive RA and firmly believes that engaging in collaborative music making and singing has helped her to thrive through the tough times both mentally and physically since her diagnosis at the age of 18.

**Singing for Wellbeing**

*“The only thing better than singing is more singing.”*  
Ella Fitzgerald

Vocal fun with invited music and singing experts spanning a range of genres and songs. Practise skills together in breathing and relaxation, posture, pitching, expanding vocal range and understanding the individuality and sound of your own voice – and learn to love it!



**STOP PRESS!**

New Wellbeing Programme course dates announced!

Course Expert	Course Dates:	Course Title:
Carolyne Bennett	28th Sept – 26th Oct	Mindfulness & Meditation
Louisa Roberts	5th Oct – 9th Nov	Singing for Wellbeing
Daisy Ilchovska	6th Oct – 10th Nov	Nutritional Therapy & RA – Diet, Supplements and Lifestyle Changes
Jess Eloise	2nd Nov – 30th Nov	Yoga for the joints

Purchase your place at [nras.org.uk/shop](https://nras.org.uk/shop)

(Dates are correct at time of print, limited places available)

# An insight into Veronica behind her smile...

## A tribute to Veronica Kehoe

(22nd February 1951 – 29th April 2021)

Before we were a couple, I called at Veronica's house one morning to go with her to work. I knocked on the front door and was welcomed by her mum, "She'll be down in a minute," she said. I stood in the hall and sure enough there was a sound of movement along the landing followed by bump... bump... bump. I looked up the stairs and there was Veronica coming down one step at a time on her bottom. I said "Hi... are you ok?" She smiled and replied, "I'll be there in a minute."

On the second last step she forced herself up, and with the help of the walls, door and furniture, she moved to an armchair next to a roaring fire. she turned to me, smiled, and said, "I'll be fine in a few minutes, I just need to thaw out." Veronica was 19 and this had been her daily routine since she was 16 and diagnosed with Rheumatoid Arthritis (RA). After a few minutes she was up, grabbed her coat and bag and walked without difficulty to the bus stop and on into work.

Throughout the day she was her happy smiling self and there was no sign of what I had witnessed that morning.

A few months after we were married, I was watching sport on the TV, Veronica was to my left and behind me doing some ironing. After a while I noticed out of the corner of my eye that she was weeping. I thought, 'today her pain must be greater than usual.' I turned to her and asked, "Why don't you leave that and come and sit down for a while?" Veronica put the iron down and gave me a telling stare! She said, "I want you to promise me you will never say that to me again... If I sit down, I will never get up." She then continued to iron faster than before.

I knew then that Veronica had an immense inner strength, will-power and determination to fight her arthritis.

We both wanted to have a family but could not have children of our own, so we

tried for a baby through adoption agencies and were rejected by the first four over a period of 4 years. We went through gruelling interviews and procedures only to be told by each agency, "Very few babies available. Many prospective parents are all AI fit. You're not - so sorry we can't list you..." There were many tears shed during this period.



Family photo

We tried one more time and with the sympathy and help of a wonderful lady, a nun, she persuaded the board in our favour, and we were accepted onto their list. Two years later and we had a baby. It was 8 years since we started. Two years more and we had another. Life was good and Veronica was an excellent mother despite the crippling pain in her hands, legs, arms and shoulders.

Many operations followed on her fingers, hands and knees. She even had both her heels broken to try to re-align her feet and prevent her from walking on the edges, which was causing huge damage and giving Veronica excruciating pain. She was in plaster up to her knees for months, though sadly it did not work; and she suffered greatly with her feet for the remainder of her life.

During this period, you would never have known any of this was happening when meeting her, you would be disarmed by her smile and cheeriness.



Veronica and John  
- the day they got engaged

For the past 20 to 30 years Veronica had to wear ugly special shoes and metal callipers to help her walk... No more skirts or dresses for her, just baggy trousers to cover them up. She still took great delight in seeing the lovely clothes and shoes that her friends and others wore and still loved to browse through the fashions in stores even though they were not for her. Each shoe and calliper weighed just over 2lbs. It must have been exhausting to strap 2lbs of dead weight to each leg from morning until night. But she never complained, just got on with it. Veronica's pain and discomfort never improved and yet despite me noticing her infrequent weeping moments, not even I was aware of what she was going through, she hid it so well.

Veronica was remarkable, her smile, her cheery and happy demeanour was real and genuine. She had no self-pity, no bitterness, no envy... It never crossed her mind. She was an amazing wife, and we were good together and we did well.



Veronica's 70th

NRAS would like to give a special thanks to John Kehoe for sharing his beautifully written and graceful eulogy in memory of his dear wife, Veronica Kehoe. It has been a great pleasure to learn about Veronica's courageous life. John and Veronica spent 49 years in marriage together.

During what can be a very difficult time, bringing family and friends together to celebrate the life of a loved one, is very important.

There are several ways to collect donations in memory of a loved one:

- A Cherry Blossom Tribute page, please visit [nras.muchloved.org](http://nras.muchloved.org)
- Please pass our details on to your funeral directors or ask them to contact us on the details below
- Directly to NRAS, please visit our website: [nras.org.uk/donate-now](http://nras.org.uk/donate-now)

We are always here to answer any questions you may have, please contact the fundraising team on **01628 823 524** (option 2) or email [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk)



NRAS Lincoln Group cheque presentation

## A tribute to Judy Thompson



Judy Thompson

It is good as a charity that we focus on the positives in our lives, sadly however, we also must take time to reflect.

Recently we lost our Lincoln group coordinator, Judy Thompson, 56. Judy was proud to represent NRAS in Lincoln, working alongside a dedicated and friendly support group. The Lincoln NRAS group met regularly both on official meeting nights but also for coffee and lunch. The group were avid fundraisers, raising both funds for NRAS directly and for the day-to-day running of the group.

As Judy's health rapidly deteriorated, she had to hang up her coordinator's hat and step away from active engagement with NRAS.

Judy had lived with Rheumatoid Arthritis and its associated conditions for over 30 years and passed away in March this year.

Judy loved NRAS, and as an ex-nurse she immediately saw the value of peer led support. She used to say, "after all, who knows our condition better than us"?

Judy will be dearly missed by the Lincoln group, NRAS and by everyone who knew her.





# A Perfectly Purple Week!



After a challenging 2020 for everyone involved with #WearPurpleForJIA the fundraising team at NRAS were very much looking forward to going full steam ahead for 2021. #WearPurpleForJIA has become a key feature in our fundraising calendar with families, schools, businesses and individuals looking forward to getting involved and taking this opportunity to get behind all that we do here at NRAS for our JIA youngsters and families. It is a time to not only raise awareness about living with JIA and share stories and experiences but a time to really have some fun and take on some very challenging events to help raise funds for our ongoing JIA services at NRAS.

This year we were delighted and excited to be able to extend the #WearPurpleForJIA day to a full week of activities. We felt it was time to offer our younger supporters and our JIA community a chance to take part in some new and exciting online classes. These were aimed at exploring new challenges and addressing mental health issues and offering a range of Facebook live events with some knowledgeable expert guests.

With the campaign launched officially in April the demand for the fundraising packs and merchandise was frenzied and the fundraising team worked hard to ensure everyone had all they needed to organise

and plan their amazing #WearPurpleForJIA fundraising activities. Social media enabled us to reach even more people than ever this year with posts popping up on Instagram and Facebook – purple was literally everywhere; people were smitten with purple!

We had some truly inspirational youngsters doing challenges such as sponsored basketball hoops and exercise challenges to baking sweets and dog treats. There were tea parties and hiking up Snowdon and the Welsh 3 peaks. Communities really got behind the campaign, organising walks and local events such as quizzes and raffles. Then there were all the schools and nurseries the length and breadth of the UK holding non-uniform days and amazing children prepared to stand up in front of their peers at schools and share their own experiences of living with JIA.

This all added up to a fabulous day of fundraising on Friday 18th June with JIA-at-NRAS very much in everyone's mind. With the support and commitment of all our wonderful JIA families who encouraged and cajoled people to get involved no matter how large or small or whatever they decide to do we literally could not raise the funds without you.

We thank and salute you all. You really do put the FUN into fundraising! Looking forward to 2022 and seeing you all again next year!



# This year as we go to press the total stands at a jaw dropping **£23,424**

- 1 4forLife Healthcare Services in Kent
- 2 Abigail Sambrooks and friend Mason
- 3 Abigail's purple cake
- 4 Busy Bees Daycare Nursery Huntingdon
- 5 Debs Wilson and Lynsey Knight outside Kensington Palace
- 6 Diane Ashcroft
- 7 Esmee Davies
- 8 Farah Mills and brother Bradley
- 9 Freya and family on bridge
- 10 Grace Loftin
- 11 Heidi and Freya Willis
- 12 Imogen Gotts and sister Myah-May
- 13 Jayden Brannock
- 14 Joshua Starr-Thacker
- 15 Katie Tumber

- 16 Lily-Mae Pattinson
- 17 Lola Chivers and her sister
- 18 Natalie Scott and family
- 19 Neve Bagley doing her exercise challenge
- 20 Nikki Maltby and daughter Kaci
- 21 Penleggar Nursery School
- 22 Purple Nadine
- 23 Reyhan Rahman
- 24 Scarlett Burchett
- 25 Sophie Carr and classmates from Cheriton Fitzpaine Primary School
- 26 Stoke Chiro Team in purple
- 27 Teddy Bear Daycare Nursery
- 28 The Walkie Talkies
- 29 Winnie from Glebe Primary School





# Event Dates 2021

13 Sept	RA Awareness Week (RAAW)
3 Oct	London Marathon
10 Oct	Royal Parks Half Marathon
12 Oct	World Arthritis Day
18 Oct	20 Challenge Celebration of NRAS' Birthday
3 Dec	NRAS Christmas Show at St Peter's Church
16 Dec	NRAS Virtual Christmas Show

\*Visit [nras.org.uk/events](https://nras.org.uk/events) for upcoming RheumZooms and Group meetings and webinars. FB Live every last Wednesday of the month.



## You could win £25,000!

You could be our next winner.  
What would you spend £25,000 on?

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 some other lotteries, gives 50p from every £1 directly to the charity.

Play today to be in with a chance of winning £25,000 and support NRAS.

Please visit [lottery.nras.org.uk](https://lottery.nras.org.uk) to sign up today!

T&Cs are on the website [nras.org.uk/play-the-nras-lottery](https://nras.org.uk/play-the-nras-lottery), players must be 18+. UK ONLY.

Play for a chance to win up to **£25,000**



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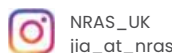
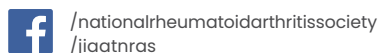
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