



nras
National Rheumatoid
Arthritis Society



JUVENILE IDIOPATHIC ARTHRITIS

Annual review 2021

20
YEARS
Anniversary

Life without limits for all those with RA and JIA



Clare Jacklin, CEO

Message from the CEO

As 2021 dawned we were all hopeful that the pandemic was nearing an end, but sadly that was not the case. While huge strides were made in rolling out the largest global vaccination programme ever undertaken, all our lives have, in one way or another, been touched by COVID-19 and it continued to dominate the work of NRAS.

Fundraising events only really recommenced during the summer and even then, they were very much restricted. The NRAS face-to-face patient events were once more all postponed as infection rates fluctuated across the UK. NRAS colleagues continued to work predominantly from home due to the restrictions and the advantages of remote working.

Naturally keeping all staff and Volunteers safe was top priority while still being able to deliver information and support to our beneficiaries, as well as supporting rheumatology healthcare services, as many struggled with the impact of workforce restrictions and backlogs.

Keeping our communities fully informed and representing their concerns during the year was critical. We worked collaboratively with many other stakeholders representing those classed as 'clinically vulnerable' or at 'high risk' and this continues to be a major part of our work. Issues which dominated were who should get vaccines/boosters and when; how to access COVID-19 treatments e.g., anti-viral treatments; what the various nations' restrictions were and how they impacted people with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA); access to benefits and work-related topics. With every new government announcement or latest briefing came some answers but, often they generated even more questions. Working collaboratively with an alliance of patient organisations representing those with immune-compromised or suppressed conditions, enabled us to liaise directly with NHS England and the Vaccine Minister to ensure the concerns of those with RA and JIA were heard and not forgotten. I'd particularly like to thank ARMA (Arthritis and Musculoskeletal Alliance) for their unwavering support to all stakeholders in the fields of musculoskeletal and rheumatic disease throughout these last two difficult years.

Despite all the challenges we did manage to keep many projects alive and delivered the first four modules of our unique online e-learning resource SMILE-RA (Self-Management Individualised Learning Environment). You can read more about that on page 6 and on our website here: nras.org.uk/smile

As 2021 was our 20th Anniversary we'd hoped to have marked it with an in-person event, but COVID-19 had other plans, so the celebrations have been postponed and we will mark our 21st anniversary instead in September 2022. However, we did not want to have such a big milestone go unnoticed and so we held a magnificent 'Do the 20 Challenge' (read more on page 16) as well as an online celebration with contributors from people who have helped, and been helped by NRAS in the last 20 years.

Some of you will be reading an NRAS annual review for the first time; some of you may have read one every year for the past 20 years. Whoever you are and however you've engaged with NRAS in the last 20 years, I thank you and hope you will continue to support NRAS as we forge ahead towards achieving our vision of a Life Without Limits for those with RA or JIA.

Message from the Chair of Trustees

2021 turned out to be another difficult year for the whole charitable sector and for NRAS it was no exception. The ongoing effect of restrictions to combat COVID-19 meant that our normal fundraising activities were constrained for a second year in a row, and the year we all expected to be one of 'getting back to normal' turned out instead to be a continuation of 2020's uncertain times. It is truly heartening though to be able to record that the year surpassed all our expectations, due to the very hard work and focus of our staff and Volunteers and also to the extraordinary generosity of our donors, large and small.

Because of the ongoing restrictions on our fundraising activities we started the year expecting to incur a loss and perhaps to draw on our reserves. By careful financial management and the efforts of the entire team, the predicted loss was steadily reduced through the year, but the icing on last year's cake was the news that NRAS would benefit in the year from several generous legacies. The end result was a year which exceeded our initial expectations and enables us to continue our work from a secure base - supporting our beneficiaries, pioneering new ways of reaching and helping people, working with our partners and campaigning effectively for new treatments and help for those impacted by RA and JIA. Our fundraising challenges have not gone away of course and we continue to look at how we can grow our Membership, make sure our fundraising efforts are as efficient as possible and reach out in new ways.

One of NRAS's main strengths has always been its patient-centred approach and its focus on delivering practical help and guidance to enable people to understand and manage their condition, and live lives which are as full as possible. We also have a strong track record in working with pharma companies and the medical professions to help in the development of new and more effective treatments through our knowledge base and our ability to connect them with real-world patient experience. As the charity develops and grows in the future, we must ensure that we retain this focus, which truly differentiates us and enables us to have an impact far greater than might be expected from an organisation of our size.

Finally, I would like to extend my heartfelt thanks and those of the Board of Trustees to the whole NRAS team: the fundraisers who have continued to raise substantial sums despite COVID-19 restrictions, often by staging imaginative virtual events, and those providing essential services and support to our beneficiaries. I also extend our grateful thanks to all our generous donors who have continued to support NRAS' work.



Simon Collins, Chair



Ailsa Bosworth MBE
National Patient Champion

Equity, Diversity and Inclusion

There is no singular, complete set of agreed definitions for terms like equity, diversity and inclusion and how these terms are understood will vary from organisation to organisation. Like many Third Sector organisations, we are all too aware that the profile of our beneficiaries, does not represent a cross-section of British society, rather they tend to fall into the White British ethnic category.

We have, for a good number of years, made active decisions and choices to address this and in 2016, in collaboration with Dr. Kanta Kumar (University of Birmingham), we launched an area on our website called 'Apni Jung' which means 'Our Fight' (against RA) in Hindi. In this area, we committed to producing resources using video and podcasts for the South Asian Communities in the UK in Hindi, Punjabi, Urdu and in time we will add resources in other Asian languages. We were aware from work we had been collaborating on with Dr. Kumar, that many in the South Asian populations had language and cultural barriers to accessing equity of care and information by comparison to their fellow UK citizens from white/English speaking backgrounds. This inequity was starkly revealed by the advent of COVID-19.



Dr Kanta Kumar
University of Birmingham

In 2021, in spite of the restrictions on income and spending imposed by a second year of the pandemic, we worked with Dr. Kumar and our Global Majority Advisory Board, to add new resources including:

- Vaccines Information: Short videos in Hindi and Punjabi to reassure South Asian communities about the importance and safety of the vaccination programme and how to keep themselves safe.
- Early Arthritis journey: A video in Punjabi with contributions from the whole Rheumatology Multi-Disciplinary team on the early inflammatory arthritis pathway.
- Website auto translation: Enabling our website to be translated into Hindi at the click of a button.

To see these resources, visit nras.org.uk/apnijung

However, whilst important, this is just one aspect of our work to address equity in access to healthcare and supportive information. Modelling inclusive behaviours and actively challenging things like unconscious bias amongst our staff has been a priority. Commitment to continuing to build an equitable organisational culture is also at the heart of our recently published strategic plan 2022 – 2025.

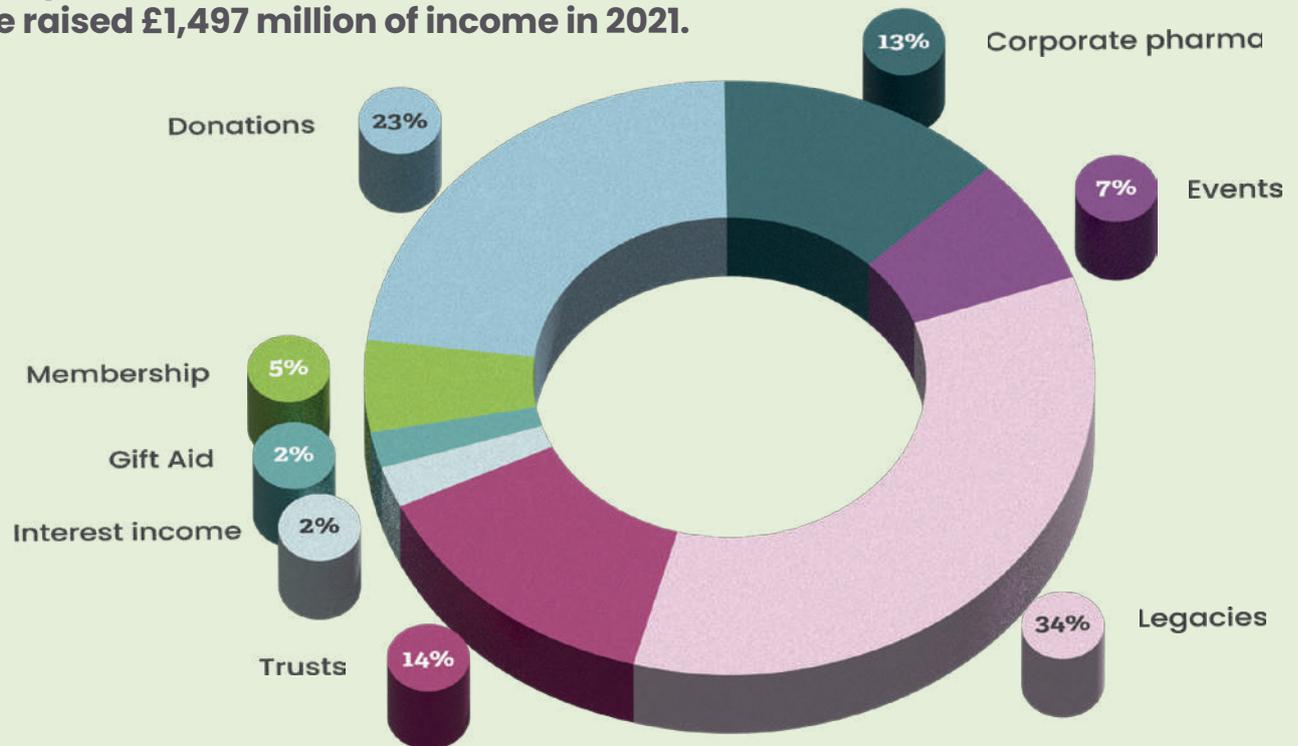
We have an ambitious future programme of work for our Apni Jung web area in 2022 including adaptation of resources on work and workplace issues as well as on the topic of cardiovascular risk, specifically for the UK South Asian population.

We are committed to working on strategies to reach all people living with rheumatoid arthritis (RA) or juvenile idiopathic arthritis (JIA) who may be disadvantaged through social deprivation, language and cultural barriers all of which will take time and funding. We will be actively looking at fundraising strategies to seek such funding from suitable trust and grant giving bodies to support our strategies to improve equity, diversity and inclusion across the board. These issues are complex and not always easy to address or find simple solutions to. The NRAS Board of Trustees, the CEO and the Senior Management Team have this important area of work firmly in their sights and all at NRAS are committed to improving equality, equity and diversity in all we do.



Where our money comes from

Thanks to the generosity of the public, companies and other funders, we raised £1,497 million of income in 2021.



Where we spent our money



In 2021
77p of every
£1 spent was on
delivering our
services



SMILE-RA

Self-Management Individualised Learning Environment in Rheumatoid Arthritis

The aim was to produce a unique, state of the art, e-learning programme for people with rheumatoid arthritis (RA). This arose as we were finding it increasingly difficult to get Clinical Commissioning Groups to invest in face-to-face supported self-management courses despite prioritisation of self-management in the NHS Long Term Plan.

.....
"... It's 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.

It is widely recognised, and research supports, that people with a painful and disabling, incurable condition like RA, have better outcomes if they are educated about their disease and learn how to manage it with the right support from their healthcare team, their family and importantly, patient organisations like NRAS. People tend to think of arthritis as an old person's disease, and though the most common age of onset is 40-60 years of age, many in their late teens, 20s and 30s also develop inflammatory arthritis.

There is therefore a huge need to develop accessible and engaging content to meet the needs of the contemporary RA patient. Services and resources providing emotional and educational support, can make a significant difference not just for the individual but for their families and the health service. We wanted to ensure that this programme would not only be unique, but easy to use and navigate with an intuitive interface, as well as being engaging and interesting. We felt it needed to be modular (bite-sized), each module focusing on a particular aspect of RA and with a maximum length of 20-30 minutes. The programme enables the user to choose where they want to go and which modules to explore based on their interests or concerns. Modules use a mix of our cartoon style branding (NRAScals) and stock imagery, lots of video and voice over presentations as well as interactive quizzes. Content has been written with input at every stage from rheumatology health professionals, people with lived experience and NRAS staff with an expert Advisory Board overseeing the content.



Choosing the right partner to develop the programme, with the kind of built-in impact assessment tools which would integrate with our Salesforce database (CRM) was key, as was fundraising in 2019 to fund the first tranche of this ambitious project. Whilst COVID-19 delayed things, we launched the first 4 modules of the programme on 17th Sept. 2021:

1. Foundation- an introduction to what self-management means (including baseline impact assessment),
2. Newly Diagnosed
3. Meet the (Rheumatology) Team
4. Managing RA Pain and Flares

A 5th module, Medicines in RA, will launch summer of 2022. The biggest challenge was getting the integration right to ensure we would be able to gather and use the data to appropriately target support and information resources making it a truly individualised programme.

The programme has been extremely successful, more so even than anticipated! It came second in Best Practice Fair at the EULAR PARE conference in November 2021, voted for by patient organisations and health professionals from across Europe. The programme, which is accessible via any device, has received all positive feedback. At end of the year, a total of 642 modules had been completed. Between 33% and 40 % of registrants had completed the baseline questionnaire (Patient-reported outcome measure - PROM) in the Foundation module. This questionnaire will be completed again in 2022 to determine changes in specific domains. Between 80 - 100% of learning objectives had been achieved for each module.



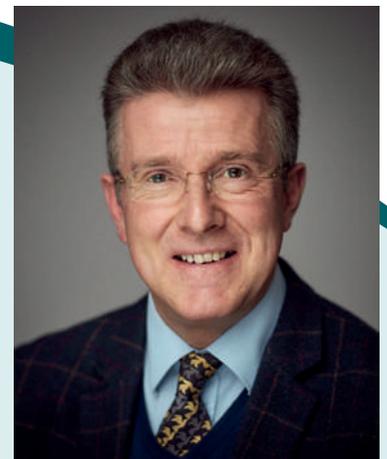
Further modules are being planned to include: 'How to have a good consultation', 'Exercise', 'How to identify and mitigate cardiovascular disease (CVD) risk' (people with RA have the same level of increased risk of CVD as those with Type 2 Diabetes), and 'Treatment in RA'. Throughout the modules, there is signposting to other NRAS services, resources, publications and support so people can interact with us in ways that suit their needs and support their preferences.

Message from our Chief Medical Advisor - Professor Peter Taylor

"Tempus fugit" – or time flies, so it has been famously said, often in the context of an admonition against sloth and procrastination.

These are charges that could never be laid at the door of the National Rheumatoid Arthritis Society (NRAS) although time has certainly flown in the 20 years since the foundation of the charity! Rather, the extraordinary achievements of the charity in supporting people living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) as well as their loved ones, carers, friends, and colleagues is truly a cause for celebration, following in all the best traditions of turning 20 years of age in 2021. Examples include patient support programmes, educational materials for patients and health-care professionals, encouragement and friendships, not to mention patient advocacy, and lobbying government to ensure equitable access to specialist services and high-cost medications. NRAS has always been a source of inspiration not only to people living with arthritis, but also to healthcare professionals. For example, the charity recognises and fosters clinical excellence and compassionate care through the healthcare champion awards ceremony which in turn facilitates innovation in service delivery and sharing of best practice.

There have also been extraordinary advances in new treatments for RA and JIA over the last 20 years such that the outlook for patients presenting with these conditions is now better than ever before. But while medication can be transformative in terms of relieving symptoms and enhancing quality of life, treatment of the disease is one issue and supporting the person who is living with the condition is another. NRAS wonderfully supports people who are adjusting to life with arthritis as well as those who have lived with it for many years. The work of the charity beautifully complements the care provided by healthcare professionals and provides a wealth of additional resources that are highly recommended to patients by their rheumatologists. It has been a great privilege for me to work with the inspirational staff at NRAS, led by Clare Jacklin, Chief Executive Officer, and founded by Ailsa Bosworth, MBE, 20 years ago. It is clear from their current vision and tireless work that the next 20 years will see ever more resources made available to support and uplift people living alongside arthritis to live their lives to the full.



Peter C. Taylor MA, PhD, FRCP, FRCPE

Norman Collisson Professor of Musculoskeletal Sciences, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford

Chief Medical Advisor to the National Rheumatoid Arthritis Society.



Sarah Collins
NRAS Ambassador

Meet one of our NRAS Patient Ambassadors

In 2021, I had the privilege of joining the industrious group of NRAS Ambassadors. The role brought me a number of opportunities and challenges and I'm looking forward to many more.

The job of an Ambassador is to promote the charity's aims and services to the public and inform healthcare providers about new initiatives - which you won't be surprised to hear are numerous. I don't know how the relatively small team of NRAS staff juggle as many balls as they do. We Ambassadors try to support whatever is current and make the most of opportunities as they arise.

In 2021, a major goal has been to promote the use of NRAS' electronic referral system: New2RA Right Start to NHS Rheumatology departments. The objective is to have newly diagnosed patients referred to NRAS services right at the beginning of their rheumatoid arthritis (RA) journey. How I wish there'd been something like Right Start in 1981 when I embarked upon mine.



I have been pursuing 5 NHS Hospital Trusts and am pleased to have signed up 2 but there are 3 more to go and I'm determined to reach them somehow!

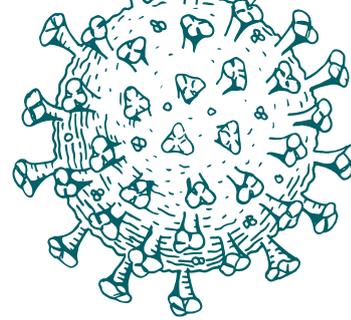
You'd think it would be fairly easy to approach your local rheumatology team to ask for an opportunity to explain how the system works. Not during a pandemic it isn't! With clinicians rushed off their feet, not seeing patients in person, let alone NRAS representatives, it's been nigh on impossible. I have been pursuing 5 NHS Hospital Trusts and am pleased to have signed up 2 but there are 3 more to go and I'm determined to reach them somehow! I've been doing internet searches to find the names of clinical leads, contacting their secretaries to brief them and set up meetings, even writing to consultants enclosing NRAS promotional literature. Once I get through to them, most departments are delighted to hear what's on offer but it's necessary to emphasise that New2RA Right Start is in addition to everything NRAS has provided for years - it's a tailored, personal package involving, amongst other benefits, two personal phone calls to patients from specially trained NRAS staff who establish what would help each individual best. As part of the staff training for making these calls I've been role-playing as a newly diagnosed person and mischievously I enjoyed throwing them the occasional curve ball. They weren't deterred and fortunately are still speaking to me!

When we're not publicising services like Right Start and now also SMILE -RA, Ambassadors are forging working relationships with a broad spectrum of people and organisations from politicians to Health Trust committees. When it's possible to do more in person we'll be out and about speaking to NRAS groups and anyone who'll listen and benefit from hearing about RA and JIA and all NRAS provides. That includes talking to local and national broadcasters and printed or online media.

Perhaps the best part of all this is that Ambassadors are supported to achieve what we can within the constraints of our own health. There's genuine support and encouragement, no pressure. I've become involved with a great bunch of Volunteers and whilst we come from diverse backgrounds, geographical, personal and professional, our common aim unites us. We pull together and pool resources. We also pull each other's legs about things which makes it all the more enjoyable.



Our ongoing response to COVID-19



The COVID-19 pandemic continued in 2021 and many living with rheumatoid arthritis (RA) or juvenile idiopathic arthritis (JIA) turned to NRAS as a trusted source of information to guide, assist and reassure them through these troubling times. The huge influx of calls, an increase in call times and the complexity of information required all continued throughout 2021. As a change from 2020 questions were regarding the vaccine rather than concerns about vulnerability to COVID-19. With guidance and information changing rapidly, the Helpline team were required to keep abreast of what was in the media that may then lead to an influx of calls, as well as ensuring the links to government information and websites were the most current.

The OCTAVE study results were released in August 2021. The study looked at vaccine response of those who are 'immuno-compromised' which includes a very wide range of people at varying levels of immune system suppression/modulation. The results of this trial show that a significant proportion of clinically at-risk patients with specific immunocompromised or immunosuppressed conditions, mount a low or undetectable immune response after two doses of the same COVID-19 vaccine. However, of this group people living with RA fared better than those with other conditions. This led to a further spike in calls from concerned people. It also led to an expansion of the study, named OCTAVE –DUO, the results of which have not yet been released. There were many other studies such as the ZOE study and Panoramic studies, that the NRAS team was kept informed of and shared the information as soon as possible via all our channels.

The Helpline team found that the questions followed trends, which created an opportunity to develop a COVID-19 'frequently asked questions' section on the website. With much discussion and varying opinions the team was required to monitor online platforms with added scrutiny to tackle any 'misinformation' rapidly.

The NRAS professional advisory board were regularly consulted about questions beyond the expertise of the Helpline team and this enabled us to maintain and grow NRAS' reputation for the highest quality evidenced based information, delivered with unwavering compassion, despite a huge increase in demand.



Number of Helpline Enquiries



Total HealthUnlocked posts monitored in 2021



Total Publications sent out in 2021

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



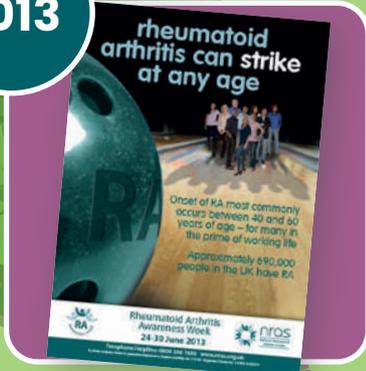
Sue Oliver appointed as Chief Nurse Advisor

2004



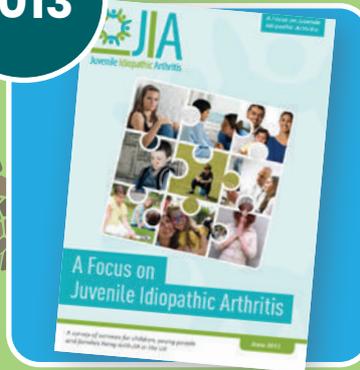
Community Award

2013



NRAS launches RA Awareness Week

2013



Focus on JIA report



Welsh Assembly visit by Welsh Ambassadors



Family Matters re

Emotions, relationships & sexuality resource landed



2014



First JIA Family Day

Mark Liddell, longest serving Trustee



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

is irreversible invisible disease can cause daily pain, and use people to feel alone.



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"

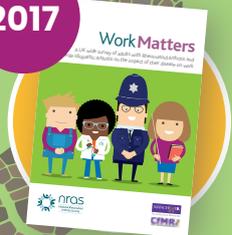
Behind the smile campaign

2015



Apni Jung resources launched online

2017

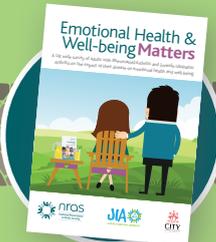
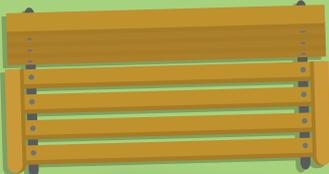


Work Matters report

2018



Diwali event



Mental Health Matters report



JIA children visit Westminster

Healthcare Champions Awards

Louise's Story

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



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



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

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



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

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



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

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



Yes okay, that sounds like a good plan Debbie.

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



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

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



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

helpline@nras.org.uk

For more information on the support we provide, please visit our websites here:

nras.org.uk/get-support & jia.org.uk

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

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

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

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

Kind regards. Louise."



NRAS JoinTogether Groups

NRAS understands the need for those living with RA or JIA and parents (or carers of children with JIA) to connect with others, as it can be of great benefit and comfort. The COVID-19 pandemic highlighted the need to find new ways to connect. In the summer of 2021, NRAS launched the JoinTogether digital groups. Through these new digital groups, our community can connect with others that have similar interests and lifestyle. Information about our groups is below, all are run by NRAS Volunteers:

- JIA Parents or Carers group
- 18 to 35 Group
- Parenting with Inflammatory arthritis
- Working with inflammatory arthritis
- Exercise and back to sport group

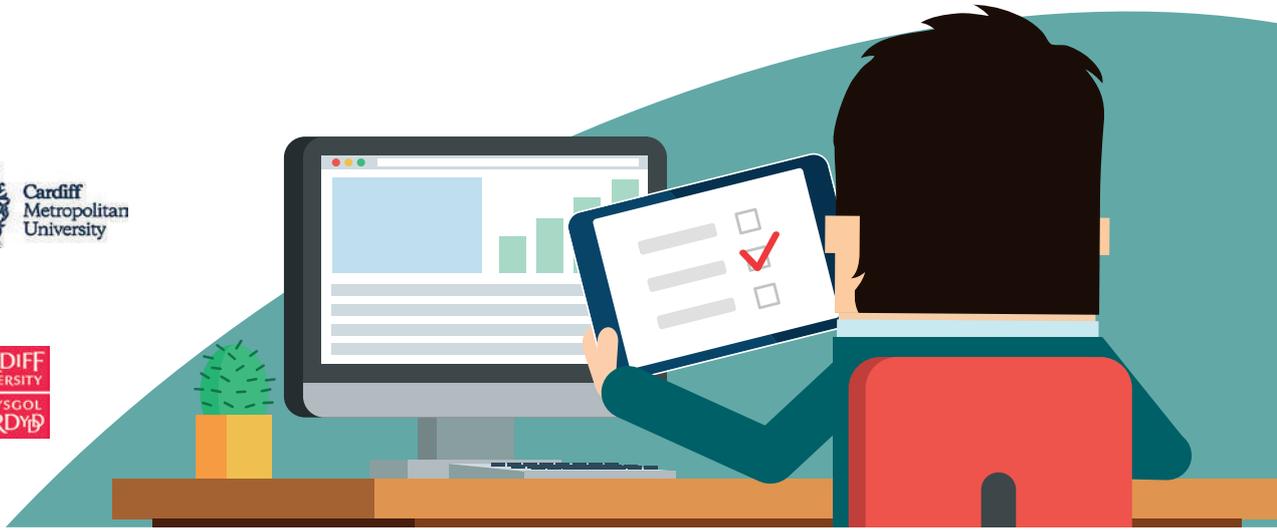
For more information, please visit

nras.org.uk/jointogether



**JoinTogether
Groups**





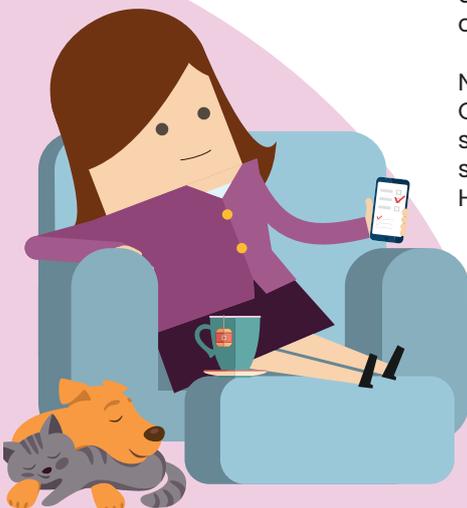
Research opportunities

2021 was the first year of the Research Coordinator role here at NRAS, which facilitated more research opportunities for the rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) community to get involved with. During the Rheum Zoom 'A Yearly Round-up of Medication and Research', a poll was held to gauge the community interest in research. One outcome of the Rheum Zoom poll was that 86% of the responses were interested in taking part or had taken part in some sort of medical research. However, 41% of these people had never been asked or given the opportunity. We also found that the most important factor to being involved in research was knowing exactly what the data being gathered is being used for. This is where NRAS' involvement in research studies can play a vital role and help both the researcher and inflammatory arthritis community by providing clear patient information and support increasing the reach and number of people that take part in a study.

To ensure research proposals meet the NRAS standards and are in alignment with our mission, processes and quality controls have been implemented. This allows NRAS to support academic research via promotion of surveys and recruitment opportunities using our website, E-News bulletins and social media platforms. This enables community involvement in studies via surveys, interviews, app/device testing or participation in focus groups. Approximately 60% of our research support consists of academic research. NRAS also is approached by commercial organisations to support studies/market research e.g. pharmaceutical companies, product design agencies, as well as funded academic studies. Such NRAS support provides additional income for NRAS by compensating for our consultation and expertise.

Not surprisingly a key focus of research during 2021 was relating to impact of COVID-19 but also included pain, fatigue, physical activity, self-management, support services and treatment experiences. NRAS was involved in two major surveys, one in collaboration with University of Oxford/Oxford University Hospitals and the other with Medac Pharma. The Oxford University survey focused on experiences of accessing rheumatology care including any remote rheumatology consultations, as well as opinions about remote consultations going forward. The Medac Pharma survey covered two areas of interest; firstly, the role that healthcare professionals and patients play in influencing treatment decisions for people living with RA or JIA and secondly, the impact of RA and JIA on quality of life, and how treatment may help to improve patient outcomes.

NRAS will be increasing the work of our research hub to include participant recruitment for studies and support for clinical, social, academic and market studies.



Thank you from NRAS

From everyone here at NRAS, thank you. We are very grateful for the support we have received in 2021.

Without you, we would quite simply not be able to provide vital information and support to all those living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) across the UK, as well as their families, carers and the healthcare professionals who treat them.

NRAS CEO, Clare Jacklin, would like to give special thanks to every individual, group, company and organisation that supported NRAS through another very challenging year.

NRAS would like to acknowledge the following organisations who supported us in 2021:

Arnold Clark Community Fund	The Rank Foundation
BBC Children in Need	The Vandervell Foundation
C Brewer & Sons Ltd Trust	The William and Mabel Morris Charitable Trust
Carr-Ellison Family Charitable Trust	Sciensus
Doris Field Charitable Trust	Cookham and Holyport Metre Markets
Edgar E Lawley Foundation	Stoke Chiro Spinal Wellness Clinic
Garfield Weston Foundation	Unity Lottery
H C Beer Charitable Trust	AbbVie Ltd.
Innovate UK	Biogen Idec Limited
John Swire 1989 Charitable Trust	Bristol-Myers Squibb Pharmaceuticals Limited
Joseph Strong Frazer Trust	Boehringer Ingelheim Limited
Sir Jeremiah Colman Gift Trust	Eli Lilly and Company Limited
Squire Patton Boggs Charitable Trust	Fresenius Kabi Limited
The C M Lowe Charitable Trust	Galapagos Biotech Ltd.
The Drapers' Company	Galapagos NV
The Eveson Charitable Trust	Gilead Sciences Ltd.
The February Foundation	Inmedix Inc.
The Hobson Charity	Janssen-Cilag Limited
The Hospital Saturday Fund	Medac Pharma LLP
The Joan Lynette Dalton Charitable Trust	Nordic Pharma Ltd.
The Lady Hind Trust	Roche Products Limited
The Logres Trust	UCB Pharma Ltd.
The National Lottery Community Fund	

We would also like to thank all the NRAS Groups throughout the UK who continued to support our work with donations during 2021.

Thank you to all of our dedicated fundraisers and supporters in the community who continued to raise vital funds in 2021.

To all those individuals, friends and family members, who lost a loved one in 2021 and chose to honour their memory with a donation to the charity, a sincere and much appreciated thank you for thinking of others during a personal difficult time.





For more information visit www.werapriority.co.uk

'RA may be invisible but we're not' – We R.A. Priority

In the autumn of 2020, we worked with Gilead Sciences on the launch of a campaign called We R.A. Priority. During 2021 we continued this project with Galapagos NV.

Since autumn 2020 and throughout 2021, the campaign has reached thousands of people across the UK. The lived experience of people with RA makes up the campaign content, which has had a huge impact by not only helping those living with RA, but also raising awareness of RA and dispelling common misconceptions amongst the general public.

During 2021 the campaign continued to evolve with more patient stories being shared on the platform as well as social media posts and live broadcasts contributing to the NRAS RA Awareness Week in September.

The campaign shines a spotlight on the many areas of a person's life that is impacted by RA – family life, work and careers, society's response to people with long term but invisible conditions, intimacy and relationships and the plan is to continue to grow the content in 2022.

We R.A. Priority

- Over 1.8 million views across WRAP branded social media channels (TikTok, Facebook and Instagram)
- Reached over 500,000 individuals across the same platforms
- Over 4,000 views of two Facebook lives hosted by NRAS & Galapagos on 1) Technology and disability and 2) Sexual relationships.
- Viewers from 19 countries have visited the We RA Priority website

Two LinkedIn Live broadcasts – Living my life with RA & Building a network

- Total video views 1,700
- Over 100 interactions (comments, likes, engagements)



#DoThe20Challenge
raised **£28,968**

#DoThe20Challenge

In celebration of the 20th Anniversary of NRAS being founded by Ailsa Bosworth, MBE, we created a fundraising challenge for supporters to get involved with raising essential funds for the charity.

Those taking part could decide on a sporty, wacky, creative or foody challenge focused on the number 20. On completion, each challenge participant received a limited edition: 'I did the 20 Challenge' medal.

This fundraising challenge ran from June until the end of the year, and raised a terrific £20,096

As part of the 20 Challenge, we created a Facebook community and added an event we called '200k Steps Challenge in September'. An amazing 380 people registered for the steps challenge and managed to raise £8,872

RA Awareness Week (RAAW) and Wellbeing Courses

RAAW:

Monday 13th – Saturday 18th September 2021

2020's RAAW campaign was such a success, we decided to build on it in 2021. The focus for RAAW 2021 was once more on mental and physical wellbeing, mainly due to the ongoing impact on countless lives of the continuing COVID-19 pandemic.

The wellbeing taster sessions we held during the week were:

- Nutritional Therapy & RA, Diet Supplements and Lifestyle Changes
- Introduction to strength resistance-based exercise
- Singing4Wellbeing
- Mindfulness: Relax, Breath & Unwind
- Chair-based fitness
- Mind Body Runner
- Tapping for pain
- Tai Chi
- Tripudio Movement
- Q&A with our NRAS Helpline Team
- Chair Yoga

In 2021 we had 1,783 people register for the one-off sessions which was an increase of 31% from 2020.

Wellbeing Courses 2021

5 expert led courses ran twice during 2021

- Nutritional Therapy & RA – Diet, Supplements and Lifestyle Changes (6 week course)
- Resistance based exercise (6 week course)
- Mindfulness & Meditation (5 week course)
- Singing4Wellbeing (6 week course)
- Yoga for the joints (5 week course)

Yoga for the joints was so very popular that some of the participants wanted to continue from the initial course and therefore created 4 private groups.

The success of these courses mean they will continue to run in 2022, with the following already being organised:

- | | |
|-----------------------|----------------------------|
| ■ Tai Chi | ■ Mindfulness & Meditation |
| ■ Tripudio Movement | ■ Dance/Movement |
| ■ Yoga for the Joints | ■ Diet/Nutrition |



Our wellbeing experts



Young Persons' Project Manager becomes CLUSTER Champion



THE CLUSTER
CONSORTIUM

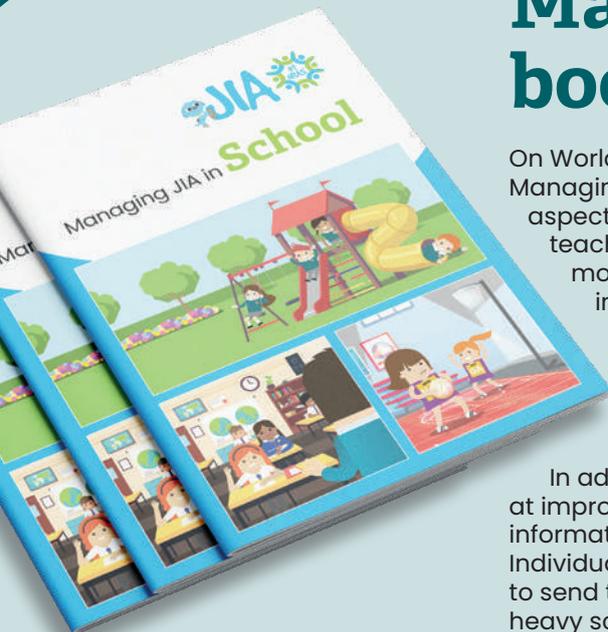
Debbie Wilson, NRAS' Young Persons' Project Manager became a CLUSTER Consortium Champion, representing patients and parents as well as the JIA-at-NRAS community.

The CLUSTER Consortium (Childhood arthritis and its associated uveitis: stratification through endotypes and mechanism to deliver benefit) was set up in 2018. The consortium is led by Professor Lucy Wedderburn (Professor & Consultant of Paediatric Rheumatology at UCL & Great Ormond Street Hospital). Professor Wedderburn is working with paediatric teams throughout the UK. The aim is to bring together knowledge, data and studies from internationally recognised leaders in childhood arthritis, JIA-uveitis, bioinformatics and industry, along with insight from our UK wide patient and parent networks to create biomarker tests to personalise treatment, find and test new treatments, and predict disease outcomes for childhood arthritis. For more information, please see clusterconsortium.org.uk.

For more information about Debbie and why she became a CLUSTER Champion please see:

clusterconsortium.org.uk/a-warm-welcome-to-new-cluster-champion-debbie

Managing JIA in School booklet – updated



On World Arthritis Day, 12th October 2021, JIA-at-NRAS relaunched their Managing JIA in School booklet. The update provides information on all aspects of education and is an extremely useful resource for parents, teachers, schools' management and for the child themselves. It provides more information about how to inform the school about a child's JIA, individual health care plan, tips for teachers and children and how to manage flares in school.

To order a hardcopy or download a pdf version, visit our website at: jia.org.uk/managing-jia-in-school.

In addition, there are now a range of articles on the JIA website aimed at improving the experience of going through school with JIA, with helpful information on a range of aspects of school life, including completing an Individual Healthcare Plan (IHP) with a template covering letter for parents to send to the school; coping with exam stress and minimising the effect of heavy school bags on the joints. Visit jia.org.uk/education.

#WearPurpleForJIA Wellbeing Week

Along with our traditional #WearPurpleForJIA fundraising day on the 18th June (which raised £31,177) we held our first #WearPurpleForJIA Wellbeing Week during 14th – 18th June. We knew that the pandemic had been tough for everyone, especially for children, so we facilitated a week of free online Wellbeing classes for children with juvenile idiopathic arthritis (JIA). In total 47 children attended the classes, and some children attended all of them.

Topics of the classes were art, yoga therapy, dance, photography and a Happy Human Project class (a company that specialise in children's mental health). Three of the five classes were run by those who have either JIA or RA who really enjoyed helping others on their JIA journey.

Throughout the week we also held four Facebook Live Sessions in the evenings, covering a number of areas relating to JIA. The first was a question-and-answer session with two paediatric specialist nurses, covering what symptoms a parent should look out for, healthcare team support, managing treatment and ended with them sharing a positive story of a child with JIA they had treated over the years. Some children may carry their JIA on into adulthood, and to offer information and support we also held a session with five adults, living with JIA, discussing and sharing their experiences. There was real resonance in their stories and many commented that it would have helped them when growing up to know that someone else was going through what they were.

Having a child with JIA also has a huge impact on the parents, siblings and the wider family. During the week we had parents share their experiences with discussions that covered journey to diagnosis coping with flares, and generally managing the ups and downs of JIA. We had Lynette whose daughter Freya had the original idea of Wear Purple for JIA campaign 5 years ago on the panel.

The final Facebook live session of the week was hosted by children with JIA themselves. 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 put questions to paediatric doctors and nurses. Only some of the questions were on JIA, 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?" When asked: "What living person do you admire most?", nurse specialist, Kit Tranter gave the best response, "Children living with JIA!"

All the Facebook Live sessions are on the JIA.org.uk website and our Facebook page for you to watch back [facebook.com/pg/jiaatnras/videos](https://www.facebook.com/pg/jiaatnras/videos)

"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".



#WearPurpleforJIA
raised **£31,177**

Campaigning success

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.

Until July 2021 only those people with severe disease i.e., having a disease activity score (DAS28) of greater than 5.1, had been able to receive treatment of advanced biologic or targeted synthetic disease modifying therapies as part of their NHS treatment. There were no such eligibility restrictions in Ireland and many other Western European countries where choice of treatment is determined by the prescribing clinician being able to use the most appropriate treatment.

NRAS & BSR campaigned 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 our campaign over the last 3 years. We challenged NICE's eligibility criteria to access advanced therapies for those with 'moderate' disease. 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 way back in February 2019.



An estimated 25,000 people living with rheumatoid arthritis (RA), may now be eligible for such treatments, making this decision the biggest game-changer in RA care since biologics were first utilised. The impact on those peoples' lives should not be underestimated. 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 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.

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



To sustain NRAS long into the future please consider leaving us a Gift in your Will. Any amount is greatly appreciated.



Helpline: **0800 298 7650**
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