



nras  
National Rheumatoid  
Arthritis Society



JIA at nras  
JUVENILE IDIOPATHIC ARTHRITIS

# Annual review 2022



**Acknowledging the work of HealthCare Champions**



Clare Jacklin, CEO

## Message from the CEO

2022 truly marked a realisation that COVID-19 was not going away, and we had to adapt to living with the threat of the virus and all that means, not just for our beneficiaries, but for the charity.

Hybrid working was to become the norm for us all, meaning a major decision had to be made regarding our offices. Rent, service charge, overheads and generally running the office is our second largest expenditure. Fortunately, we had a break clause in our 10-year lease, so were able to give notice and start the hunt for smaller premises that would suit our changing needs. Due to a great deal of hard working by many of my colleagues, but in particular, our Office Manager Sam, and Finance Director, Helen, we were able to execute a fairly smooth transition to smaller and more economically affordable premises in November with minimal disruption to our services.

Returning to 'normal' is something that we heard a great deal about during the pandemic, but I must be honest, I was not that in favour of this. 'Normal' wasn't that great to start with; I felt that the pandemic gave us all many opportunities to rebuild better and stronger. There are many aspects of the charity's work that have changed for the better because of the pandemic, and have now been adopted as usual practice e.g. online NRAS group meetings 'JoinTogether' and regular NRAS broadcasts.

Keeping our communities fully informed, and representing their concerns, remains a top priority. Many of the alliances between similar patient organisations, formed because of the pandemic, will continue to collaborate, as it's clear our voices are stronger together to represent those classed as 'clinically vulnerable' or at 'high risk' now being referred as the 'Forgotten Lives'.

Some highlights of 2022 have been that, despite all the challenges, we delivered two more modules of our unique online e-learning programme SMILE-RA (Self-Management Individualised Learning Environment). A brand new NRAS service was launched in December 2022 to offer support to families with a child or young person diagnosed with JIA, New2JIA Right Start. We also launched a new resource called Blood Matters, which has been in huge demand by both health professionals and individuals living with inflammatory arthritis.

2022 marked our 21st anniversary, and we combined our celebrations with an Awards' ceremony to honour individuals and healthcare professionals, who were nominated by patients, for going above and beyond in their work to help others. This means a great deal to the winners, who were presented with their trophies and certificates at the Gala Dinner on Friday 9th September. Sadly, our celebrations were curtailed considerably by the news the day before that Her Majesty, Queen Elizabeth, had passed away. We did deliberate whether going ahead with the event was the correct decision, but felt that Her Majesty, having spent her life in the service of others, would not have wanted us to miss recognising the work and dedication of the charity and the award winners. You can watch a behind the scenes video by scanning the QR code.

Some of you will be reading an NRAS Annual Review for the first time and some of you may have read one every year for the past 21 years. Whoever you are, and however you've engaged with NRAS in the last 21 years, I thank you all and hope you will continue to support NRAS, as we forge ahead towards achieving our vision of Life without Limits for all those with RA or JIA.





# Message from the Chair of Trustees

The past year has been one of positive change for NRAS in a number of directions. Firstly, we started to emerge from two years of COVID-19 related pressures and restrictions which had both increased the demand for our services, particularly our helpline and advisory activities, and reduced our income from volunteer fundraising and other events. Other long-term effects of COVID-19 remain however, such as the increased challenge of recruiting which continues to be experienced by NRAS and other charities. This places additional pressure on many members of our team and in particular on senior management.



*Simon Collins, Chair*

Secondly, we have now settled into our new offices in White Waltham, after a huge amount of planning and work by the team. The move, whilst of course disruptive in the short term, will generate significant long-term cost savings for the charity. The new office, though smaller than our previous base, is a pleasant working environment and well suited to the needs of our flexible team.

Financially, we had budgeted to make a loss in 2022; planning to use our strong reserves position to enable us to continue our activities at the same level as the previous year, despite anticipated funding reductions. In fact, I am pleased to report that the loss in the year was much less than forecast due to tight cost control, despite the one-off costs of office re-location, and higher than expected income. Whilst fundraising across all areas remained challenging, income from legacies was well more than our forecast. People generous enough to leave NRAS a sum in their Will can be assured that their gift will be well used towards our objectives to support those living with the impact of RA and JIA through information, education, advancing care and treatment and raising awareness.

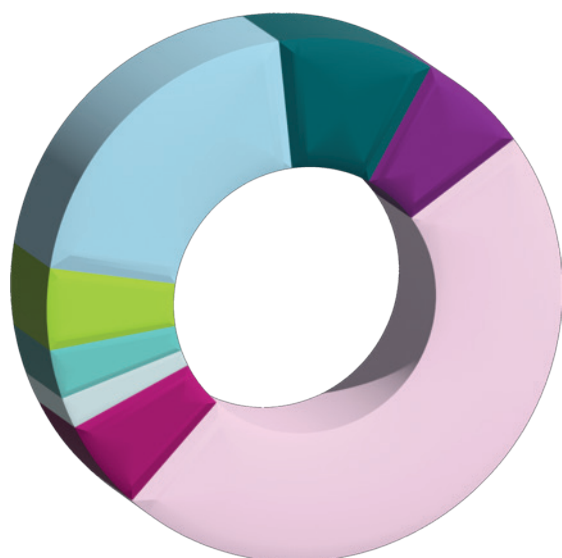
Whilst we are always enormously grateful to all those who leave bequests to NRAS, broadening and diversifying our income streams continues to be an important objective of the Board of Trustees, both to grow funding in absolute terms and to increase its stability and predictability.

In terms of outputs, NRAS has continued to develop new ways to reach and help those who need its services, in particular those who are newly diagnosed, when the support, information and advice we provide can make such a difference. During the year we have added to the range of our well researched advisory publications which provide a wealth of useful information made available free to all. Recognising the growing importance of the digital sphere, we have continued to develop our engaging SMILE-RA e-learning programme, adding two new modules. Our Right Start initiative also continues to go from strength to strength, reaching out to those who have been newly diagnosed and connecting them to support, information and practical advice. Last year Right Start was extended to include those newly diagnosed with JIA and their families.

None of this would be possible without the tremendous and ongoing efforts of our staff and Volunteers, together with the generosity of our funders. We are fortunate indeed to be able to rely on the efforts and skills of our committed team and I would like to take this opportunity to thank them all on behalf of the Board.

# Where our money comes from, and how we spend it

Thanks to the generosity of the public, companies and other funders, we raised £1,647 million of income in 2022.



- Corporate pharma 10%
- Events 7%
- Legacies 47%
- Trusts 6%
- Interest income 2%
- Gift Aid 3%
- Membership 5%
- Donations 20%

## How we spent our money



For every £ raised in 2022 we spent 86p on delivering our charitable services



# NRAS Champions' Awards

On 9th September we held our 21st Anniversary Gala Dinner and Awards ceremony in Windsor at the Castle Hotel. As well as marking a significant milestone in the history of the charity, it helped raise vital funds for NRAS. We decided to take the opportunity to combine this special event with the NRAS Champions' Awards.

I'm sure there are many more worthy winners out there working hard to improve the lives of those living with rheumatoid arthritis (RA) or juvenile idiopathic arthritis (JIA), so while we have identified these marvellous winners, may I suggest that they are representative of the hundreds of hard working, dedicated Volunteers and health professionals. Thank you to all who go above and beyond to help achieve 'life without limits for all those with RA or JIA.



Clare Jacklin, CEO

## Winners



**Katy Pieris** is awarded the Individual NRAS Champion Award for outstanding contribution to the work of the society. Katy has been an exemplary Member and Volunteer for many years, representing people living with RA at many events and in media campaigns. Katy lives with her husband and young son in London, has a demanding career, and still finds time to support others living with RA. She does this by leading the Croydon NRAS Group, as well as being a 'Here For You' telephone support Volunteer, and has also been instrumental in setting up and leading on the NRAS JoinTogether online groups.

Katy was nominated for this award for her work supporting others and raising awareness of RA, as well as being an amazing fundraiser for NRAS; a true inspiration for others. Janet, who nominated Katy, said: *"Her dedication to supporting those with RA in the most positive way possible is second to none and I can't think of a more worthy Champion. Katy has a lovely caring nature and the NRAS Volunteer community is so lucky to have her!"*



**Dr Lizzy MacPhie**, Consultant Rheumatologist from the Minerva Centre in Preston, Lancashire, is the winner of the Individual Rheumatology Champion Award having received two glowing nominations from Sarah Fish and Deborah Whiteside. Lizzy also impressed the judges' panel with her exemplary work, especially during the pandemic, when she led the Clinical Guidance Group with the British Society for Rheumatology.

This is what Sarah had to say in her nomination for Lizzy: *"Lizzy has facilitated and organised the speakers for the NRAS meetings to deliver many different sessions including medicines updates, exercise, joint protection and assistive devices. During the COVID-19 pandemic, Lizzy organised a Zoom account to ensure she could still meet with the NRAS patient group regularly to provide updates and support, as well as answering questions and concerns. The members of the NRAS group really appreciate her and value her support, as do her entire clinical team".*



Deborah in her nomination said:  
*"Dr MacPhie is the most caring, knowledgeable and compassionate Consultant. She gives a totally individual patient approach to treatment. She is empathetic and*

*totally understands the needs of her patients and enables them to live their lives as they wish by tailoring treatments to the individual. She is amazing!"*

## Individual Paediatric Rheumatology Champions



**Jenny Wyatt**, Paediatric Rheumatology Nurse Specialist, Musgrave Park Hospital, Belfast.

*"Jenny has always been a friendly face on the ward, she goes above and beyond for her paediatric patients, always available on the phone and always willing to help. She is extremely patient and interacts with my daughter so well; she [daughter] often remarks that she loves going to see Jenny at appointments. Ward visits are made easier, and sometimes even looked forward to, as Jenny is such a ray of positivity. She always provides kind words, addresses my child rather than me (on a level she understands fully), and has such a caring and compassionate attitude towards her. When we first received the JIA diagnosis, Jenny was invaluable for information, detailed explanations and information relating to procedures and medication. Overall, she has made our arthritis journey much more positive and deserves recognition for this."* Mairead Mullen, nominator.



**Sam Small**, Paediatric Rheumatology Specialist Nurse, Southampton Hospital.

*"I am nominating Sam for all the support, time and patience she has given my little boy Owen. Sam has sat on the floor for hours trying to cannula Owen, keeping really calm and working with him, through his extreme needle phobia. Previously, Owen required sedating to get his cannula for his biological drug infusions, and before his weekly drug injections, which often took 2-3 visits of trying to get the injection into Owen. Sam, through it all and her busy workload pressures, has kept her patience with my little boy and over time gained his trust to now be able to cannula him within seconds of being in the room. I know for a fact we would not have moved forward with his needle phobia without the kindness and time Sam has given us both. I feel nurses like Sam are few and far between and feel so grateful for her support and help during these hard times. Sam will always be a big part of our journey of life with JIA. I will always be grateful"* Rebecca Edwards, Owen's Mum and nominator.



## Rheumatology Team Champion Award

### **The Rheumatology Team at East & North Herts NHS Trust,**

Lister Hospital, Stevenage was nominated by two people; Glynis Rogers and Teresa Shakespeare-Smith. Within her nomination, Teresa said the following about the terrific support she has received from the team as a patient, but also as an NRAS Group leader: *"I can contact Fidelma and Alex by WhatsApp for blood test results and medication tweaks to save time. Alex even contacted me when he was off with COVID! Fidelma went the extra mile to provide letters for my insurance company, so I was able to receive payments during shielding, reducing my stress which is, for me, a real flare-trigger. Fidelma also saw me late at night in Christmas week to give me a steroid injection for a bad flare. Dr Ellis introduced me to NRAS while setting up the Hertfordshire NRAS Group; the entire team continue to support the local group, and a couple of years ago all participated in a sponsored abseil/relay as an NRAS fundraiser, as well as raising funds for a department*



*ultrasound machine. They all work ridiculously long hours. I'm included in decision making about my treatment; they always listen and make me feel part of the team."*

Glynis said of the team: *"They are kind, caring and supportive. Even more so when my husband passed away suddenly, plunging me not only into despair, but a worsening flare. My consultant, Jeremy Axon, answers emailed questions out of hours. I feel very supported by this amazing, proactive team. I'm very grateful to be under Jeremy, Fidelma, Alex and whole team's care."*

## Paediatric Rheumatology Team Champion Award

### **The Paediatric Rheumatology team from NHS Highland** based at Raigmore Hospital Inverness.

Jane Kelly, Mum to Eva who has JIA, said this of the team in her nomination for the award: *"My daughter has received consistent and caring support from the Inverness team for over 14 years. As she prepares to transition to adult services, we'd like to acknowledge the phenomenal and increasing paediatric rheumatology support we've received. In all the JIA ups and downs my daughter (Eva) has been treated as an individual whose opinion and experience matters. The commitment shown, and the links to specialists across Scotland, has meant the service we have received has been speedy, responsive and inclusive. We are remote geographically, but the quality of*



*care means we do not feel left out or neglected in anyway. As a parent I have appreciated the 24/7 access to information, advice and care. Eva knows them, they know her, and above all the team go above and beyond to promote her well-being".*







# Research supported during 2022



NRAS undertakes its own social research on different aspects of the impact of rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) on those who live with it as well as their families and carers. This research helps us to develop and deliver services to best meet the needs of all those affected by these conditions as well as campaign to effect change with government, the NHS and those who commission health and social care services. A key piece of social research which started in 2022, sponsored by Inmedix, was 'Stress Matters' and was a hands-off educational grant. The project aims to enable a better understanding of how stress can trigger immune responses within the body and expand on how patients and their rheumatology team can work together to reduce stress and its adverse impact on inflammatory arthritis. The project started with a survey developed by NRAS with input from Emma Caton, Research Assistant, King's College London to gather lived experience of how stress impacts inflammatory arthritis as well as insights into what kind of support, if any, had been sought/offered that helped (or not). A key output of the survey is a report to be published in 2023 and the development of a patient-facing publication later in the year.

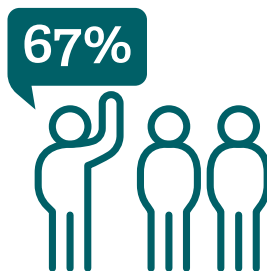
The Stress Matters survey elicited 1,250 responses within 10 days indicating the level of need in this area and highlights the reach that NRAS has within the community. The research team collaborates with the Marketing & Communications department to get research messages out via email, website, eNews, social media and HealthUnlocked. We posted the Stress Matters survey on NRAS media, with email being very successful, reaching 12,000 people living with RA with a 5% response rate that same day. We drove nearly 750 people to our research webpage in the 10-day period that the survey was live. We have a great following on our social media as well as our online community HealthUnlocked. Staging surveys on our platforms opens the survey up to the wider community. The research team utilises these media channels with PhD students, pharmaceutical companies, product design agencies, as well as funded academic studies.



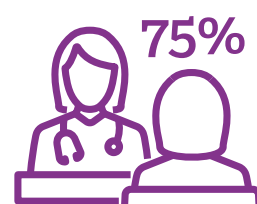
1265  
people completed the survey



56%  
Stress had negatively impacted their RA



67%  
Not asked at time of diagnosis about stress in their lives



75%  
Not asked routinely about emotional/mental health in consultations

Some other key research projects worked on throughout 2022, where NRAS provided Patient and Public Involvement and Engagement (PPIE) and which will continue into 2023 are:

<b>Research Title</b>	<b>TaILOr – trial of patient-initiated care leading to improved outcomes in rheumatology.</b>
<b>Principal Investigator</b>	<b>Prof. Laura Coates, University of Oxford</b>

TaILOr is a study encompassing a clinical trial across more than 40 hospital sites to determine the clinical and cost effectiveness of a Patient Initiated Follow Up (PIFU) strategy compared to traditional follow up care pathways in people with inflammatory arthritis treated with long term immune suppressing therapies.

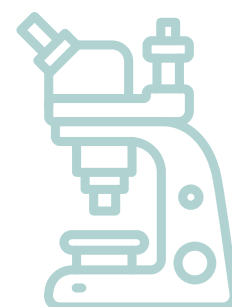
<b>Research Title</b>	<b>MISSION-RA – Moving to Support Sustained Improvement of Outcomes in Rheumatoid Arthritis.</b>
<b>Principal Investigator</b>	<b>Dr. Sally Fenton, University of Birmingham</b>

The study is to develop a new way to help people with RA increase their daily physical activity. This will be achieved through the design of a wearable activity tracker linked to a smart phone app. The tracker and MISSION-RA app will be personalised specifically for people with RA using artificial intelligence. NRAS are a key partner with the University of Birmingham in this work providing PPIE patient leaders, patient panel recruitment involved at all stages of development including contributing to written materials, website development, leading focus groups, qualitative interviewing and prototype testing.

<b>Research Title</b>	<b>Developing trust and confidence between patients and clinicians in remote monitoring</b>
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Phase 2 of this work was funded by the Health Foundation, QLAB is part of a larger collaborative partnership which NRAS is playing a key role in called Digital Rheumatology (DR). Project managed and led by Health Improvement Scotland, this work involves the piloting of a Citizen Wallet (smart phone app which works across organisations and borders) in a sandbox environment. Built around a core, co-managed digital care planning tool, DR allows patients with RA to input information about their condition, that can be reviewed by their rheumatology care team, as well as the patient themselves, during and between remote or face-to-face consultations. When combined with the patient's clinical measures, this gives an assessment of their disease status not currently possible, representing a step-change in the management of these patients. Information can be viewed between appointments at critical times, for example if a patient is flaring and may need to be assessed rather than having to call a nurse helpline or wait much longer to be reviewed. Other key stakeholders such as third sector (NRAS in this case), community pharmacy and others can also be contacted by the patient using the Citizen Wallet on their phone. This work represents a new service delivery model and has the potential to improve outcomes in the context of outpatient transformation in a post pandemic NHS landscape.

As can be seen from the examples above of the kind of work we are supporting across the UK, the NRAS research team can offer UK clinical and academic researchers significant value in advertising studies through the research area on our website and providing multiple services from recruitment, survey opportunities, social media awareness raising to full PPIE involvement.





Sarah Watford  
Information and Support  
Manager



# New2RA Right Start service helping those in need

## Sarah's account:

The nurse referral came through to NRAS in mid-June 2022; the notes I had said that Denise had only been formally diagnosed a month or so ago, but was feeling overwhelmed, low and anxious, and could we make this call asap? We called Denise on 20th June to make the arrangements and the appointment was booked with me for 22nd June.



**Hi Denise, my name is Sarah, and I work for the National Rheumatoid Arthritis Society. You have been referred to our Right Start Service by your specialist nurse. Are you happy to participate and is now still convenient to talk?**



Denise updated me about her situation. She had been on hydroxychloroquine for about 3 weeks, as well as Naproxen, and was not noticing any improvement. This initial call lasted 55 minutes, and we covered a lot of information, from RA itself, to the medications, to diet and exercise. We then posted out a tailored package of information resources to her and agreed a follow up on the 12th August, and arranged for a volunteer to call Denise.

At the follow up call, Denise had been 9 weeks on her medication and was still no further forward. Whilst Denise was prepared to see the 12 weeks through\*, I suggested she call her specialist nurse IF after 12 weeks there was still no improvement in her symptoms, to see what they could suggest. We also talked about stress management, as this can negatively impact RA symptoms.

## Denise's Story:

Despite having lots going on in my life, I was extremely active with a very can-do attitude to things. Gardening, playing hockey, horse riding on occasions, walking for miles, an outdoor type of person, ate healthily and was never overweight. I'd never previously been ill in my life, hardly even ever had a cold with no real illnesses in my family. Longevity was the norm, my grandma lived until almost 98 and only took a calcium tablet, no other complications. In Jan 2021, both my parents and I had COVID-19 and we were all extremely poorly, whilst my mum recovered, my dad was admitted to hospital, but we didn't see him again.... I was too ill to do anything, my mum went into nursing care. ....

In June 2021 I was struggling with my ankle, my hands and fingers, this prompted me to go to my GP and get blood tests and was diagnosed with RA. I was working at a local estate agent at the time, and I was at work when the GP rang me, I really didn't fully comprehend what RA was. I eventually had to stop working as my job was out in the field and I was struggling with pain every waking moment. I was referred to NRAS Right Start Service by my RA nurse.

## What was my experience of the Right Start Service?

I feel it has been a great service, they listen and are very empathetic. They definitely understand how you feel, how RA affects you, they are knowledgeable about the medications and try to suggest possible solutions or just a way forward..

They just know..... They are always just a phone call away.

When you go from being a normal part of society to what feels like a former shadow of yourself, it's a very overwhelming & lonely place. NRAS is an immediate response. I never feel I am dealing with this condition on my own. I feel they really do care. They have a lot of knowledge on this condition and offer help, emotional support & advice wherever possible and they are very patient.

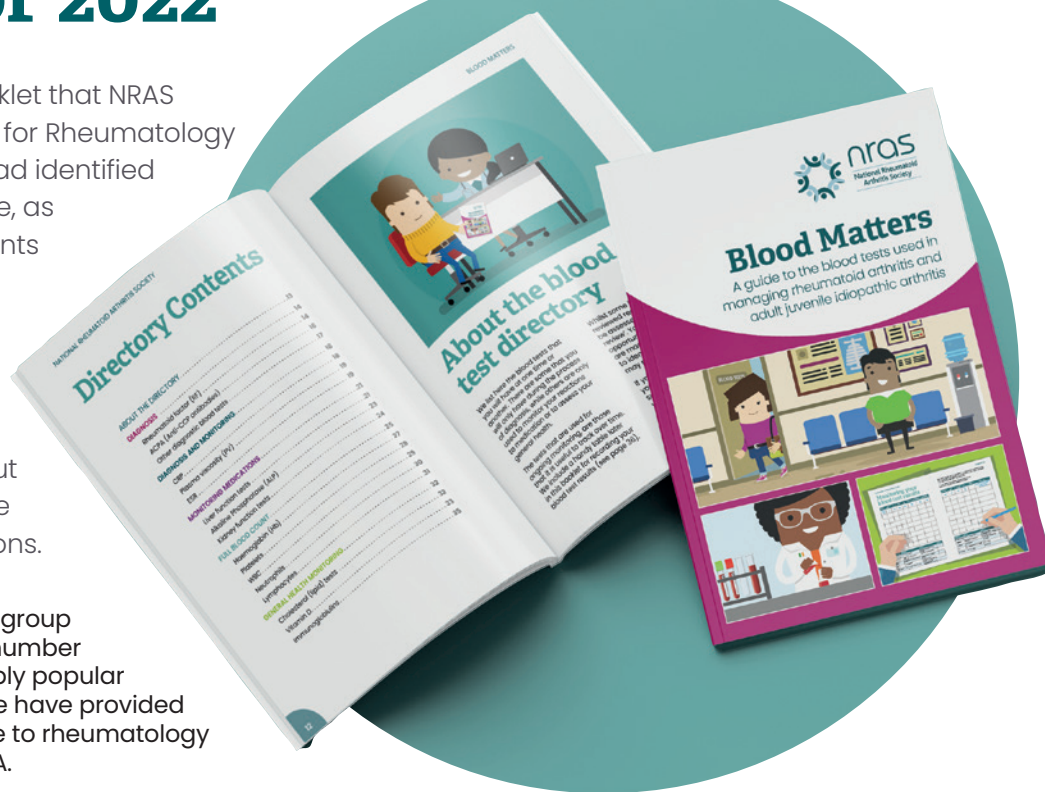
\* Most disease modifying medications take about 12 weeks to start really showing efficacy.



# Our popular brand-new resource for 2022

'Blood Matters' was a new booklet that NRAS launched at the British Society for Rheumatology conference in April 2022. We had identified a real need for such a resource, as health professionals and patients were finding it increasingly difficult to access supplies of the methotrexate blood monitoring booklet. It was apparent that more information was required about the various blood tests that are conducted, and for what reasons.

We were delighted to work with a group of patients and clinicians over a number of months to develop this incredibly popular resource and since the launch, we have provided thousands of this unique resource to rheumatology units and individuals living with RA.



What makes this publication unique, is that no other resource exists that provides information on what blood tests may be used to aid diagnosis; which ones are for monitoring disease progression; which ones are for monitoring side effects of medications and blood tests are used for assessing risks of co-morbidities. For an individual living with inflammatory arthritis, we strongly believe that understanding of blood monitoring and the test results will empower people to engage more effectively with their health professionals and have more influence in their disease management. This has never been more important than it is now, with the introduction of Patient Initiated Follow Up (PIFU) pathways, that patients themselves can monitor and understand their own test results, hence know when to seek appropriate help.

## RAAW 2022 - #RAFactOrFiction Quiz!

In 2022, the theme of RA Awareness Week 2022 was our brand new #RAFactOrFiction Quiz. This was a week to focus on dispelling the myths that surround this incurable invisible condition.

We created a series of statements on RA, some of them were not too serious, and the idea was to get as many people to take the quiz as possible. As the RA community are only too aware of the misconceptions that other people have around inflammatory arthritis, we wanted people to share the quiz with their friends and family to see how well they knew the condition. From questions such as, "Can pets, like cats, get RA?" and, "Does smoking raise your chances of developing RA?", the idea was to teach people about the condition and also start conversations about it.

The quiz was promoted on digital radio, website banners and on social media, with various visuals to catch the eye (examples).

A staggering 3389 people took the quiz. We were so pleased with the result, the quiz is still available to try for yourself! Visit [nras.org.uk/factorfiction](https://nras.org.uk/factorfiction)





Patricia (Trish) Sidgwick,  
1950 – 2021



Peter and his grandsons



Peter and Barry Hawkins  
(Snooker professional)



On the mend



Peter and Patricia

# 230 miles for Patricia Sidgwick

## From Hednesford to Stratford-On-Avon, Oxford, Slough, Blackheath, Maidstone and finally St Margaret's Bay...

Fundraising and supporting the charity can come in many different forms. Peter Sidgwick chose to pay tribute to his dear wife, the late Patricia (Trish) Sidgwick through an eventful, 6-day cycling trek across the UK, at the grand age of 74 and a half.

He began his cycling journey on 25th May 2022 and it took him 6 days to travel down to St Margaret's Bay, from his hometown Hednesford. With the help and support of his two daughters, his grandchildren and son-in-law, Peter was able to trek across the UK in all different weather conditions, routes and locations.

Four days into his journey and in London, he pedalled towards his next stop at Victoria Coach Station. He explained, "This was a very important point in my journey because it was there, 50 years ago, that I would meet my beloved girl when she came down for weekend stays at my parents' house in London. This was before we were married and settled in Hednesford. It was a very emotional moment for me as I stood outside the magnificent Art Deco entrance and thought of my girl."

Peter was also able to re-connect with old friends and colleagues on his journey, with which he enjoyed reminiscing the "good old days," childhood pranks and happy times in London.

For the final stretch, Peter was joined by two of his dear friends, Simon and Stuart. "Ahead of us, I could see an overhanging cow parsley plant which Simon swerved to avoid. I attempted the same manoeuvre, but my bike shot off the curb and sent me crashing onto the road surface. Amazingly, the fast-moving traffic managed to stop in time, so I was not run over. Lucky, or what! But not that lucky as I had hit the deck with enormous force. I lay on the tarmac unable to move, with blood pouring from my nose and an agonising pain in my right arm and shoulder. I was driven to hospital by my second daughter, where the orthopaedic doctor tended to my dislocated shoulder."

You may think that the whole trip was a foolish endeavour at my ripe old age of 74 and a half and it probably was. But I did it! I guess it was a kind of pilgrimage back to the place where she died so suddenly but where we had fourteen years of happiness together.

It was also my way of trying to make amends for my failure to properly face up to her rheumatoid arthritis (RA), my failure to take account of her fatigue, her need to walk slowly, and the pain of the flares in her joints. I did at least appreciate how much she loathed the literally sickening after-effects of her Wednesday dose of methotrexate.

Mercifully, neither one of us understood just how RA can increase the possibility of a heart attack. Mercifully too, she was taken in an instant, at least I have to believe that was the case.

I would like to say thank you to my fantastic family for all their support and loving care of me not just during this ride but in all the months since my girl was taken. Thanks also to all at the National Rheumatoid Arthritis Society, especially Bronwen and Emma.

Finally, I must give thanks for our 52 years together and our 49 years of marriage. My girl, Patricia (Trish/Mum/Granny), was the kindest, most loving person that I have ever known. I did not deserve her but despite my many flaws she chose me and I will be forever grateful that she did.

She was the love of my life and she lives on in my heart and those of my girls and grandkids for ever."

With the support and generosity of his family and friends, Peter has raised a wonderful **£4743.46** in memory of his dear wife. Thank you so much, Peter, for thinking of NRAS and well done on an amazing achievement!



# FIRST EVER JIA Awareness Week

NRAS held the first ever JIA Awareness Week from 13th to 17th June 2022, on the theme of #SameJIADifferentDay. Each day a new short film was released on our social media platforms highlighting the fact that no two days are the same for those living with JIA due to the fluctuation and diversity of symptoms.

During conversations with families, children and adults living with JIA, a common theme kept coming up – **‘why can’t people understand that JIA is a fluctuating condition?’** Due to the lack of understanding of this disease some children have been asked whether they are faking it. They told us, ‘We (NRAS) need to help teachers to understand how diverse and fluctuating the disease is from day to day, I’m not lying about my symptoms, they do change.’ We attempted to show that no two days are the same living with JIA, so we created the campaign #SameJIADifferentDay.

In the short films, a good day with few symptoms is juxtaposed with a day with a bad flare-up by showing a teenager or adult with JIA engaging in the same everyday task or activity but with very different outcomes. All these films can be seen on our YouTube channel – scan the QR to visit the page.



Debbie Wilson,  
Young Persons' Project Manager



Throughout the week, many individuals, companies and charities got involved in #SameJIADifferentDay, by sharing, liking and re-tweeting on social media about the research and work they do for JIA and by sharing their stories.

Pam Duncan-Glancy MSP, spoke about her own experience of living with JIA on media channels and tabled a motion in the Scottish Government. Nicola Sturgeon praised the work of charities who support those living with JIA.

Other events also took place that week, including a JoinTogether JIA Parent/carer group online meeting, a Facebook Live session and ending the week with the annual #WearPurpleForJIA day which saw social media awash with purple.

The results of the week showed that engagement across all the JIA-at-NRAS platforms had increased by 189% with a 387% increase in Facebook page visits and an increase of 168% of profile visits on Instagram. Some of the comments left on social media were:

*Thank you all for sharing your stories. I can completely relate, & it's nice to hear from other people going through the same things. I was diagnosed young & no one thought I could have arthritis as I was too young!.*

*Thank you for your empowering work & sharing JIA experience. Your work is making the very important difference in JIA sufferers' lives.*

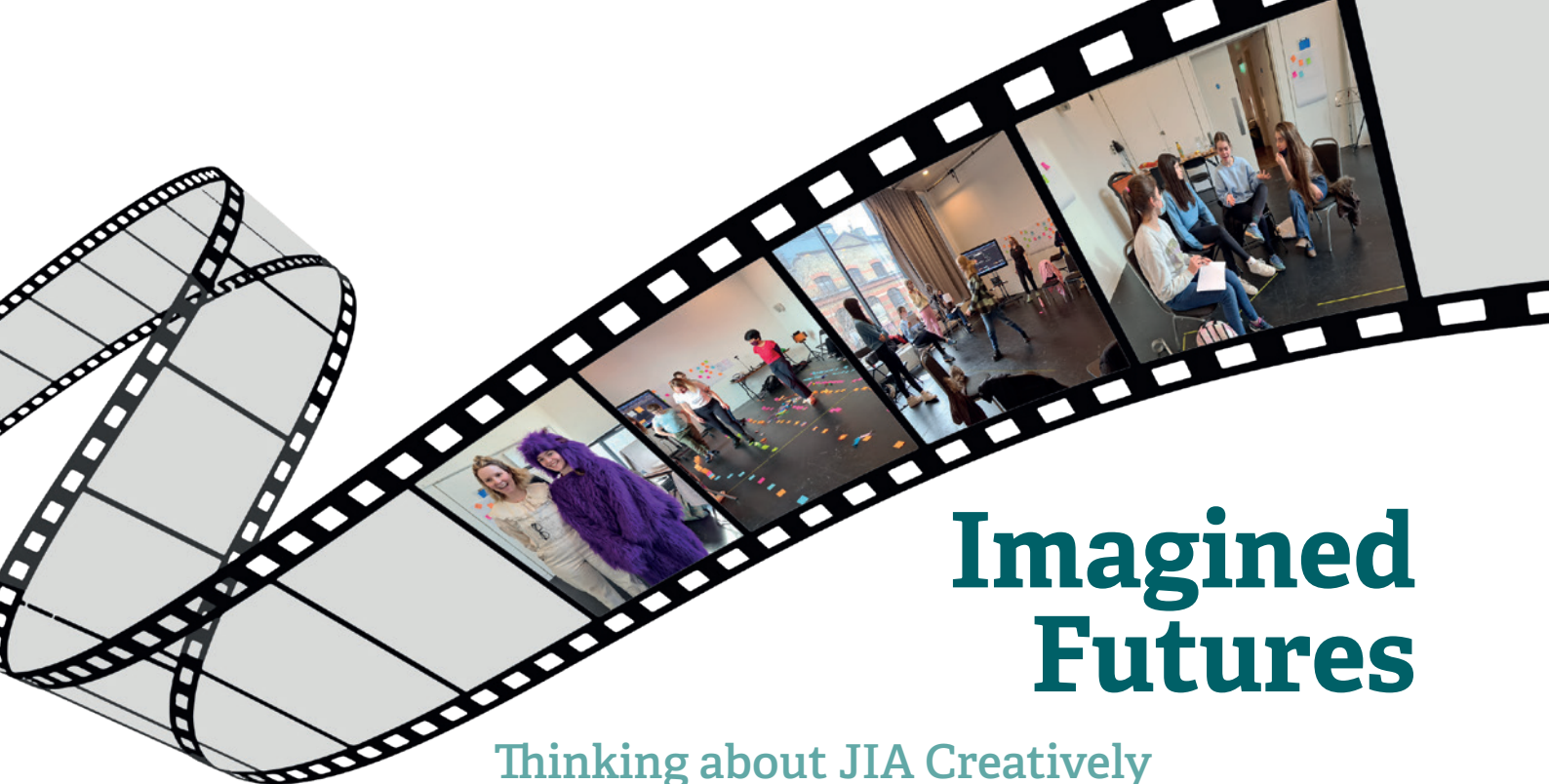
*This is important recognition that a condition diagnosed in early childhood can continue to impact on your life as an adult.*

*"Simple video that speaks volumes".*

*I'm loving the social media posts for #SameJIADifferentDay, that is exactly what my child is like.*

JIA Awareness Week will be back again on 3rd – 7th July 2023, #BustingJIAMyths.





# Imagined Futures

## Thinking about JIA Creatively

Anna Woolf is a researcher and theatre maker with a keen interest in digital storytelling. The PhD that Anna is undertaking is in relation to young people with JIA transitioning into adult care. Creative health is a field in which she is particularly interested, as a way of working in collaboration with people experiencing health conditions. What is important to young people with JIA in their developing lives, and what are they worried about? The use of creative arts offers a different platform for young people to communicate what's going on in their lives and to demonstrate how they and others understand and perceive their condition and their emerging identities.

The Imagined Futures project was funded by a grant from Children in Need and devised by Anna and NRAS. During the February half term, 2022, we worked with seven young people living with JIA, at the Unicorn Theatre in London. Working in this fantastic creative space alongside filmmaker Chuck Blue-Lowry, we made short films, TikTok content and played games that enabled young people to express their thoughts and dreams. The young people were brilliant at showing and expressing a range of feelings and scenarios about their lived experiences of JIA. What was most powerful was the temporary community that we built during the week – the young people encountered other people just like themselves, experiencing the same problems and came up with creative and fun ideas together; it was incredibly powerful.

At the end of the week, we held a sharing event enabling parents and carers to watch back all the stories they had created, filmed, and edited and to be a part of a final celebration. There were very few dry eyes as this emotive content was shared with their families.

We went on to develop online sessions during the summer, where young people could still engage creatively with ideas around their JIA, and health, and feel empowered to continue sharing the breadth of their collective experiences, all with other young people just like them. Four young people joined these online sessions and even though we didn't have the space of the theatre, this didn't restrict the young people's ability to openly discuss their experiences of living with JIA. Their own 'manifesto' was created to share what they would like other people to know about what it is like to live with JIA.

**All the films/TikToks are on the JIA YouTube Channel [jia.org.uk/youtube](https://jia.org.uk/youtube)**



# Thank you from NRAS

We are very grateful for the support we have received in 2022 and on behalf of the thousands of people NRAS has been able to help and support we'd like to say Thank You.

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.

Our CEO, Clare Jacklin, would like to give special thanks to every individual, group, company and organisation that supported NRAS.

Specific acknowledgment is due to the following organisations for sizeable donations and grants given to NRAS during 2022:

Arnold Clark Community Fund	Sciensus
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The Eveson Charitable Trust	Galapagos Biotech Ltd
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The Hobson Charity	Inmedix Inc.
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The Marsh Charitable Trust	Ono Pharma UK Ltd
The Michael and Anna Wix Charitable Trust	Pfizer Inc.
The Vandervell Foundation	Roche Products Limited
The William and Mabel Morris Charitable Trust	UCB Pharma Ltd
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We would also like to thank all the NRAS Groups throughout the UK who continued to support our work with donations.

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

To all those individuals, friends and family members, who lost a loved one in 2022 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 difficult time.



# JIA Mental Health Collaboration

JIA-at-NRAS along with other charities, CCAA, JAR, SNAC and Versus Arthritis, as well as the British Society for Rheumatology (BSR), developed an online survey for those affected by juvenile idiopathic arthritis on the topic of mental health services and support. The survey was established due to a shared need to do more to raise the profile of the importance of providing mental health support in paediatric rheumatology.



We know that children and young people with arthritis may experience various challenges while managing their condition that can affect their mental health including worry about medications, coping with injections and much more. The aim of the survey was to help the alliance of charities, and the BSR, champion and advocate for improved psychological support services for children, young people and their families across all four nations of the UK.

The survey results were presented by Dr Polly Livermore (Rheumatology Matron / NIHR BRC GOSH Clinical Academic Programme Lead, Professional NRAS Volunteer) at the BSR PARC in Brighton in September 2022. The presentation was very impactful, with the qualitative quotes read out by different audience members. The stark statistics showed that not only does a JIA diagnosis impact a child or young person, but it affects all members of the family including siblings. 82% of parents said their child's diagnosis of JIA impacted their own mental health.




The full analysis of this survey will be published in 2023. Work is continuing with all charities to campaign for a child psychologist in all tertiary paediatric units.



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**NRAS is committed to minimising the impact of its activities on the environment. All paper used in this publication is FSC (Forest Stewardship Certified) and sourced from sustainable woodlands.**

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