

**YOUR** newly named Members' Magazine!

# NewsRHEUM



**nras**

National Rheumatoid  
Arthritis Society

**SPRING 2020**

As a Member of  
**National  
Rheumatoid  
Arthritis  
Society,**  
feel secure in the  
knowledge that  
we are always  
here to support  
you and those  
close to you  
every step of  
the way.



*"I've used the helpline  
a couple of times over the past  
week or two, I really wanted to say  
thank you so very much, these early  
weeks have been difficult and I would  
be quite lost and utterly  
overwhelmed with everything  
if I hadn't got your help."*



**NRAS LOTTERY**

Join the NRAS Lottery  
*Win up to £25,000 Every Week*



**HEALTH  
UNLOCKED**

See inside for more info



**COVID-19**

Statement on page 4



By Clare Jacklin

NRAS CEO

# Dear Members

As you can imagine, my first letter to Members, written in January, was very different to what you are reading now. Now into the new decade, it has been a trying time for everyone due to the global pandemic that is Coronavirus. Here at NRAS I want to assure you we are doing all we can to support YOU, our Members and the wider RA and JIA communities. Our helpline has been inundated with calls from many worried people living with RA and we are keeping our Coronavirus statement on the website as up to date as possible.

With most of our events and meetings cancelled or postponed considerably, we will be doing all we can to find other innovative ways of connecting and communicating with you. Luckily in this day and age and all the fantastic digital opportunities, there are many ways we can 'virtually' keep in touch! Please keep an eye on our website and social channels for any webinars, Facebook live Q&As and videos, to keep you up to date. The NRAS HealthUnlocked community has grown vastly in the last month and is there to offer and receive support and friendship to others during this time of heightened anxiety.

I promised in the winter issue to share with you some of my hopes and dreams for NRAS. So, while I don't have 2020 vision (quite the opposite my left eye is very weak!), here's a brief insight into what I hope is ahead for NRAS in the next few years when we are out the other side of this pandemic.

NRAS has been leading the way since 2001 for the rights of those living with RA and JIA to have access to the right care, at the right time provided by the right people. A challenge that is still ongoing. Despite so many promises and policies being made by various stakeholders over this last decade, there is still evidence of the UK being victim to postcode lottery health care. Most recently we were alerted to the issue in some areas of the country where restrictions were being imposed on the number of biologics (advanced therapies) that an individual was allowed to be prescribed i.e. 3 or 4 strikes and you're out. While physicians were clearly identifying that their patient had not responded to the first 3 or 4 RA medicines and needed to try the next NICE approved therapy, funding restrictions were being implemented, resulting in the patient being left on basically what could be called 'palliative' care. NRAS felt this was wholly unacceptable and upon further investigation, discovered there was some misunderstanding and misinterpretation of the NICE recommendations for RA treatment pathways. We then asked

for some clarification from NHS England and were delighted when in January, they issued a statement that makes it very clear that there should be NO restriction on the number of recommended and approved medicines that a physician can prescribe for their patient, in an attempt to bring their disease under control. You can read the full statement on our website at [www.nras.org.uk/news/important-statement-from-nras-about-access-to-medicines](http://www.nras.org.uk/news/important-statement-from-nras-about-access-to-medicines).

Also in 2020, NRAS will be launching our two new websites (one for NRAS and one for JIA at NRAS), as well as the first of our e-learning modules. All of which along with our informative resource booklets are aimed at giving people living with RA or JIA the knowledge, tools and confidence to keep on demanding what is rightfully theirs...the right to be part of their own care and treatment. You can play your part in spreading the news of these new resources by sharing on Facebook, telling your rheumatology team, re-tweeting, or plain old passing on the message to a friend, after all it's good to talk! Naturally due to the circumstances these have been delayed slightly, but we are still working hard on making this all happen this year.

We are all in this together, and as you may know, as a charity we will be particularly hard hit with many of fundraising events being cancelled or postponed. This is where I reach out to you, NRAS Members, in asking that if there is any way you can help your society bridge this difficult time to ensure we are able to sustain and upscale our NRAS support services to meet the growing demand of 100s of requests every day. A donation online or over the phone big or small will make a difference. While self-isolating why not connect with others by holding a 'Virtual' Tea Party. A Facebook Birthday Fundraiser to connect with others if they can't be with you on your birthday? Or playing the NRAS lottery is another great way of giving that little extra. Your support in our hour of need will ensure we're there for the many thousands that are reaching out to us in their hour of need.

Stay informed, stay in touch and most importantly stay safe

Warmest regards to you all

A handwritten signature in black ink that reads "Clare". The script is fluid and cursive.

Clare  
Chief Executive

# Members' MAGAZINE

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

Editors of this issue:  
Tracy Bracher and Eleanor Keenan

## Lifetime Membership

Lifetime Membership of NRAS is a great way to know you will always be kept up to date on all the latest news from the charity, current research and updates on medication AND you will be part of something incredibly special, the NRAS community. You will also be supporting future generations with RA and JIA, it's a great legacy, and as part of that legacy your name will go on our Lifetime Member page of our new website if you choose.



*“I joined NRAS as a life member as I was very impressed with the local group I attended, they were so organised and offered a wide range of information booklets. When I read more about the organisation and went online, I was really impressed with the quality of the information and was signposted to the online community too. Having been diagnosed only 6 months ago I found this information invaluable so felt I just had to support such a great organisation”*

*“What appealed to me about NRAS and made me want to join as a Lifetime Member was their connection with people at grass roots level, the work the society is doing and the quality of the information via the webinars and the magazine too”*

Comments from new Lifetime Members

Lifetime Membership is £500, and you receive all the benefits of Membership for life plus we will send you a NRAS pin badge to wear with pride.

## 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.

## Name YOUR Magazine!

We asked you in the January Members E-News to give us your ideas for a name for your NRAS Magazine. Thank you to everyone who contributed and you can see from the lovely front cover the name chosen was NewsRHEUM. We hope you like it!!!



# Coronavirus: What we know so far

We understand that many people with RA or JIA and their families may be very concerned at the Coronavirus epidemic described by the World Health Organisation as 'a global public health emergency'.

Given the fast moving pace of government announcements regarding Coronavirus, we have updated our statement on Monday 16th March and on 23rd March have added in an FAQ section following our first Facebook Live event on the topic.

## What is Coronavirus?

Coronaviruses are a common group of viruses known to infect both animals and humans. At the end of 2019 a new strain of coronavirus was identified as causing a cluster of pneumonia cases in Wuhan City, China. It causes a respiratory illness known as COVID-19 that most frequently consists of mild symptoms of persistent cough, fever and shortness of breath. In a minority of cases, COVID-19 can lead to serious problems like pneumonia or even death.

## Useful links:

### Key websites where you can get 'official' information

Please refer to the following organisations' guidance for further information on the outbreak and how to protect yourself. Please note that the advice about what to do may vary between the devolved nations.

NHS  
<https://www.nhs.uk/conditions/coronavirus-covid-19/>

<https://www.england.nhs.uk/coronavirus/secondary-care/other-resources/specialty-guides/>

- NHS 111 has an online coronavirus service that can tell you if you need medical help and advise you what to do: <https://111.nhs.uk/service/covid-19> (available in England, Scotland, Northern Ireland and Wales)
- England: Public Health England has a blog on the virus which they are updating regularly <https://publichealthmatters.blog.gov.uk/2020/01/23/wuhan-novel-coronavirus-what-you-need-to-know/>
- Scotland: Health Protection Scotland are updating their website with the latest news daily: <https://www.hps.scot.nhs.uk/a-to-z-of-topics/covid-19>
- Wales: Public Health Wales are updating their website with the latest news daily: <https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19/>
- Northern Ireland: Public Health Agency are updating their website with the latest news daily: <https://www.publichealth.hscni.net/>

British Society for Rheumatology: <https://www.rheumatology.org.uk/news-policy/details/Covid19-Coronavirus-update-members>

EULAR (European League Against Rheumatism)  
[https://www.eular.org/eular\\_guidance\\_for\\_patients\\_covid19\\_outbreak.cfm](https://www.eular.org/eular_guidance_for_patients_covid19_outbreak.cfm)

### Government advice links

- <https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public>
- <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>
- <https://www.gov.uk/foreign-travel-advice>
- <https://www.gov.uk/government/publications/guidance-to-employers-and-businesses-about-covid-19/guidance-for-employers-and-businesses-on-coronavirus-covid-19>
- <https://www.gov.uk/government/publications/guidance-to-employers-and-businesses-about-covid-19/covid-19-guidance-for-employees>
- European Medicine Agency: <https://www.ema.europa.eu/en/news/ema-gives-advice-use-non-steroidal-anti-inflammatories-covid-19>
- <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>

Are people with Rheumatoid Arthritis or children/young people/adults with Juvenile Idiopathic Arthritis at greater risk i.e. in the 'vulnerable group' referred to in Government advice?

**Answer** – Yes meaning you should be from 20th March self-isolating as instructed by the Prime Minister on Monday 16th March.



Are people on biologic/biosimilars/ advanced therapies at higher risk than those on conventional DMARDs? (if you are not sure about the distinction between these types of medicines you can order for free our Medications in RA booklet or visit [www.nras.org.uk/ra-medication](http://www.nras.org.uk/ra-medication))



The following is taken from the NHS England guidance <https://www.england.nhs.uk/coronavirus/secondary-care/other-resources/specialty-guides/>

**Immunosuppressant or indicative medications**

Use of immunosuppressants (conventional or biological) is probably more relevant in defining risk rather than the underlying individual disease. Many patients are on more than one of these drugs, thus increasing their overall risk. All of the drugs listed [in the link above] would put an individual at an increased risk. The presence of additional risk factors would put them at a high risk or very high risk. These risk factors include: high doses; use of multiple immunosuppressants; active disease; presence of other co-morbidities. Some patients with very active disease, e.g. newly diagnosed may be at very high risk.

The following examples illustrate this:

- female aged 35, RA, no co-morbidity on methotrexate – increased risk
- female aged 35, RA, no co-morbidity on etanercept – high risk
- female aged 75, RA, COPD and renal impairment on etanercept – very high risk.

Patients must **not** suddenly stop prednisolone.

Patients can continue hydroxychloroquine and sulfasalazine if they are infected with coronavirus.

If a patient is infected with coronavirus, they should **temporarily stop** their conventional DMARD and biological therapy. They should contact their rheumatology service for further advice about when to restart treatment.

# Coronavirus: What we know so far *continued*

## What can I do to keep myself safe?

We recommend following the current government and Public Health England advice and taking precautions such as regular handwashing, covering your mouth and nose when coughing and sneezing, and avoiding close contact with people who are unwell. We should all now be social distancing and by the time this goes to print we may well be in a very different environment and under even stricter restrictions

## What to do if you feel unwell

If you have an underlying condition such as RA or JIA and feel unwell or notice any of the symptoms mentioned above, you should call NHS 111 and seek further advice on whether you need to be tested be sure to tell them what medications you are on and what condition you have including any comorbidities. If you are very unwell with fevers, as is the case with any infection, follow the practice you have been advised by your rheumatology team which would normally be to pause immunosuppressive therapy such as biologics/biosimilars or JAK inhibitors, except steroid, for the duration of the infection and until you feel well. It is very important not to stop steroids (prednisolone) abruptly as this could make you unwell. If possible, discuss details of your individual case with your GP or the Rheumatology team. This may be difficult to do during this crisis but many units and GP surgeries are doing telephone consultations rather than face to face during this time of capacity issues.

Further information on what to do can be found here:

<https://www.nhs.uk/conditions/coronavirus-covid-19/>

As per normal advice (with or without the threat of coronavirus), for people who are immunosuppressed, influenza and pneumococcal vaccines are recommended. If you have not had your annual flu vaccine we would recommend that you do so as soon as possible and this can be arranged via your GP or Pharmacist. People aged 65 and over only need a single pneumococcal vaccination. This vaccine is not given annually like the flu jab. People with a long-term health condition may need just a single one-off pneumococcal vaccination.

For more information about vaccines, visit [www.nras.org.uk/statement-about-flu-vaccines](http://www.nras.org.uk/statement-about-flu-vaccines)



## Contacting NRAS

As you might imagine, our helpline is receiving a hundreds of calls most days which is unprecedented so you may experience some delay in getting a response. Bear with us we are doing our very best with limited resources. So that you get the information you need from us quickly as possible, here are some tips:

1. People who don't have symptoms of the virus, haven't come into contact with anyone and are otherwise well (apart from their RA/ JIA) can get their questions answered by reading the information in this bulletin on our website and on the other official sources of government information listed above.
2. Anyone who believes they have the virus or may have been in contact with someone who has the virus should follow the advice above, under 'What to do if you feel unwell'.

It is important to recognise that the situation is changing not daily but hourly so all this information was correct at the time of going to print. We will be regularly updating the guidance on our website as new information becomes available.

## STOP PRESS

Scottish Paediatric and Adolescent Rheumatology Network (SPARN) has released on 24th March advice for Parents and Patients about COVID19 and we have posted this on our JIA website as well as on our COVID19 landing page. <https://www.jia.org.uk/news/coronavirus-what-we-know-so-far> or [www.nras.org.uk/coronavirus](http://www.nras.org.uk/coronavirus).

# NRAS Challenge Events



## Royal Parks Half Marathon

Sunday 13th October 2019

'It was a bit of a rainy day, but the atmosphere was great!'

Both Rachel and Lucy completed the Royal Parks Half Marathon in just 2hours and 20mins and raised an amazing

**£2,175**



Rachel Heath & Lucy Begg

**A big thank you from NRAS.**

## Everest Base Camp Trek

Monday 4th November 2019 – (2-week trek)

'I was diagnosed with RA – an autoimmune disease that attacks your joints. It can affect anyone at any age. I'm extremely lucky and grateful that I can manage mine without much discomfort, however some people suffer extremely badly, and are in continuous pain daily. As the theme for this year's Rheumatoid Arthritis Awareness week is that RA can affect anyone at any age, I've decided to try and increase awareness of RA and raise some funds on my trek'

Nicola raised a fantastic **£1,323**



Nicola Cromwell with her husband



## Group Santa Run

Victoria Park, London,  
Sunday 8th December 2019

'We have chosen NRAS as my Mum suffers from rheumatoid arthritis and is going through a really tough time at the moment so we are trying to spread a bit of Christmas cheer and put a smile on her face going into the festive season'. (Charles Lawton)

They raised an amazing

**£1,909**



Lily Fitch, Charlie Collins, Harry Greenway, Nonie Sanders, Nick Ward, Ed Harling, Joe Lawton, Sophie Rainer & Charles Lawton

# The Health Benefits of Singing

"I enjoyed it so much that I wished I could come every day! It is just such a treat to have some 'me' time and do something that is just fun, without any pressure."

Jane and Sing Your Pain Away choir



## Sing Your Pain Away

While the feel-good effects of singing have long been recognised, there's growing evidence that it can have a positive impact on a whole range of physical and psychological conditions, from reducing pain by producing pain-relieving endorphins, to reducing anxiety and lifting mood. Joining a singing group also has the social element of meeting other people and achieving something together.

Jane Gatfield, founder of "Sing Your Pain Away!" knows for herself the benefits of group singing, as she suffers from Ehlers Danlos Syndrome, a condition that gives constant pain and joint dislocations. "Over the years I have explored all

kinds of different ways to help me manage my pain, but I was really delighted when I found how much group singing reduced my pain as well as lifting my mood."

Sing Your Pain Away Christmas Big Sing



Jane found it difficult though to find a singing group that suited her needs – "there are lots of brilliant choirs locally, but I didn't want the pressure of having to get everything note perfect for performances, nor could I physically cope with long rehearsals or extended periods of standing or sitting. And so I decided to start my own singing group – and Sing Your Pain Away was born! We meet for an hour each week, we sing uplifting, feel-good songs and we laugh a lot!"

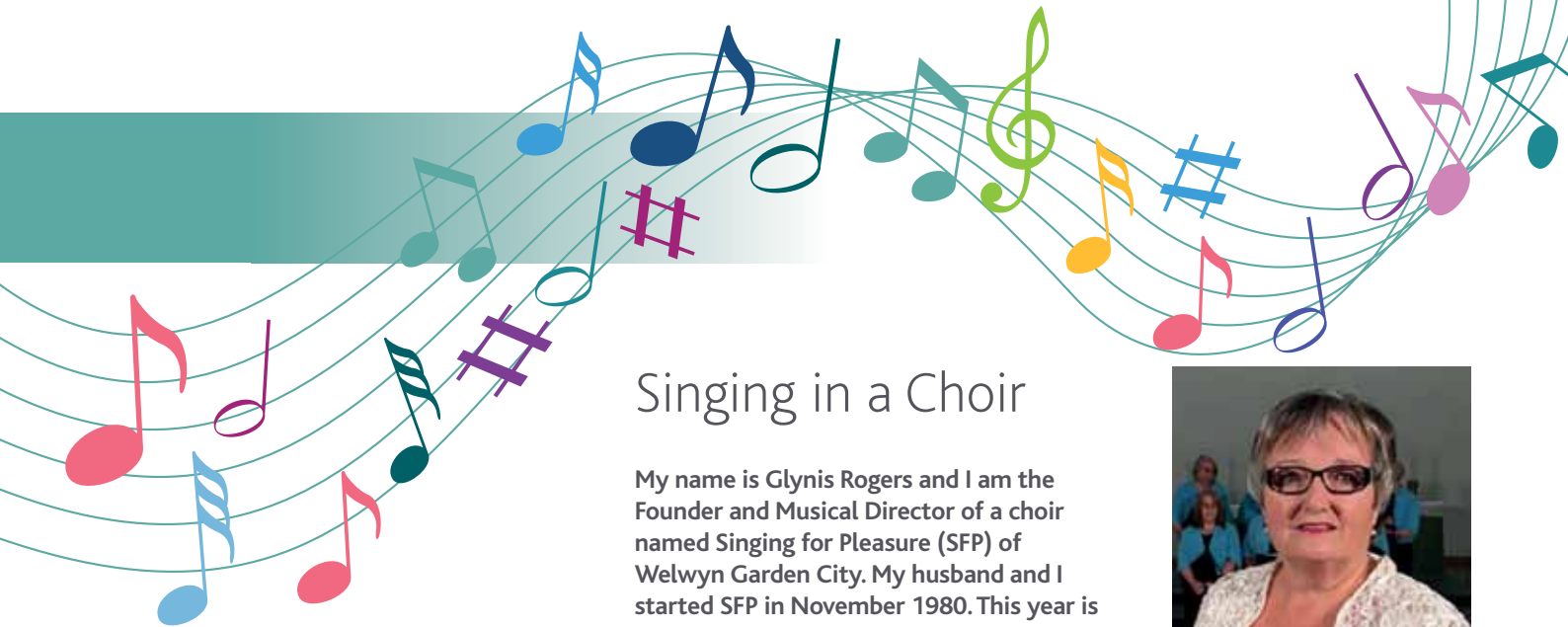
The concept has proved so popular that in the last year Sing Your Pain Away has expanded from 1 to 7 groups and now has classes in Bourne End, Gerrards Cross and Amersham in Bucks, Henley-on-Thames in Oxon, Twyford in Berkshire and Romsey in Hampshire, with more being added.

Classes are pay as you go, and open to all regardless of singing ability. Jane is also offering a free trial session to Members of NRAS.

For more information contact [jane@singyourpainaway.co.uk](mailto:jane@singyourpainaway.co.uk) or visit [www.singyourpainaway.co.uk](http://www.singyourpainaway.co.uk)







## Singing in a Choir

My name is Glynis Rogers and I am the Founder and Musical Director of a choir named Singing for Pleasure (SFP) of Welwyn Garden City. My husband and I started SFP in November 1980. This year is very important to me as the choir I started reaches its 40th birthday. During our 40 years we have raised over £200,000 for local and national charities.



### By Glynis Rogers

Musical Director,  
Founder and Chair of  
Singing for Pleasure of  
Welwyn Garden City



*Singing for Pleasure Choir*

Some choirs are now turning virtual! Sing with your friends online. If your choir is not meeting in person why not suggest this as an alternative!

Over 20 years ago, I was diagnosed with rheumatoid arthritis. As we all know, RA is a long-term chronic condition and we must all learn to adapt our lives and, in my case, I will not give in to it!

Cliff and I decided not to hold auditions, as we both felt strongly that there is a lot of "untapped talent" locally who would love to sing but are put off by the audition process.

Unfortunately, my husband passed away very suddenly 5 years ago, it was my choir and my family that kept me going. My RA just flared and flared. But, having to take a rehearsal meant a supreme effort on my part to even get out of my chair, let alone stand for 2 hours and teach everyone pieces of music in harmony.

I found during this process, something I had not really paid much attention to previously, that is the "feel-good" factor after a rehearsal, a kind of euphoric feeling and no pain. The endorphins released during singing meant no pain during rehearsals and for a while afterwards. This applies not only for us that have RA, but in all walks of life, whatever your situation. I watch my choir arrive for rehearsals, shoulders rounded, heads down, but by the end of the rehearsal, everyone is standing up straight, laughing, talking avidly with friends made within the choir. There is a general buzz in the air.

I would certainly advocate joining a choir, I find it the most relaxing part of my week

[www.singingforpleasure.org.uk](http://www.singingforpleasure.org.uk)

The endorphins released during singing meant no pain during rehearsals and for a while afterwards.

# Tributes to two amazing NRAS Volunteers



Beverley Newell (right) with fellow Oldham NRAS Coordinator Caroline Wallis



Sandra and Terry Almond

Towards the end of 2019, two long-standing NRAS Volunteers sadly passed away; Sandra Almond who was a Volunteer with the Bolton NRAS Group and Bev Newell, a Volunteer with the Oldham NRAS Group. Both Sandra and Bev (who both lived with rheumatoid arthritis) were founder Volunteers of their respective NRAS Groups, both giving so much of their time over the years to supporting NRAS and others living with RA. On behalf of everyone at NRAS, and all the people Bev and Sandra helped and supported over the years, we send our thoughts and condolences to the families. "No one is more cherished in this world than someone who lightens the burden of another." – Author Unknown. The tributes that follow were written by close friends and fellow Volunteers of Bev and Sandra.

Bev will be very sadly missed by the Oldham NRAS Group, our thoughts and prayers are with her family. Bev was a founder NRAS Volunteer Coordinator for the Oldham Group and was vital to its inception back in 2011. She was always positive about her rheumatoid arthritis and brought knowledge and communication skills that kept the group together and thriving.

Bev would always be the first to volunteer her time for the cause, manning NRAS stands at awareness days, offering her own home for planning meetings, and gave so much to help others.

She will always be remembered by this NRAS Group as smiling, jolly and dedicated to a cause which can only inspire us in her memory.

Sandra Almond, 3rd July 1946 - 4th October 2019

When I was asked to write a tribute to Sandra my first thoughts were, loyal friend, passionate about the Bolton NRAS Group, a driving force and very brave.

The Bolton NRAS Group was formed twelve years ago this October; there was a campaign at the Royal Bolton Hospital earlier that year. Consultants, Nurses and representatives from NRAS asked for volunteers to come together to run the branch with Sandra and another six of us said yes.

Sandra saw us through good and bad times. She organised trips out and wonderful Christmas parties; in later years arriving with fairy lights round her wheelchair. Sandra we will miss you - you were a legend, from your friends at the Bolton NRAS Group.

Both Beverley and Sandra's families chose donations in lieu of flowers in support of NRAS, each raising over £300. We are incredibly grateful to them for choosing to support NRAS in this generous way.

# Hertfordshire NRAS Group

Teresa Shakespeare-Smith – our NRAS Hertfordshire Group Co-ordinator, held a very successful reverse tombola stall at Langford Christmas fete on 14th December, raising £243.

Teresa explains "On fete day we run our 'reverse tombola' stall where tickets ending in 0- or 5- win consolation prizes such as small chocolate bars, but all the other tickets win a main prize which the winner chooses. They just decide which category they wish to pick from and help themselves. The reverse tombola can be quite addictive with people coming back again and again. Parents have complimented us on having the best value prizes."

Teresa has a loyal team of helpers - daughter Steph, son-in-law Lewis, son Greg, daughter-in-law Liz, her NRAS Healthcare Champion Nurse, Sharon Pearson, her mum Joan and her husband, Ray.

Teresa says "We attend 3 to 5 events per year and have raised £1,000 to £1,400. I buy prizes from car boot sales for a maximum of 50p each. I check and clean them all and divide them into categories. Sharon (NRAS Healthcare Champion) is a real Trojan and stays to the bitter end helping to pack away. At the Langford Christmas fete she even swept the village hall floor still dressed in her Christmas onesie!"

*Pictured is Teresa, her son Gregory White and Sharon Pearson.*



## We are Stronger Together

We know this is an unsettling time for many of you. We have had to postpone a lot of our events and put our groups on hold and there is a lot of uncertainty around at the moment.

***BUT NRAS is here for YOU and the RA community, YOU ARE NOT ALONE.***

Contact us on the helpline, chat with others on Health Unlocked, speak to us via Social Media and keep checking our dedicated pages on our website for the latest on Covid-19.

We have had a huge increase in helpline calls, emails and comments via our social media channels. We have upscalded our amazing helpline team and they are responding to as many of those questions as they can. Like most organisations and individuals we have been hit financially. To ensure we are here supporting the RA and JIA community for many years to come we have made as many cost savings as possible and are tightening our belt.

If you can, a donation of any amount will help us weather this storm and allow us to continue to support you.

You can donate on our website [www.nras.org.uk/donate](http://www.nras.org.uk/donate), donate via Facebook, call the fundraising team on 01628 823524, or by cheque (made payable to NRAS) and send it to NRAS, Ground Floor, 4 Switchback Office Park, Gardner Road, Maidenhead, SL6 7RJ.

*Thank you so much and stay safe.*



# Support NRAS by shopping online



It's a challenging time for many, but our work supporting those with RA and JIA goes on. At a time where you may be thinking of protecting yourself by ordering online, you may be pleased to know that any online purchases you make could also support us.

With Give As You Live, you're able to earn a donation equivalent to a % of your spend at 4,400+ online retailers, at no cost to you or us.

You can also support us by logging into your Amazon account through Amazon Smile – who will then give us 0.5% back on all purchases you make through their site. Such a simple click can raise hundreds of pounds for NRAS and something you can encourage your friends and family to do too.

Find out more on our website: <https://www.nras.org.uk/give-as-you-live> or <https://smile.amazon.co.uk>

*We'll be eternally grateful  
for your help.*



## NRAS Christmas Concert

Friday 6th December 2019

Such a spirited way to start the festive season - the NRAS Christmas Concert held at St Peter's Church, Maidenhead, a short walk from the NRAS Office. A perfect setting for a fantastic evening of singing, readings and music. Once again it was full house which created a cheery and joyful atmosphere.

We were delighted to welcome some special guests: The Right Honourable Theresa May MP; and The Deputy Mayor of Windsor & Maidenhead, Councillor Gary Muir.

NRAS would like to thank all the schools and musical groups that took part in the event and Mr Roger Witney, our Music Director for the night.

Every year we are supported by local businesses with donations or refreshments for the night, so thank you again to Michael Burbridge, Tesco Extra- Furze Platt and Sainsburys – Wootton Way.

***NRAS raised a fantastic total of £790  
from donations on the night.***



William Hayes - Compere



NRAS Ronnettes



All Saints Junior School Choir



Langley Grammar School Jazz Band

# Publication of new Quality Standards in RA by NICE

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



By Ailsa Bosworth, MBE  
National Patient Champion for NRAS

## NICE Revise the Quality Standards in RA in line with the updated Guideline NG100

In July 2018, NICE (National Institute for Health & Care Excellence) published an updated version of their Guideline for adults over the age of 16 with Rheumatoid Arthritis – NG100. I was a lay member of the Guideline Development Group and also had the pleasure of working on the NICE Expert Group who developed the updated Quality Standard reflecting the guideline in 2019. We had a tough job as we had to distil the guideline into just five quality statements instead of the seven we had previously developed. The new Quality Standard – QS33 - was published in January this year.

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. QS33 can be read in conjunction with the guidance and quality standard on patient experience in adult NHS services.

The quality standards provide concise recommendations against which rheumatology units can be measured. The current national audit – National Early Inflammatory Arthritis Audit, the NEIAA, is measuring the ability of rheumatology units in England and Wales to meet the previous quality standards prior to the update just published. You can see how your rheumatology unit is faring by referring to the British Society for Rheumatology 1st year report which was published last October visit [www.rheumatology.org.uk](http://www.rheumatology.org.uk)

*The following statement from the 2013 quality standard for rheumatoid arthritis in over 16s is still supported by the evidence and may still be useful at a local level, but is not included within the current quality standard:*

People with suspected persistent synovitis are assessed in a rheumatology service **within 3 weeks of referral**.

The new quality statements as of January 2020 are:

**Statement 1**

Adults with suspected persistent synovitis (inflammation of a synovial membrane) affecting more than 1 joint, or the small joints of the hands and/or feet, are referred to rheumatology services within **3 working days** of presenting in primary care. [2013, updated 2020]

**Statement 2**

Adults with active rheumatoid arthritis start conventional disease-modifying antirheumatic drug (cDMARD) monotherapy (just one medication) **within 6 weeks of referral**, with monthly monitoring until their treatment target is met. [2013, updated 2020]

**Statement 3**

Adults with rheumatoid arthritis are given **opportunities throughout the course of their disease to take part in educational activities that support self-management**. [2013, updated 2020]

**Statement 4**

Adults with rheumatoid arthritis and disease flares or possible treatment-related side effects receive **advice within 1 working day** of contacting rheumatology services. [2013, updated 2020]

**Statement 5**

Adults with rheumatoid arthritis have a **comprehensive annual review** that is coordinated by rheumatology services. [2013, updated 2020]

The NRAS New2RA Right Start service for people newly diagnosed with RA which you can read more about in this issue, enables health professionals to comply with NICE quality statement 3:

*“Adults with rheumatoid arthritis are given opportunities throughout the course of their disease to take part in educational activities that support self-management.”*



At the time of writing (mid-February) we have 27 hospitals referring their patients direct to NRAS for support, education and access to high quality self-management resources and NRAS is delighted to announce that the NRAS New2RA Right Start service is on the NICE Shared Learning website as an example of good practice.



# The BIO-FLARE Study

What is the study about?

BIO-FLARE stands for Biological Factors that Limit sustained Remission in rheumatoid arthritis.

Most people with rheumatoid arthritis (RA) would recognise both periods of stability (remission) and periods where the disease is active (flare). There is very little known about what causes flare and what exactly happens inside the joint when arthritis flares. The BIO-FLARE study hopes to address these unanswered questions so we can learn more about flare in RA. We also hope that our research will help to identify patients whose arthritis is stable who are more likely to be able to stop their medication without having a flare.

The study is run across three collaborating universities in Newcastle, Glasgow and Birmingham, each of which are part of the Research into Inflammatory Arthritis Centre Versus Arthritis (RACE). We aim to recruit 181 participants who have RA that is in remission on either methotrexate, sulfasalazine or hydroxychloroquine (or a combination of these drugs). BIO-FLARE participants stop their RA medications and are followed very closely for 6 months.

Based on earlier research, we predict that 50% will stay in remission at 6 months and 50% will have a mild flare in their disease, in which case they will restart their previously effective medication and have a steroid injection if needed. We take blood and urine samples throughout the study and, if possible, may take a small sample of the lining of one of the joints (a synovial biopsy) at the point of flare.

## Why it is important and what do we hope to discover?

Ultimately our study aims to understand the causes of flare, find markers that predict the risk of flare and improve the confidence of people with RA and their healthcare teams in making decisions about treatment withdrawal or reduction. To do this each of the Universities will try to understand how the immune system changes between the states of remission and flare.



Newcastle University will look at how the immune system is behaving by profiling cells present in the blood. All cells have different markers on their surface, and we can use these to identify the different cell types present in both remission and flare.



University of Glasgow will be looking at genetic control of the immune system, assessing if the control of our DNA is different in those who stop their medication and flare, and those who stop their medication and remain in remission.



University of Birmingham will be investigating why the joint lining (synovium) can continue to appear thickened on ultrasound scans long after treatment has taken away pain and swelling. By looking at samples of the joint lining from people in both remission and flare we hope to understand more about the flares of arthritis from the centre of the action.

## The research fellows who are conducting the trial.

### Dr Fiona Rayner, Newcastle

*The BIO-FLARE study was particularly intriguing to me as I had seen many patients in clinic who were keen to come off their medication. One of the benefits of this job is that I get more time with each patient compared with a normal clinic appointment and I really get to know them while they are in the study.*

**Dr Andrew McGucken, Glasgow**

Many people find taking medication every day difficult, struggle with medication side effects and want to cut down the number of medications they are taking. BIO-FLARE has the potential to personalise our approach in medicine and help many people who suffer from RA in years to come, which I think is rather exciting!

**Dr Bernard Dyke, Birmingham**

A major challenge I have appreciated working with people with RA, is that flares often occur unpredictably, and their impact can be very difficult to capture during routine clinic appointments. An important feature of this study which appealed to me was the flexibility to work closely alongside people with RA to paint a detailed picture of the true burden of a flare. In future, identification of the earliest signs of a flare could signpost people to the healthcare team, and maybe even identify treatments or lifestyle changes which can prevent a flare developing.

**Comments from patients**

"I've been under the care of doctors since the age of 14, with all kinds of medical problems, so if I get asked to help out in some research for one of my conditions, I jump at the chance!

All of my conditions have affected me greatly, but RA has certainly been the most painful, especially leading up to diagnosis. Research is the key to all diseases/conditions, I believe, and if I can help the amazing doctors to better understand these conditions, and to possibly find cures, or to find out why they occur, I am more than happy to do so!"

Participant from Newcastle

Once the study is completed, we will publish a summary of the findings on our NRAS website.

## Improved pregnancy outcomes for RA patients following 'ideal clinical pathway'

Results of a recent study run by the Italian Society for Rheumatology showed that RA patients following a recommended 'ideal' clinical pathway during pregnancy were 40% less likely to experience adverse pregnancy outcomes (complicated birth, pregnancy loss, or perinatal death) than those who did not.

The study followed 443 women with RA, out of which 141 followed the ideal pathway. Findings in this group were then compared to a control group of 6097 women who did not have RA.

The ideal pathway was broken up into 3 areas:

- **Diagnosis:** blood tests, musculoskeletal imaging, and tests for antiphospholipid, extractable nuclear antigen (ENA), and antinuclear antibodies (ANA)
- **Treatment:** based on no exposure to methotrexate and leflunomide or the drug no longer being in their system (in the case of leflunomide this may be through a 'wash-out' procedure, to remove the drug from their system), and no exposure to biologic drugs from conception to delivery

- **Prenatal follow-up:** with at least one visit to a rheumatologist.

Of these 3 areas, the researchers conducting this study found that the most important factor to adhere to was treatment. Adherence to this recommendation within the pathway resulted in a 72% risk reduction.

Around three quarters of pregnant women with RA experience a sort of temporary 'remission' or very low disease activity during pregnancy. However, for the other 25%, RA symptoms can continue throughout some or all of their pregnancy and can be severe. With this in mind, though it might be considered safer overall for women with RA to stop their disease modifying drugs throughout pregnancy to improve pregnancy outcomes, this will need to be weighed against the risk to their overall health and well-being and the effect that uncontrolled RA could have on them before and after the baby's arrival. This is especially relevant to the 25% whose RA symptoms continue in pregnancy. Any decisions on treatment should therefore be made through consultation with your rheumatology team.



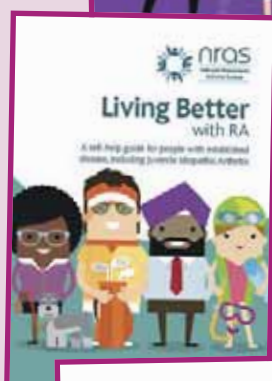
# Our range of publications



Whether you're a new or long-standing member, newly diagnosed or having lived with RA for some time, you may not be fully aware of all our publications, so here is a run down of some of our key publications.

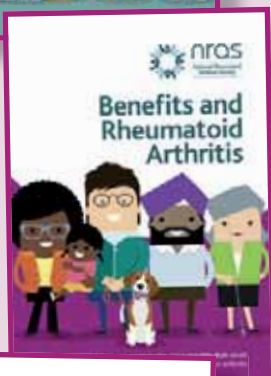
## 10 Healthcare Essentials

This leaflet summarises what good care looks like and what you should ask of your rheumatology team. The *10 Healthcare Essentials for People with Rheumatoid Arthritis* are based on National Institute for Health and Care Excellence (NICE), Scottish Medicines Consortium (SMC), Sign, NHS and British Society for Rheumatology guidelines.



## Medicines in Rheumatoid Arthritis

The aim of this booklet is to give you information about all your current, and possibly future, RA medications in one place. The latest version of the booklet now also includes individual sections on each of the biologic drugs and their biosimilars, as well as the JAK inhibitors.



## Fatigue

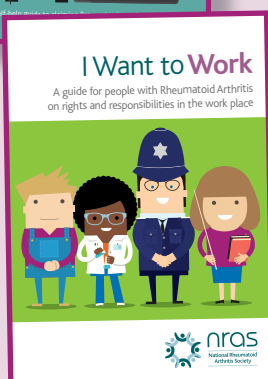
Our *Fatigue Matters* booklet is a guide to dealing with fatigue, looking at the typical causes and contributors to fatigue, as well as giving you useful tips on how to manage this common RA symptom.



## Benefits

If you are looking to claim benefits or just want to see if you might be entitled to any benefits or grants, these booklets may be useful to you.

*Benefits and Rheumatoid Arthritis* is an overall guide to the benefits that people with RA could be entitled to. Not everyone with RA is entitled to benefits, as this depends on how the condition affects the individual.



One of the most commonly claimed benefits among RA patients is *Personal Independence Payment (PIP)*. It is not means tested, so can be claimed by those in or out of work. The forms and assessments for PIP are quite in depth, but our comprehensive guide, *Personal Independence Payment (PIP)* can guide you through it all.

## Newly Diagnosed and Living Better

If you're still in the early phases of diagnosis (the first year or two) and still finding your way with information about your condition, our *New2RA booklet* is the best place to start. You can order this on its own or in our *New2RA pack*, where it is included with *Fatigue Matters and Medicines in Rheumatoid Arthritis*.

If you have been living with RA for longer, our *Living Better with RA booklet* is aimed at you and again, this can be ordered as a stand-alone publication or alongside *Fatigue Matters and Medicines in Rheumatoid Arthritis* in our Living Better with RA pack.

## What is RA? Fold out cards

Recently redesigned and expanded for more detailed information, these cards serve a dual purpose, giving you information about both NRAS and our services and rheumatoid arthritis itself. The bite-size information on all aspects of RA can help you when explaining your condition to other people.



## JIA

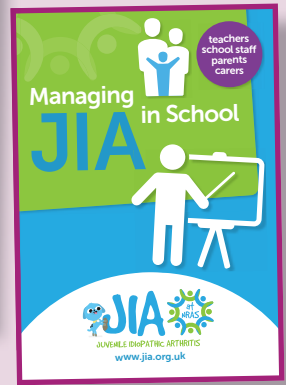
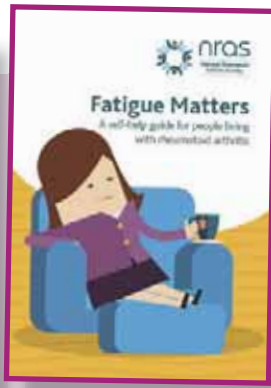
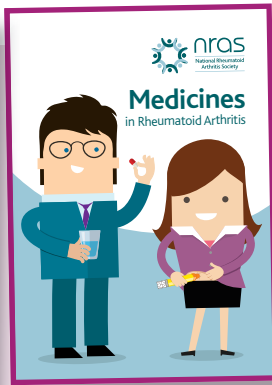
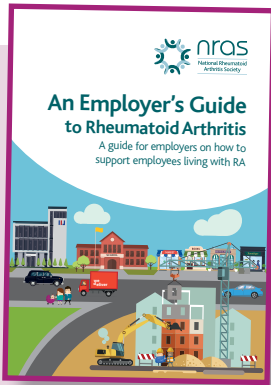
For parents of children with juvenile idiopathic arthritis (JIA) and young people living with JIA, we have 2 useful guides, which can be ordered separately or together in a pack. *JIA Explained* is a useful guide to all things JIA, while *Managing JIA in School* is a useful guide for students, parents and teachers alike.

## Work

RA can impact on every aspect of life, including work. Knowing what your rights are at work and how your employer can support you can make a big difference.

We have two booklets on work, one called *I Want to Work* and one called *An Employer's Guide to Rheumatoid Arthritis*. The former is for you, to help you to understand your rights, what to ask for, who to contact for help etc. The latter is a guide that you can give to your employer, to help them to understand more about your condition and how it might affect you at work and how they can support you.





All of the above publications, along with many others, including our reports and surveys are available to download for free on our website: [www.nras.org.uk/publications](http://www.nras.org.uk/publications).

Downloading publications from our website helps us to keep our postage costs down, but sometimes a hardcopy is easier to read through and notate or pass on to someone to read. Hard copies of publications can be ordered from the above link as well, and should you wish to donate towards our printing and postage costs, you can do so by visiting: <https://www.nras.org.uk/donate>.

# The BSRBR-RA Finally Goes Digital

The British Society for Rheumatology Biologics Register for Rheumatoid Arthritis (BSRBR-RA) based at the University of Manchester has been carefully monitoring the use of biologics and other newer therapies used to treat rheumatoid arthritis (RA) for nearly two decades. This research study has now registered over 30,000 study participants under the care of NHS hospitals across the UK. As part of routine clinical care, consultant rheumatologists are asked to register, with their consent, all patients in the study starting these new drugs and then to regularly provide follow-up data to the team in Manchester to track the health of patients over the long-term. Until last year, the study used purely paper-based data collection questionnaires which was slow and expensive.

In June 2019, all existing clinical data submitted to the study was transferred to a new online digital system and hospitals can now send data directly to the team in Manchester at the touch of a button using the internet. The new system is more efficient, more accurate, provides better communication and has improved security with the data being fully encrypted. Feedback from the nurses and doctors on the new system has been very positive with users being able to see all clinical data previously submitted to the study and any outstanding queries from the team in Manchester on the data provided.

The study has been teaching doctors and patients about these drugs by bringing together information on lots of patients to help improve

rheumatologists' understanding of the best and most effective ways to use the drugs, provide information which may influence if patients should stay on their treatment and also provide better information for those who are considering starting these treatments in the future.

If you have begun treatment on any of the biologics or newer drugs listed here within the last six months, or your consultant is proposing to start you on treatment soon, please do ask them, or your specialist nurse, about enrolling you on the BSRBR-RA. If you or they would like more information about the Register, just visit [www.bsrbr.org](http://www.bsrbr.org) or email us at [biologics.register@manchester.ac.uk](mailto:biologics.register@manchester.ac.uk).

We are still following study participants directly with paper questionnaires to find about how their RA affects their lives and any changes to treatments via our 6 monthly patient diaries, but the team would also like to move to an online system/app for study participants to submit their data to the BSRBR-RA and will be working with NRAS on this project. If you would like to get involved in the development of this new system, please email [emmab@nras.org.uk](mailto:emmab@nras.org.uk)



# Foot Health Study

Top Ten Research Priorities for Foot Health: results from the Foot Health and James Lind Alliance priority setting partnership.



In November, 2018 a unique Foot Health research project was launched that enabled people with foot health problems, their carers and clinicians to identify the unanswered questions (uncertainties) about diagnosis, treatment and prevention of foot health problems in the UK, arriving at a “top ten” research priorities at the end of September, 2019. The Foot Health priority setting partnership (PSP) was established in December 2017 on behalf of the Dr William M Scholl endowment fund and led by The James Lind Alliance and the University of Salford. NRAS was represented within the Steering group for this project by Mr Ralph Bell, one of the NRAS Ambassadors for Manchester and by the NRAS membership who kindly took the time to complete both surveys that formed part of the project process. This project has now reached its conclusion with the successful launch of the Foot Health (PSP) top ten priorities for foot health research on the 1st November 2019 at the British Medical Association in London.

The foot health PSP top ten priorities for research:

1. How does poor foot health impact on people's lives (including work, leisure and social activities)?
2. What can people who are categorised as 'high risk' do to prevent foot health problems (e.g. People with poor circulation, diabetes or other conditions that could cause serious foot problems)?
3. How important are specialised tests (such as diagnostic ultrasound imaging/advanced vascular and gait/functional assessment) learned at post-graduate level, in the diagnosis of foot health problems?
4. What is the impact on health and social care services when known foot health problems are neglected?
5. Are current clinical pathways (treatment plans) fit for delivering high quality foot health provision?
6. What is the impact of delayed or infrequent foot assessment on foot health in relation to foot problems?
7. What are the most effective therapies for treating musculoskeletal foot problems, other than foot orthoses?
8. What evidence is there that foot health research is used in clinical practice and the impact that it has on clinical outcomes?
9. How do health professionals prevent/reduce the risk of foot ulceration occurring or getting worse, in patients with diabetes?
10. How can people prevent foot health problems?

The profound threat to lower limb health posed by chronic conditions such as, diabetes, lower limb arterial disease and arthritis (NICE, 2018, 2019) together with the significant prevalence of disabling foot and ankle pain in the older population (Thomas et al, 2017; Keenan et al, 2019), demands that the public have access to a gold-standard, evidenced based foot health service. A recently published comprehensive systematic review (Edwards et al, 2017) revealed that there is very limited high-level supportive evidence for podiatry, concluding that strategically prioritised research could have an important impact on the field of foot health and podiatry. Therefore, it is timely that the results of the Foot Health PSP are ready for dissemination and action.

The James Lind Alliance (JLA) was established in 2004 to bring patients and clinicians together to identify questions about treatment effectiveness. The JLA method is a flexible and responsive, transparent and rigorous framework that has evolved since its inception, enabling patients, carers and clinicians to equally take part in setting the research priorities. The JLA argues that research can sometimes fail to recognise the uncertainties and requirements of patients or those caring for or treating them. Detailed methodology and findings have been provided through a final report that can be accessed via the Foot Health PSP website (<https://foothealthpso.org/>) and the JLA website (<http://www.jla.nihr.ac.uk/priority-setting-partnerships/foot-health/>).

Further information is also available from Dr Andrea Graham, Foot Health PSP Coordinator. Contact Andrea at: [a.s.graham@salford.ac.uk](mailto:a.s.graham@salford.ac.uk)

# Cognitive impairment more common in patients with rheumatoid arthritis

A study investigating cognitive impairment in RA patients found statistically significant differences between RA patients and a control group in almost all cognitive domains.

The study examined 210 patients with RA and 70 healthy controls, recruited from the same rheumatology unit from January 2016 to December 2018. Patients had to be 18 years old or older and, any diagnosed with dementia prior to their RA diagnosis, were excluded.

Concerningly, more than two thirds of RA patients included in the study were classified as cognitively impaired. Mean average scores for the Mini-Mental State Examination (MMSE) and Montreal Cognitive Assessment (MoCA) were significantly lower for RA patients, while anxiety and depression scores were significantly higher in the RA group and nearly 70% reported subjective memory complaints.

RA patients often refer to a 'brain fog' following diagnosis, causing them to find it harder to recall and retain information, which this study appears to back up. Interestingly, patients on biologic medication were less likely to be cognitively impaired and those who were positive for the rheumatoid factor antibody were more likely to be cognitively impaired, both of which could point to disease severity/ disease control being important factors.

However, it was not possible for this study to determine the exact causes of these findings, and limitations noted by the researchers included the fact that the sample group would not be entirely representative of all patients with RA. It does, however, demonstrate that mental health and RA needs to be taken seriously and should be discussed openly between RA patients and their healthcare team.



## Effectiveness of methotrexate not altered by antibody presence

A recent study has found methotrexate (MTX) to be an effective initial treatment for RA, regardless of the presence or not, of rheumatoid factor (RF) and anticitrullinated peptide antibodies (ACPA).

The study was initiated to investigate whether or not treatment should be tailored to a patient's 'antibody status' when considering MTX as a first-line disease modifying anti-rheumatic drug (DMARD) but found no evidence that this should be considered a factor.

The study had 1826 participants with RA from an international observational database (METEOR), and compared the numbers achieving remission within 3-6 months. The results were almost identical, at 17% for those positive for RF and/or ACPA and 18% for those negative. Additionally, when looking at whether the patients were taking methotrexate alone or in combination with other DMARDs, little difference was seen.

**UNDERSTANDING Methotrexate**

Did you know that methotrexate is available as an oral or injectable medication?



Want to know more about how it is used and why? A short, animated film is available to answer the most frequently asked questions about methotrexate.

Take a few moments to view by visiting [www.nras.org.uk/methotrexate](http://www.nras.org.uk/methotrexate)

For more information on this or any other aspects of living with Rheumatoid Arthritis or Juvenile Idiopathic Arthritis, call NRAS on 0800 2987650 or visit [www.nras.org.uk](http://www.nras.org.uk)





# New2RA Right Start

– a new service for people newly/recently diagnosed with Rheumatoid Arthritis

NRAS has campaigned to inform and shape NICE quality standards, leading to improved treatment of the RA community. A fundamental pillar that NRAS has pushed for is:

**NICE Guidance 100, Quality Standard no3**

***“Adults with rheumatoid arthritis are given opportunities throughout the course of their disease to take part in educational activities that support self-management”***

After years of providing a dedicated telephone support service, we are acutely aware of the importance of engaging newly diagnosed RA patients. Receiving the right support at the beginning of a person’s journey with RA is especially important. This is where unhelpful health beliefs, anxiety and incorrect information can influence how someone responds to prescribed medication and treatment, subsequently impeding their ability to achieve the best outcomes. We know, for example, that many people do not take their medication as prescribed reducing their chances of achieving remission or low disease activity state.

Responding to fears and concerns, unanswered questions relating to medication, health, relationships and employment is therefore critical. The need for a calm reassuring voice that understands the process and normalises their life changing diagnosis is vital in supporting them in their new RA journey.

In May 2019, we launched **New2RA Right Start** service, an intervention designed and crafted to this need and critical juncture in the RA journey.

The challenge we faced was creating a gateway for newly diagnosed patients to be referred. GDPR and data management issues always add additional challenges and a layer of complication. We overcame this by creating an online referral portal for HCPs capturing patients’ consent. The patient’s information is received through a secure link, and a one-hour assessment is booked at a time that suits the individual. This session provides the person living with RA with a safe and secure space to explore anxieties or concerns

that have developed post diagnosis. The process creates an enhanced experience of personalised care for the individual, placing them firmly at the centre of the process.

At the end of the session a tailored package of paper-based resources is dispatched, and this is complemented with access to electronic resources such as self-management Apps, educational webinars, access to research and referral to an online community.

Furthermore, the service user is offered the opportunity to speak with an NRAS trained telephone peer volunteer. This prospect reinforces the normalisation of the diagnosis whilst embracing the power of peer mentoring as a stabilising factor drawing on lived experience.

In the 8 months since launching, we have 25 active hospitals and have received 104 referrals. King’s College Hospital tops the leader board for referrals with 16.

An NRAS core value is gathering evidence of the significance and outcome of any NRAS intervention. Data analysis on the service is being carried out by King’s College Hospital London. They are comparing the results of patients who have been referred to Right Start with a 3 month follow up MSKHQ (Musculoskeletal Health Questionnaire) against those patients who have



not participated in the scheme. We hope to have enough numbers to complete this work in the coming months.

Here's some anecdotal feedback we have received about the service to date.

*"I have found Right Start to be an excellent resource for people who have recently been diagnosed with RA. When time is limited in clinic, a referral provides the patient with tailored information which complements the education I have been able to provide. Feedback from patients has been positive particularly relating to the phone calls with the NRAS helpline team and the NRAS volunteer with RA. I would definitely recommend the service."*

**Diane Home**  
**Consultant Nurse - Rheumatology**

### Feedback from our telephone support service

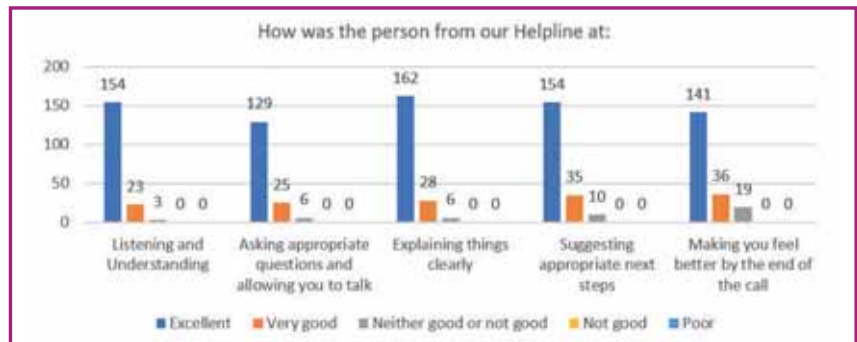
*"I was so pleased with my volunteer call as part of the Right Start programme, it was very helpful to be matched so closely as we were both sero negative and a similar age and with similar experiences. It's good to know that there is light at the end of the tunnel. The support of NRAS is invaluable"*

### Conclusions

The service has a high patient rating in terms of experience and value. We are keen to increase access to more patients and would welcome new hospitals coming on board and encourage all rheumatology units to start using the Right Start referral service.

Making a referral could not be easier, and you can also order marketing material for both staff and patients. This will be dispatched free of charge to you, to order your pack visit

[www.nras.org.uk/new2ra-right-start-service](http://www.nras.org.uk/new2ra-right-start-service)  
 or call 01628 823524  
 or email [enquiries@nras.org.uk](mailto:enquiries@nras.org.uk)



# A critique of the PIP process and tips on how to claim.

By Archie Cresswell

Personal independence Payment, or PIP, is the replacement for Disability Living Allowance (DLA). It is comprised of weekly payments, between £23.50 and £148.85, for those between 16 and 64 to help pay for the additional costs of living with long-term ill health or a disability. Since its introduction, PIP has not been without controversy. A third of all benefits issues reported to Citizens Action Cymru, for example were regarding PIP, and of those 88% were eligibility issues.

Having applied for PIP, you will be sent a thirty-three page form to complete, outlining your conditions and daily struggles. ('PIP2: How your Disability affects you') The next stage of the process is a meeting with a healthcare professional to discuss your situation.

If applicants are to be successful, it is essential that they complete this form to a high standard, with enough detail. This, however, may be easier said than done due to the fact that many applicants find the form not only an extremely intimidating task to begin with, but also a difficult and even mentally agonising task to complete due to the personal and sensitive nature of the information applicants are required to send to strangers. Some applicants have described the form as 'incredibly demeaning' and 'very distressing'. A recent survey of over 500 applicants found that those who completed the form rated both parts of the form – 'Daily Life' and 'Mobility' – on average greater than a seven out of ten in terms of difficulty. A difficulty rating of ten was the most common response for both parts.

The form, though a crucial part of the process, is clearly a very challenging task to complete well.

At this point, you may be filled with dread at the thought of your application. However, though the process is long and strenuous, if approached in the right way, it can be much more manageable. Simply follow these tips for your PIP form:

- Before you begin to write your application, it can be helpful to keep a diary of your daily struggles. This will allow you to have a clear understanding of which tasks you find difficult and need assistance with on a day to day basis. This clarity will ensure you do not forget to mention any aspects of the day to day difficulties you experience and will also help you to write clearly and succinctly. You may also submit this as additional evidence alongside your application.
- It is also helpful to prepare and practice before beginning the form. This may begin by researching the form - copies of the PIP form can be easily found online. It is also useful to go onto [turn2us.org.uk](http://turn2us.org.uk) and look at their 'PIP Test Guide' as this shows the number of points - a points system is used by assessors to measure your needs - likely to be given for different responses. This can indicate to you what to expect in response to the answers you write on the form.
- In addition to this, approaching the task in the right way can make an enormous difference. You are given an entire month to complete and return the form so there is no rush to complete it, nor does it need to be completed all in one go. Take all the time you need and ensure that you get it right. Split the thirty-three-page document into manageable chunks and try to complete a section at a time. Moreover, doing it in the company of a trusted friend or family member not only ensures you do not forget to mention anything, but may also help to ease the mental discomfort of the form.
- Before committing yourself to writing the actual form, it is beneficial to draft your responses, for the long answers, on a sheet of paper before you write them on the form itself. This, again, allows you to be confident that you have included everything and ensure your answers will make sense when read by someone who doesn't know you and isn't aware of your situation.



- It is really important that you include detail. The assessors reading your form only know what you tell them, so if you neglect to mention something, the assessors simply will not know. You must ensure that they understand your struggles and the only way to do this is by explaining to them clearly. Remember that in the long answers, it is better to include details that are not relevant than to miss out ones that are. You are not confined to the space given as there is extra room at the end of the form and additional paper may also be used.
- Detail is the key! As difficult as it may be, it is not the time to be proud and skim over the details. The simple and unfortunate reality is that you will not be granted PIP if you do not make your needs clear.
- Gather your evidence: Remember to include supporting evidence with your form, such as letters from healthcare professionals, such as your rheumatologist, specialist nurse and/or anyone else involved in your care, to back up what you have said on the form. The more evidence you can supply for the assessors to read at the initial stage the better.
- Finally, it is important to understand what completing a task actually means in order to make your needs clear. For example, you will have to answer a question regarding your food preparation struggles. The question refers to you preparing 'a simple meal'. This means a fully prepared and cooked one-course meal. Therefore, if you can only heat a microwave meal, this does not mean you can prepare a simple meal. You must be able to wash vegetables, peel, chop and boil them and so on. Do not underestimate the number of steps that make up each task. Moreover, if you can start a task but it becomes painful and you must stop, even if you can carry on after a period, this does not mean you can complete it. For example, you can walk fifty metres but then suddenly experience pain and have to stop for a period of time. You then can continue and walk another fifty metres. In terms of the form, you are capable of walking fifty metres, not one hundred. This is especially pertinent for people with conditions such as RA, due to the fluctuating nature of the disease.



If you still feel this is all too intimidating, please do not hesitate to contact the citizens advice bureau for an appointment with one of their benefit advisors, to help you complete the PIP application form. They will also be able to assist you should you have to appeal against the DWP's decision.

If you do all of the above and are still unsuccessful, remember that there is an appeal process, and that a large number of cases have been overturned on re-consideration or appeal.

Just keep all these straightforward tips in mind and you will be well on your way to writing a successful PIP form. Though the system may be poor, there is still a way through.

For more information on PIP, see our booklet, *How to claim Personal Information Payment*: [www.nras.org.uk/publications](http://www.nras.org.uk/publications)



**Helpline 0800 298 7650**

# Who are the top RA bloggers to follow?



For anyone who is unsure of what a blogger is, essentially a blog post is a website or website pages, often written by one individual, forming a regular record of thoughts, opinions and experiences. It can be a bit like an online (and public) diary, of events, situations and opinions as they occur. It is often in an informal, conversational style and people will follow bloggers whose style and subject range appeals to them, reading their blog regularly.

Some people with RA have general blogs online, which cover all aspects of their life and opinions, of which RA is a part, while others might be solely centred around the condition.

There is a wealth of RA related blogs out there, and narrowing a list down was hard, but the following is a mix of some of the more popular RA blogs, along with some that have been recommended by NRAS contacts who have RA themselves.

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## Rheumatoid Arthritis Guy

Based in: The US

*"I'm not a patient who suffers from rheumatoid arthritis. I'm a person who LIVES with rheumatoid arthritis."*



RA Guy has created a superhero persona, and describes how 'RA Guy' navigates through life with this condition. His webpage has further details about his blog and podcast.  
[www.rheumatoidarthritisguy.com](http://www.rheumatoidarthritisguy.com)

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## Chronic Eileen

Based in: Canada

*"Through my struggles with pain I found my voice and my purpose. I found myself. Arthritis is my villain and my blessing in disguise."*



Diagnosed in 2015, with a young family and while still in her 20s, Eileen had a family history of inflammatory arthritis, but had not realised the extent to which it affects life until her own diagnosis. She now uses her own experiences to help others.  
[www.chroniceileen.com](http://www.chroniceileen.com)





## Pollyanna Penguin

Based in: UK



*"Am I glad I've got it? Don't be silly. But there are still plenty of positives to talk about ... and when I'm having a negative moment I can come back to my blog and remind myself of them!"*

Pollyanna Penguin is neither a penguin nor is she called Pollyanna. The Pollyanna part of her blog name comes from her attempts to find the positive in living with RA and playing 'the glad game', which will be familiar to anyone who has read the Pollyanna novels or seen the film.  
[www.pollyannapenguin.wordpress.com](http://www.pollyannapenguin.wordpress.com)

## Life with RA (LWRA) Guy

Based in: UK



*"Your Ability Is Stronger Than Your Disability."*

Steve was diagnosed one month before his 25th birthday. He has had RA for nearly 3 years and started his blog page in September 2019, so he's relatively new to blogging and to his condition, but the content he has on his blog page so far is well worth a read!  
[www.lwra-guy.com](http://www.lwra-guy.com)

## Giggles over Tears with RA

Based in: The US



*"If these poems can help at least one person smile, chuckle a little, laugh out loud or spit out a drink - then my day was not wasted."*

This is a page with poems about the daily struggles of living with RA. Its purpose is to help others laugh and it was set up by a lady called Donna, who is a talented artist as well as poet.  
[www.facebook.com/GigglesOverTearsWithRa](http://www.facebook.com/GigglesOverTearsWithRa)

## RA Warrior

Based in: The US



*"I did not have a comprehensive source of information and compassionate help available. I worked hard on my own to piece together information about how to protect my joints, organs, and life."*

Kelly is a student of rheumatoid arthritis because of the axiom: Know your enemy. Since her diagnosis in 2006, she has relentlessly worked to learn more about rheumatoid arthritis. She gains satisfaction in helping others to understand their options and make educated choices. She promotes self-education and encourages RA patients to direct their own medical treatment decisions.  
[www.rawarrior.com](http://www.rawarrior.com)

Reading blogs and following bloggers won't appeal to everyone, but some people find it comforting or informative, or perhaps a bit of light relief from someone who understands RA and has an interesting spin on the subject.

# Community Fundraisers

Thank you to our fabulous fundraisers who always go the extra mile to make a difference! Here are just some of our wonderful supporters and the amazing things they have been up to...

## Local Theatre groups show their support.

December is Panto Season! This year Maidenhead Drama Guild had a very successful run of the Christmas family adventure, Dick Whittington, at the Desborough Theatre. The cast decided they wanted to support NRAS with our offices also being based in Maidenhead. Opening night was Wednesday 11th December and 4 members of NRAS staff went along to show support and boo, hiss and cheer! It was an excellent and very professional show, opening to a packed house of mainly highly excitable local Scout groups. An added bonus was the 'meet and greets' by the cast at the end of the performance. The obligatory selfie with your favourite character was a must, especially amongst the younger members who were able to grab a selfie with the popular and very funny 'Rot n Stench' the Rats. NRAS were delighted to receive a fantastic £293 from the collections after the show each night.



*Lacey Green players production of The Ladykillers*

Lacey Green Players amateur dramatics group based near Princes Risborough in Bucks, was formed in 1983 and over that time have given over £66,000 to various charities. In November last year the National Rheumatoid Arthritis Society was chosen as one of the charities to benefit from their production of *The Ladykillers*, a classic black comedy. In January we received a fantastic cheque for £325 from the group, along with a letter explaining that one of their members had found our support and services of great help and had very kindly nominated us to be one of their chosen charities.



*Emma Sanders, Individual Giving Fundraiser, with Scot Kitson and Martin Selman who played Rot n Stench*



## Guess who?



Tracy Bracher NRAS Membership officer

Getting into the festive spirit back in early December our lovely Membership officer Tracy took part in her local Santa Dash in Newbury. We think you will agree she wore the costume well and raised a cracking Christmas amount of £244. Well done Tracy from all your colleagues at NRAS.



Joe Wildes and Ray Gibbons Charity Boxing match

## Boxing gloves at the ready

Fundraising comes in many guises, but on 18th October 2019 one of our supporters Joe Wildes faced his long-term adversary, Ray Gibbons, in a Charity Boxing rematch. Last time Joe and Ray met in the ring was in 2014. Joe wanted to help raise awareness about rheumatoid arthritis after supporting his devoted wife Sandra and experiencing first-hand over the past 27 years the effects on day to day life this disease has upon her. The eagerly awaited contest had fantastic support on the night, with a good crowd attending the historic York Hall in Bethnal Green. This iconic venue, considered the home of British Boxing, has seen the likes of Lennox Lewis and Joe Calzaghe battle it out against opponents. Friends and family have shown immense support for Joe and his brave fundraising challenge and he and Sandra are thrilled to be able to donate £2518 from the event to NRAS and share Sandra's story to get people listening and understanding more about RA.

All photos by Matt Cocklin LRPS



Joseph Wildes and opposition Ray Gibbons at York Hall Boxing



Joe Wildes and daughter Hannah Wildes

# Doing it for his dad

Graham Hutton contacted the team as he wanted to do some fundraising in December 2019 and decided to do this for NRAS. Graham set up an online fundraising page through Just Giving. He kicked off the fundraising at Osterley Park Winter 10k Race.

'My late dad struggled with rheumatoid arthritis for over 40 years of his life and I could see the terrible effects this horrible disease had on the quality of his life.'

Graham's father Leonard had sadly passed away in 2017, aged 81 and as Graham had mentioned on his fundraising page, he had lived with RA for over 40 years.

When Leonard died the family decided a fitting way to remember Leonard was to set up a Tribute

Fund – which is a wonderful way to have an everlasting online memory that can be shared with family and friends. Tribute funds are often used at the time of a loved one's passing to ask for donations to your chosen charity – in this case NRAS, at the time of the funeral. However as it is everlasting it can be used and added to at any time, and so when Graham raised a fantastic £371 from friends and family in sponsorship money he asked for this to be added to his dad's overall tribute fund to continue growing it.

Tribute funds can be a place of comfort, support and inspiration and we are grateful to Leonard's family for choosing to continue to support NRAS in this way. Leonard's tribute fund is full of wonderful images of Leonard and his family and some very touching thoughts, words and poems written by family members. **leonard-hutton.muchloved.com**



Graham Hutton

If you would like more information about setting up a Tribute Fund, please do contact us in the fundraising team at NRAS. Please email **fundraising@nras.org.uk** or call us and ask to speak to Emma Sanders or Bronwen Cranfield on 01628 823524.



By Ailsa Bosworth, MBE

Founder & NRAS National Patient Champion

# NRAS E-Learning

As many of you will know, NRAS has been delivering face to face supported self-management programmes and courses since 2011. However, they have only been commissioned over that period of time in relatively few locations. We know from data collected that experiencing this kind of programme can be life-changing for many but only a minority of people have been able to access our programmes. Whilst representing very good value, they nonetheless cost us money to put on in regard to initial and ongoing training of volunteers and health professionals to deliver the courses, resources and materials, travel costs, etc. and we have consistently found that the commissioners (those who buy health services for their local populations) don't want to pay for these kinds of services or have other priorities for their budgets that don't include patient education. Whilst some long-term health conditions, such as diabetes, do have courses available in quite a number of areas, widespread availability of disease-specific courses in lots of health areas does not exist and we are not alone in finding it difficult to get face to face courses commissioned.

This is in spite of the fact that NHSE Comprehensive Model for Personalised Care brings together six evidence-based and inter-linked components, each of which is defined by a standard, replicable delivery model. The components are:

1. Shared decision making
2. Personalised care and support planning
3. Enabling choice, including legal rights to choice
4. Social prescribing and community-based support
5. Supported self-management
6. Personal health budgets and integrated personal budgets.

As a consequence of the above, NRAS has been raising money in the last 18 months to develop an entire suite of e-learning modules in RA and started developing these in December 2019. We hope to launch the first few modules directed

at the newly or recently diagnosed at this year's British Society for Rheumatology congress in

Glasgow from 20th – 22nd

April, where we shall have an exhibition stand. We hope

that many nurses and allied health professionals will visit the stand to find out more about how these e-learning modules in our first programme called SMILE-RA can support their patients. SMILE stands for Self-

Management Individualised Learning Environment and we hope you like the acronym!



After registering and completing a short evaluation questionnaire so that we can evaluate how this new learning experience might benefit participants, there will be a foundation module to complete before going on to do further modules. You can then choose to do modules which are of interest and value to you as an individual. We shall add modules as they are developed over time. We very much hope that by developing our e-learning web area, many more people will be able to benefit from our SMILE resources complementing our other resources and services. The newly/recently diagnosed module will be particularly useful for people who are accessing our New2RA Right Start Service.

For more information, please contact [ailsa@nras.org.uk](mailto:ailsa@nras.org.uk)

**\*Due to Coronavirus, some of the filming and voice over work for our e-learning cannot be carried out as currently planned, so launch of SMILE-RA will be delayed.**



nras  
National Rheumatoid  
Arthritis Society

E-Learning

Smile-RA

Self-Management  
Individualised Learning Environment

# #wearpurpleforJIA at NRAS

Friday 6th November 2020

This year our JIA awareness and fundraising campaign will be held on Friday 6th November. We hope that all our JIA families and supporters, and anyone else that would also like to get involved, will be turning everywhere and everything purple for the day. Our aim is to get people talking more about JIA and the impact JIA can have on the day to day life of children and young people. Last year we had an incredibly successful day with schools up and down the UK getting involved and supporting pupils that live with JIA, on a daily basis. The day raised a wonderful £45,000 for our JIA services at NRAS and we hope, this year, to raise that and more!



Wear Purple has been postponed due to the escalation of Coronavirus

We will keep you updated via the JIA websites and #WearPurple Facebook page. Thank you for your patience and cooperation.



## New JIA Website Coming Soon!



For the last few months here at NRAS, we have been working hard behind the scenes creating a brand-new website for JIA. This is part of improvements we are making across our services, creating a new site with easier navigation and lots of engaging content. We are investing in the future for those living with RA and JIA. If you would like to be one of the early testers of this website before this goes live, please email [website@nras.org.uk](mailto:website@nras.org.uk).



# A new paediatric rheumatology specialist unit in Cardiff

## Good News for Children and Young people with JIA and other paediatric rheumatological conditions!

Some children and young people were having to travel to England to receive care and we know how difficult it is for families to have to travel long distances to get the care they need

As long ago as early 2012, a delegation from NRAS went to Carmarthen to meet a senior executive from the Welsh Health Specialised Services team to discuss the major issue that Wales was the only country within the United Kingdom which did not have a specialist paediatric rheumatology centre. At the time, we were gathering evidence from adult and specialist centres all over the UK to inform our 'JIA in Focus' report, published in 2013. We felt strongly, reinforced by the enthusiastic support of Dr. Jeremy Camilleri, a consultant Rheumatologist who has provided a paediatric service at Cardiff for many years, that there should be a specialist centre for children and young people established at Cardiff with a full specialist multi-disciplinary team.

We had shown the **Welsh Health Specialised Services Committee (WHSSC)** the breakdown of the specialist teams at Bristol and Alder Hey (Liverpool) which very much reinforced the need for the under 16 population of South Wales to be able to access the additional resources which were comparable with specialist paediatric resources elsewhere in the UK. Some children and young people were having to travel to England to receive care and we know how difficult it is for families to have to travel long distances to get the care they need.

We continued to campaign for the next 6 years with Dr. Camilleri, visiting Carmarthen again 2 or 3 times. We appreciated that it would take considerable time to bring about major change, especially during years of cutbacks in the NHS. We also held family events to galvanise the support of local families. In 2014, NRAS wrote to all Local Health Boards in Wales to highlight the publication of the Focus on JIA report and draw attention to a number of our concerns. Letters concentrated on two campaigning priorities:

- Gaining additional resourcing to enable Cardiff to become a recognised specialist centre for paediatric rheumatology

- Creation of a Managed Clinical Network for paediatric rheumatology in South Wales
- In 2018, recognising the power of combined voices and joint effort, we invited the British Society for Rheumatology and Cymru Versus Arthritis to join the campaign and together succeeded in getting a debate on the subject in the Welsh Assembly with the support of David Melding AM which resulted in the Assembly passing a motion which called on the government to support calls for the development of a *multidisciplinary paediatric rheumatology centre* in Wales.

The motion passed with significant cross-party support. The debate included supportive contributions from Conservative, Labour, Plaid and UKIP Assembly Members.

Mr Melding said: "I am so pleased that this extremely important motion has passed through the chamber. Wales is in desperate need of a multidisciplinary paediatric rheumatology centre; we have been left behind for too long".

We were all delighted to receive a copy of a letter from WHSSC in 2019 confirming that funding would be provided to establish a paediatric rheumatology service at Cardiff.

Things started to happen last autumn and a new Paediatric Rheumatology Consultant, Dr. Joanne May, started at Cardiff on 1st October 2019. Ailsa Bosworth, National Patient Champion and Samuel Lawes, Policy and Communications Manager spoke to her on 4th February to ask about her new role, the new service and find out a little about her plans.

Dr. May trained at Great Ormond Street and Bristol and worked at the paediatric rheumatology service at Oxford and is keen to maintain her strong links with these and other paediatric rheumatology centres across the

UK. She said, "I want to ensure that we create a centre delivering the right standards of care in line with other centres across the UK and that the children across South Wales have access to the care they need."

New positions have been offered but the people are not yet in post, and include:

- A band 7 full time paediatric specialist physio
- A band 7 full time paediatric specialist nurse
- Dr. May is also hoping to be able to recruit a specialist OT.

Dr. May's goal is to get the necessary funding for a *full* MDT including in phase 2, psychological support, rehabilitation, pain services and a research nurse so that she can include children in studies. In the meantime, she is focussing on getting to know the relevant health professionals and services across the region and maximising education and learning opportunities with other teams so that outreach clinics can be established in due course.

There is a huge amount to do when developing a new service, it takes time to establish and there is a long way to go yet, but Dr. May is working extremely hard on all fronts to establish regular clinic slots, injection lists, joint clinics with ophthalmology and many other activities to get the new service firing on all cylinders. NRAS wish her and her new team, when they come on board, every success in her aims and we have reassured her that we and our colleagues in The British Society of Rheumatology and Cymru Versus Arthritis will do all we can to help support the new service.



Dr. May said "I want this service to be up there with the best services in the UK. There's no reason it can't be".





The Treasury, Whitehall

# Policy: the year ahead

In 2019, NRAS continued its work with third sector partners and practitioners around the UK to press for improvements in services for people with RA and JIA. 2020 will be a busy year for our new Policy and Communications Manager, Samuel Lawes, who joined NRAS a few days before the General Election last year.



Our thanks to our Patron, Rt Hon Theresa May MP, for her continued support

More funding is promised for NHS services, as well as research for new treatments for long-term diseases

## NHS 10 Year Plan & Boris' Manifesto

Over the last five or six years, the government and NHS England have developed a strategy to put NHS England's decision-making on a longer-term footing. In 2014 NHS England published its Five Year Forward View; last year this was followed by the ten-year NHS Long Term Plan.

NRAS will work with practitioners, partners and other patient organisations to contribute to this plan on behalf of our members. The government's newly-endorsed manifesto promises:

- to extend social prescribing;
- to extend the Cancer Drugs Fund to other conditions, renaming it the 'Innovative Drugs Fund';
- a commitment to improve early diagnosis and treatment of major conditions;
- to publish a 'National Strategy for Disabled People' before the end of 2020.

In Wales, Scotland and Northern Ireland, many of these issues are devolved to the local governments. We will contribute to those conversations, too. Often best practise can be shared. NRAS Ambassadors have an important voice in Scotland and Wales, as well as in Manchester, where health and social care are devolved as well.

## Work Matters

Many employers across the UK do not know enough about RA or JIA, and this adds to the challenges faced by many living with the conditions in work. This was addressed in the Work Matters report, available to read on the NRAS website ([www.nras.org.uk/publications/work-matters](http://www.nras.org.uk/publications/work-matters)).

Over the coming years NRAS wants to see best practice and learning from this report reaching more local communities and especially small and medium-sized employers.

This means working with MPs and other local leaders to raise awareness of schemes like Access to Work, as well as NRAS resources including our 'Employer's Guide to Rheumatoid Arthritis'. Local Members and Volunteers can play a big part in publicising this information.

## Emotional Health and Wellbeing

It is great that as a society we talk much more now about our emotional health and wellbeing. The conversation about mental health has come a huge distance in a generation. In recent years politicians have said that mental health should be treated on a level with physical health. There are lots of things we can do to make this a reality for people with RA and JIA – in particular, NRAS encourages rheumatology teams to talk about it with every patient they see.

NRAS are also involved in efforts to promote self-management and social prescribing. There are excellent initiatives around the country that should be spread, for example making sure GPs know about hydrotherapy sessions in their local area. NRAS are on the lookout for other great initiatives, so if you think you have one to share with us, please email [samuel@nras.org.uk](mailto:samuel@nras.org.uk).







7th to 13th September 2020

# Save the Date!

Since National Rheumatoid Arthritis Society (NRAS) was founded in 2001, one of our key aims has been to increase public understanding and awareness of rheumatoid arthritis (RA).

In 2013, NRAS started a campaign called Rheumatoid Arthritis Awareness Week (RAAW) to raise the awareness of the condition and eliminate the misconceptions about what RA is by educating and informing friends, family, employers and the general population about what rheumatoid arthritis is. Last year, we reached over half a million people with our #AnyoneAnyAge theme, and this year we want to reach even more people!

RA Awareness week will be taking place from 7th until the 13th September, so you can start planning your activities and events now.

More details to follow on our Website and via E-News with our exciting plans and how you can get involved!

**#RAAW**

"Aren't you too young for that?"

"I have a bit of that in my knees."

"You don't look ill..."

"What is autoimmune?"

"My granny has that."

# Fundraising for JIA

We have had some great fundraisers supporting, raising awareness and funds for our Jia services at NRAS. We had a busy year with lots of families getting involved. As the year came to a close we had a flurry of JIA fundraisers to help us finish up the year in style and showing their great commitment to the charity.

## Wear Purple Ball in Somerset.

Heidi Kelly had planned her #wearpurpleforjia at NRAS event back in the summer, but wanted to hold a Charity Purple themed ball in November. She had great support from friends and family and they held the ball in November at Long Sutton Golf Club in Somerset. They had a fabulous night supporting two causes JIA at NRAS and Krakos Gym club where Olivia has lots of fun. A total of around £400 was raised. Heidi's daughter attends Stoke St Gregory Primary School and her daughter Olivia's class dug out their purple attire to really get into the spirit and raised donations of £100, the day before the ball on the 22nd November. Heidi was keen to keep her fundraising and awareness going so pulled on her snazzy #wearpurpleforjia T shirt and with her partner Lewis they took part in the New Year 10K event in her village on the 5th Jan. A huge thanks to Heidi her partner Lewis and all her family and friends who have been supporting JIA and NRAS. We look forward to seeing what 2020 will bring!



Heidi Kelly, Lewis Pimm, and his mother Charlotte attending the Wear Purple ball November



Heidi at Purple Ball with Krakos gym instructors Bex and Craig



Olivia Kelly and her classmates from Stoke St Gregory Primary School



Heidi Kelly and Lewis Pimm running in 10K New Year's Day Purple T shirts.

## Lighting up JIA

The Sage family from Dawlish had their annual Christmas garden and house light decorations this year and decided to give all money collected by visitors to JIA at NRAS as their daughter has had JIA for 7 years. They collected money at the house and raised a festive £166. They had their official switch on November 30th to the delights of neighbours and friends. Thank you for creating such joy and fun at Christmas.



Pictured is Acacia and Nevaya at the official Switch On!

## Aquatic Amigos

Back at the end of November Alfie Adams and 3 of his friends decided to set themselves a challenge to swim 100 lengths each in support of Alfie's younger brother Austin age 9 who has JIA. Austin had only been diagnosed with JIA early 2019 and by May had already undergone an operation on his joints. Alfie and his 3 friends, Luke, Owen and Sam had wanted to do something to raise awareness and to show Austin they were there to support him every step of the way. The boys trained for the best part of the year putting in many hours in the local swimming pool in Harwich. On November 30th they took the plunge and achieved their target of 400 lengths – we hope you agree truly amazing! They raised an amazing £185.



Alfie Adams and Friends

# EULAR Edgar Stene Prize Competition



Each year EULAR (the European League Against Rheumatism) hosts the Edgar Stene Prize Competition, which gives people living with rheumatic diseases, such as RA, the opportunity to submit an essay on a previously determined topic. 2020's topic was: 'Being a person with a rheumatic or musculoskeletal disease (RMD) – How my voluntary work benefits me'. People from all over Europe enter the competition, and the winners are invited to the Annual EULAR Congress and special congress dinner. We are delighted that a handful of NRAS Volunteers submitted essays, and we will be featuring one per magazine in 2020. We start with Rachael Clark who was diagnosed with RA in 2012 at only 22 years old. Rachael has been a Volunteer with NRAS since 2017 and has contributed so much of her time to helping others and supporting our work by fundraising. Thank you, Rachael, for being one of our amazing Volunteers... here's her story:



When I sit and reflect on how voluntary work helps me, it seems almost counter-intuitive, as surely everyone starts volunteering with the intention of helping others? But, actually, being a volunteer has helped me in more ways than I could ever have imagined!

Being a volunteer provides me with the opportunity to network and socialise with fellow 'RA warriors', and healthcare professionals in my vast RMD community. This has been of massive benefit to my mental health, in that it serves as a reminder that I am not alone – a feeling of isolation that I have often felt whilst living with rheumatoid arthritis. Looking back, the mental health side of my disease has been just as prevalent as the physical side, and whilst volunteering as a telephone support volunteer for NRAS, this has really unveiled the true impact of the disease on my mental well-being. Talking really is therapy, even writing this piece in fact, and whilst speaking with other RA sufferers I get to offer a listening and supportive ear, but it also brings me a sense of comfort in knowing that my fears, hopes and dreams, are ones that we all share!

My journey into voluntary work, was really rooted in my unshakeable desire to help spread awareness of my RMD. For years, I had felt frustration surrounding the lack of understanding about rheumatoid arthritis, in particular that it is not just a disease of the 'old', having been diagnosed at the age of 22. Volunteering for

NRAS has opened up so many opportunities to do this, from speaking at pharmaceutical events, to even being invited to Downing Street – and what an unforgettable experience it was! Speaking at such events has not only improved my confidence with public speaking, but also in managing longer travel distances on my own (something that I often rely on my husband to support me in!). Sharing my experiences of work and relationships, with healthcare professionals, is helping to improve understanding and the evaluation of best practice which ultimately benefits me as the patient.

As a volunteer, I have been able to use the power of social media to raise awareness through a video production, conference call events with NRAS, participating in surveys and getting stuck in with the RA awareness week every year. Participating in the Bupa half marathon to raise money for NRAS, was by far my biggest physical achievement since being diagnosed, and crossing that finish line whilst in complete physical agony really proved to myself that whilst this is a debilitating illness, nothing will stop me in achieving anything that I set my mind to!

Being a volunteer has helped me to gain a better understanding of how to live a full and rich life with my own disease, and to NRAS I am indebted! Wherever you are, and whatever your RMD, please join our volunteering community. You have no idea how much it will help not only others, but most importantly yourself!

Being a volunteer has helped me to gain a better understanding of how to live a full and rich life with my own disease



By Chris Lowe

NRAS Ambassador

# Greetings from sunny Manchester

from local NRAS Ambassadors.

Yes – it is actually sunny here in Manchester. What have we been up to as NRAS Ambassadors

We've been engaging with NHS staff, consultants, trainee GPs and researchers. It's an interesting process, as me and Ralph do a bit of a double act. We are like the two Ronnies of rheumatoid arthritis. It's always fascinating for us and a bit of an eye opener for them. We tell them our different stories of diagnosis, medication, struggles and living with RA.

We tell it as it is from the patients' perspective with our everyday life issues and complications.

Ralph's is the more positive story. He's doing very well on the meds, working and getting out and about. Ralph talks about his father and his struggle with RA, and how treatment has changed over the years.



Ralph on a horse!

But mine is a more difficult story, the 'what on earth are we going to do with her now' story. I tell them about my diagnosis. I went to the doctor with a lump on my elbow and at the time was taking no medication at all. He thought it was tennis

elbow. By the time I left I had a thyroid problem, rheumatoid arthritis and a strange Swedish disorder I couldn't even pronounce – Sjögren's Syndrome – never mind spell.

I tell them about my struggles with work and subtle discrimination due to this insidious disease. I started work late in the day because of the fatigue and consequently finished later

at night and at the time it took its toll on me. I struggled to re-educate my colleagues and managers on the impact of the RA. Some of them thought I just couldn't be bothered getting up in the morning.

I also explained the everyday hazards to the NHS staff about struggling to drive to work when your joints don't work and you're on a flare up. One morning I tried and tried to take the handbrake off the car and in desperation got in the passenger side and – with a superhuman effort – pulled the handbrake up with both hands and had to run round to the driver's side as the car started rolling down the hill. Not my best moment, I have to say. I subsequently had to retire on health grounds.

We also do a question and answer session to give medical personnel the opportunity to ask us anything we haven't covered and find out more about us. This is about life, but not as they know it – as we with RA know it and experience it.

Our goals for this year are to do more of these sessions and increase awareness whenever we can with medical personnel. I have a planned talk at the WI this month on 'Living with RA'. We hope to build up closer relationships with our local hospitals in terms of awareness, information dissemination and helping to get newly diagnosed patients steered towards NRAS for support and help.

Anyhow – best wishes to you all from the Manchester Ambassadors, and for now, it's Goodnight from me and it's Goodnight from him!

We hope to build up closer relationships with our hospitals



# Important Statement from NRAS about access to medicines

\* Please refer to our Coronavirus statement on Page 4 about medications

For some time, NRAS has been concerned that some Clinical Commissioning Groups (CCGs) have been artificially restricting access to advanced therapies (biologics, biosimilars/JAK inhibitors) and undertook a Freedom of Information request to all CCGs about this.

Last year we asked NHS England to look into this matter as we were advocating on behalf of a small number of people who had contacted us to say that they were being denied access to a fourth advanced therapy as previous treatments had failed to control their disease adequately.

We are very pleased to inform that the NHS have published clarification on the sequential use of biologic medicines via an Advisory Statement from the Regional Medicines Optimisation Committee which clearly states the following:



Regional Medicines Optimisation Committee  
(RMOC) Advisory Statement  
Sequential Use of Biologic Medicines  
January 2020

*"A policy adopted by a commissioner that would serve to limit patients' access to appropriate treatments based on a number of prior treatments being attempted would be counter to the provisions of the NHS Constitution."*

*The NHS Constitution pledges that patients have the right to drugs and treatments that have been recommended by NICE subject to being clinically appropriate, and patients have the right to expect local decisions on the funding of drugs and treatments to be made rationally and following the proper consideration of evidence.*

*Clinical assessment of the appropriateness of treatments should be the overriding factor rather than the implementation of policies for cost saving reasons."*

If you are someone who has had 2 or 3 advanced therapies but now need to move to another and are experiencing any difficulty in getting your treatment funded, please share this article with your consultant. We would also like to hear from you so please share your experience via email to [Samuel@nras.org.uk](mailto:Samuel@nras.org.uk)



# My Story

Joy Gravestock

**"Oh yes, you poor thing, this is definitely rheumatoid arthritis".**

Those were the first words I heard from my consultant as she held my hands almost two and a half years ago now.

Her diagnosing what was wrong was in many ways a relief. I had been unwell for months, and looking back realised an established pattern of unwellness over many years. Mysterious periods

arose in my life when I would feel impossibly tired, and I would struggle to move in the mornings, or I had one joint suddenly swell and become painful....yet each time I presented at the GP surgery, such obvious manifestations would have abated. My doctor husband had queried RA, but there was never any "evidence". We now believe I was probably presenting with palindromic rheumatism which can be a precursor to more consistent RA.

On "D day" (diagnosis day!) my relief was coupled with an almost immediate reduction of my physical pain as I had my first steroid injection. Miraculously within two days I appeared "cured"! Little did I know then that such a positive

response to steroids almost certainly indicates that an inflammatory arthritis is causing the problems. It has taken me the past couple of years to become acquainted more closely with my new "constant companion", RA.

My immediate priority was to ensure that my hands would not be further damaged. As a violinist it never for one moment entered my head that this disease was going to mess with my playing! I began methotrexate (tablets initially, "graduating" to injections) and thankfully this drug has to a great extent preserved my finger joints. This is not entire however and I currently have two extremely "fashionable" finger splints to prevent the "swan-necking" that is already occurring.

Before long though, my constant companion was taking up residence in other joints. Gradually over time my wrists, elbows, shoulders, hips, knees, ankles, and even my costal cartilage and manubial sternum have become affected. This has meant "doing the drug run" which all RA patients are no doubt familiar with. Sulphasalazine became toxic to me, and eventually I met the criteria to commence on biologics. Then began the litany of exotic and hard to pronounce named drugs! First benepali (which sounded deliciously like an Italian/Indian fusion meal!) which was unsuccessful. Then tofacitinib (sounded a bit like toffee, but made me very unwell). Currently about to start adalimumab (sounds like the newest member of the Teletubbies, though apparently it's not nearly as cute!).

This apparently experimental journey through medications has occurred with impossibly bad timing in my life (isn't it so for all of us?!). I had not long commenced a PhD when diagnosed. I was determined to carry on with my studies which I am passionate about. I work as a music therapist and am writing my thesis on music therapy as an intervention with adoptive families. As a violinist myself, I have long recognised the power of music. Prior to training as a music therapist, I was intrigued by music's multiple affects; it could induce powerful emotions in someone, or soothe a child to sleep, or enable someone with dementia to sing, or someone with Parkinson's disease to move more freely. Knowing the value of music in my own life caused me to embark on a career path which is deeply fulfilling for me and one where my violin has had a special role to play. There are misconceptions about what a music therapist does but at its



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As a violinist myself, I have long recognised the power of music.



essence music therapy is a relationship between two individuals, wherein people of all ages, whose lives might be impacted by injury, illness, disability, or emotional trauma can be supported psychologically and have special consideration given to their emotional, cognitive, physical, communicative and social needs.

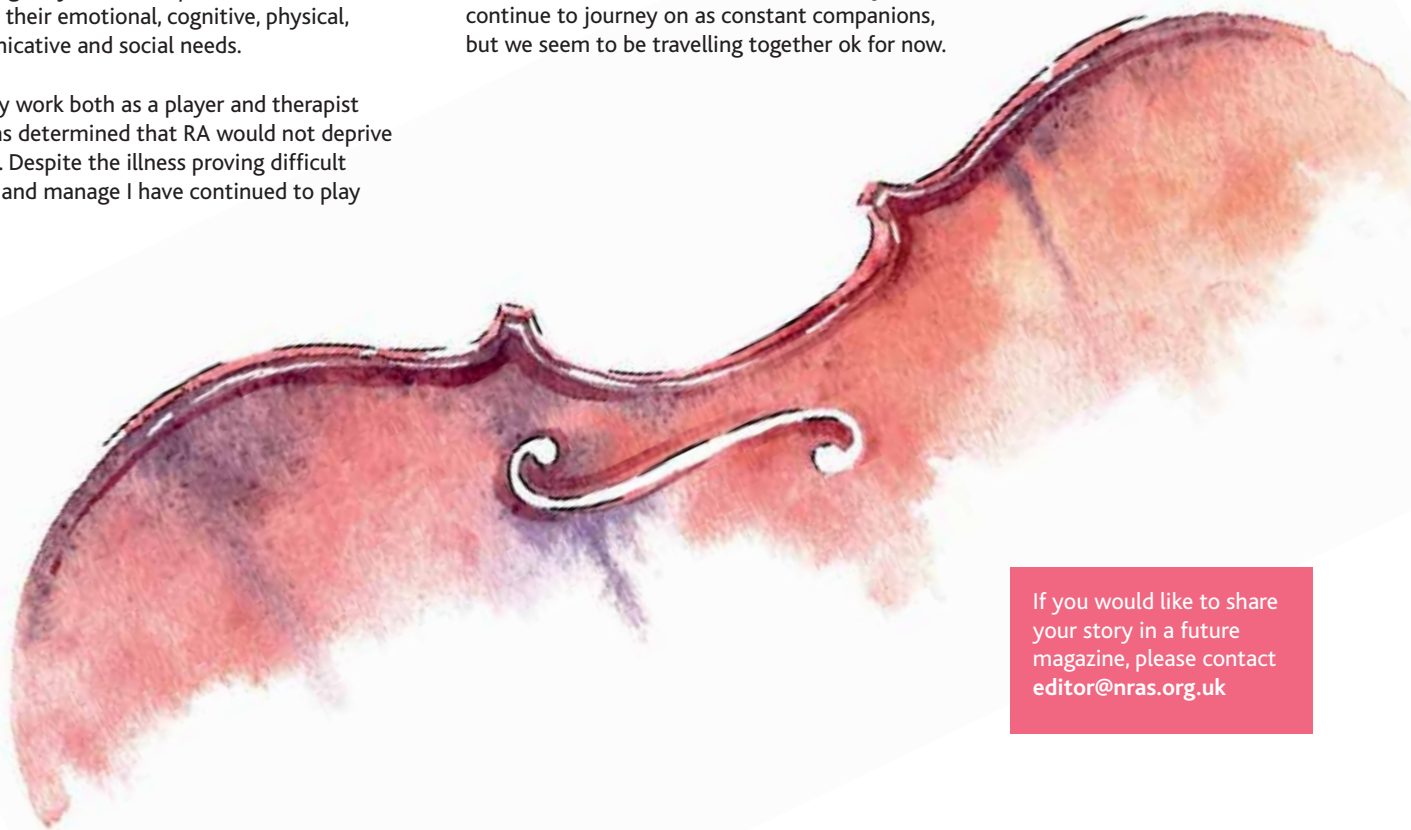
I love my work both as a player and therapist and I was determined that RA would not deprive me of it. Despite the illness proving difficult to treat and manage I have continued to play

(multiple orchestra concerts, many musical theatre shows, quartet gigs etc!). My PhD studies have meant presenting papers at international conferences, including the World Congress of Music Therapy in Japan! In addition, in 2019, I completed a book (available with Jessica Kingsley Publishers, September 2020) on music therapy and adoption and have had academic papers and book chapters published. I had to learn the trick of "mixing it up", i.e. ensuring my days are filled with varying activities...perhaps a bit of practice, a music therapy session or two, and some PhD work. This way I don't put stress on a particular joint for a long period.

Life had to change, that's for sure, but in many ways for the better. My constant companion has taught me to go more slowly, and given me fresh insights into the disabilities of people I work with. I intend to keep playing and was delighted to be able to play for

the NRAS concert last December. Opportunities to speak about the illness are important whilst showing that most definitely my whole identity is not invested in it. RA and I will inevitably continue to journey on as constant companions, but we seem to be travelling together ok for now.

I love my work both as a player and therapist and I was determined that RA would not deprive me of it.



If you would like to share your story in a future magazine, please contact [editor@nras.org.uk](mailto:editor@nras.org.uk)

# Events Diary

16 August	RideLondon – 100
13 September	Great North Run
7 – 13 September	NRAS Rheumatoid Arthritis Awareness Week (RAAW)
20 September	Brighton Marathon
26 September	The Gathering. Edinburgh, Scotland
4 October	London Marathon
11 October	Royal Parks Half Marathon
12 October	World Arthritis Day
17 October	Rheum for You Leicester Racecourse
6 November	Wear Purple for JIA Day



## Looking for a Challenge for 2020?

For more information contact [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk)

## You could win up to £25,000!

At the end of last year, we were delighted to have our 12th £1,000 winner on the NRAS Lottery! The winner was a supporter who has been an NRAS Member for the past six years. By playing the NRAS Lottery you could win anything from £25 to £25,000 and 50p in every £1 goes directly to supporting those living with RA and JIA in the UK. Why not encourage your family and friends to sign up or organise a work syndicate?

For every £1 you play each week, you'll receive a unique 6-digit lottery number.

- Winning numbers are revealed each week. Match your numbers to win up to £25,000!
- To win you need to match three, four, five or six digits of the winning number in the correct sequence.
- Players must be aged 16 years or over.

Join online <https://www.nras.org.uk/lottery> or contact NRAS and we can send you a postal form for you to complete and return (FREEPOST).

**Good Luck!**  
and Thank you for your support



BeGambleAware.org<sup>®</sup>

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