YOUR *Members' Magazine!*

NewsRHEUM

nras
National Rheumatoid Arthritis Society

SUMMER/
AUTUMN
2020

WEAR PURPLE FOR JIA
6th November

See inside for more info

NRAS
CHRISTMAS CARDS

Leaflet enclosed

RAAW
7th - 13th September

See inside for more info

By Clare Jacklin

NRAS CEO

Dear Members

I am writing this in early June and it is difficult to predict where we may be by the time you read this in early autumn. We are living through challenging and unprecedented times which are impacting on every aspect of our lives: the nation's health (both physical and mental), employment prospects, socio-economic systems, family life, educational institutions and practices, and global relations have all been affected by this global issue. Having lived in this strange new world for many months, with the constant news reports and daily briefings we can easily become de-sensitised to the impact in our country, communities, and families on a human level. Many of you may have been personally impacted by this pandemic, either through the loss of a loved one, friend or neighbour so you will already be only too aware of the devastating impact of COVID-19 on individuals. To you I wish to express my own sympathy as well as on behalf of the entire NRAS family. Many more of you are coping with shielding or enhanced social distancing that comes with their own challenges and hardships, to each and every one of you I want to say we are here for you every step of the way to help and support.

Many of our friends and members working in the NHS have made huge sacrifices and put their own health and safety at risk in order to care for those in intensive care or COVID-19 wards, some of whom have sadly paid the ultimate price. We may have stopped clapping on a Thursday evening but, we have not stopped being immensely grateful and in awe of all those key workers not just in the NHS but in our wider communities. THANK YOU to you ALL.

On the subject of thanks I must also express my personal thanks to the amazing support I've had from all my colleagues at NRAS, our volunteers, our board of Trustees and especially YOU, Members of NRAS for the many personal messages of support I've received. This has been my first year as your CEO and I am positive I would not have coped without knowing I had such a great team around me and great support from you all out there. THANK YOU.

The pandemic has most definitely dominated the majority of our work at NRAS since March and we had to pause many of our projects to ensure, that despite a massive reduction in income due to fundraising activities being severely reduced, we could continue to deliver our core services. I am pleased to say that our prompt and decisive action in those very early days has, so far, paid dividends and we are weathering the storm quite well but, there is still a long way to go. Despite all these challenges, remarkably we have managed to maintain not only NRAS' core services but we've been working hard on developing our two new websites. Additionally, we have started work on upgrading the "Know your DAS app" which I believe may start to play a key role in RA care going forward (more about that later in the section on COVID-19).

So...what's ahead for NRAS and RA rheumatology care? Let me consult my crystal ball! Joking aside, it is a bit like that, as no-one really knows what the next few months will bring. However, I want to reassure you that NRAS as a charity is in a good and stable position due to prudent and cautious planning. We are also embracing new ways of working and offering support, which while introduced as a direct response to COVID-19 are likely here to stay. I'm talking about; our new 'Chat Bot' Susan on the website, the new virtual Rheum Zoom; virtual focus groups; virtual local NRAS group meetings; online well-being sessions; as well as our self-referral 'Here for You' service. Every cloud has a silver lining and like many other businesses, the pandemic forced us to rapidly adopt new ways of working and communicating, which we are now feeling comfortable with adopting more permanently.

Likewise, changes have occurred in rheumatology care with many of you having virtual consultations during this pandemic. NRAS is working with a number of units as they begin their 'recovery' programmes, to help give input from the patient's perspective as to what works and what doesn't. We should remember that the 'old' health service wasn't perfect and it didn't necessarily work for everyone, so these days of recovery present us with great opportunities for everyone- the NHS, health professionals and patients to work together to build a new and improved way of caring and treating those with long term conditions like RA.

I am very much a glass half full sort of person and truly believe that there are opportunities for positive change that will come out of this crisis. To quote Francis of Assisi, [illegible]

Finally, my wish to you all is to stay safe and stay positive.

Warmest regards

Clare

Clare
Chief Executive

P.S A great way to support NRAS is by joining the NRAS lottery and/or buying Christmas cards. Please see the two leaflets enclosed.

Front cover:
Thank you to our key workers

NewsRHEUM

Contents

To comment on this issue or to submit a story or article for a future issue please email **editor@nras.org.uk**

Editors of this issue;
Eleanor Keenan and Tracy Bracher

Membership Survey

Thank you to everyone who took the time to give feedback in our Membership Survey in March of this year. Of course we realise we launched the survey just as events in the world were starting to unfold and the timing might have seemed a little strange but we were trying to keep working on our projects as planned for as long as we could. The information we gathered has been really useful and we have been busy working on Membership for 2021. Of course now the world is quite a different place and some of the answers you gave may not be as relevant today as they were back then, and we may before we launch any new Membership packages ask you a couple more questions in E-News but we just wanted to take a moment to thank you for your input, your views are always important to us as it is and always will be YOUR Society.

Thank you,
Tracy
Membership Officer

Members' E-Newsletters

As well as this lovely magazine, every month we send out an E-Newsletter to our Members, to keep you up to date with all the latest news in between the magazines. It's a great and cost-effective way we can keep in touch with you on all the latest research, opportunities to get involved with campaigning and much much more. If you haven't been receiving the E-Newsletters do email us at membership@nras.org.uk to check we have your up to date email address and contact preferences.

COVID-19

Resources and research update

All through this pandemic we have endeavoured to keep you as up to date as possible with information and where to get the support you need, when you need it.

The website is obviously an ideal platform for this and we are able to upload information as it becomes available to us.

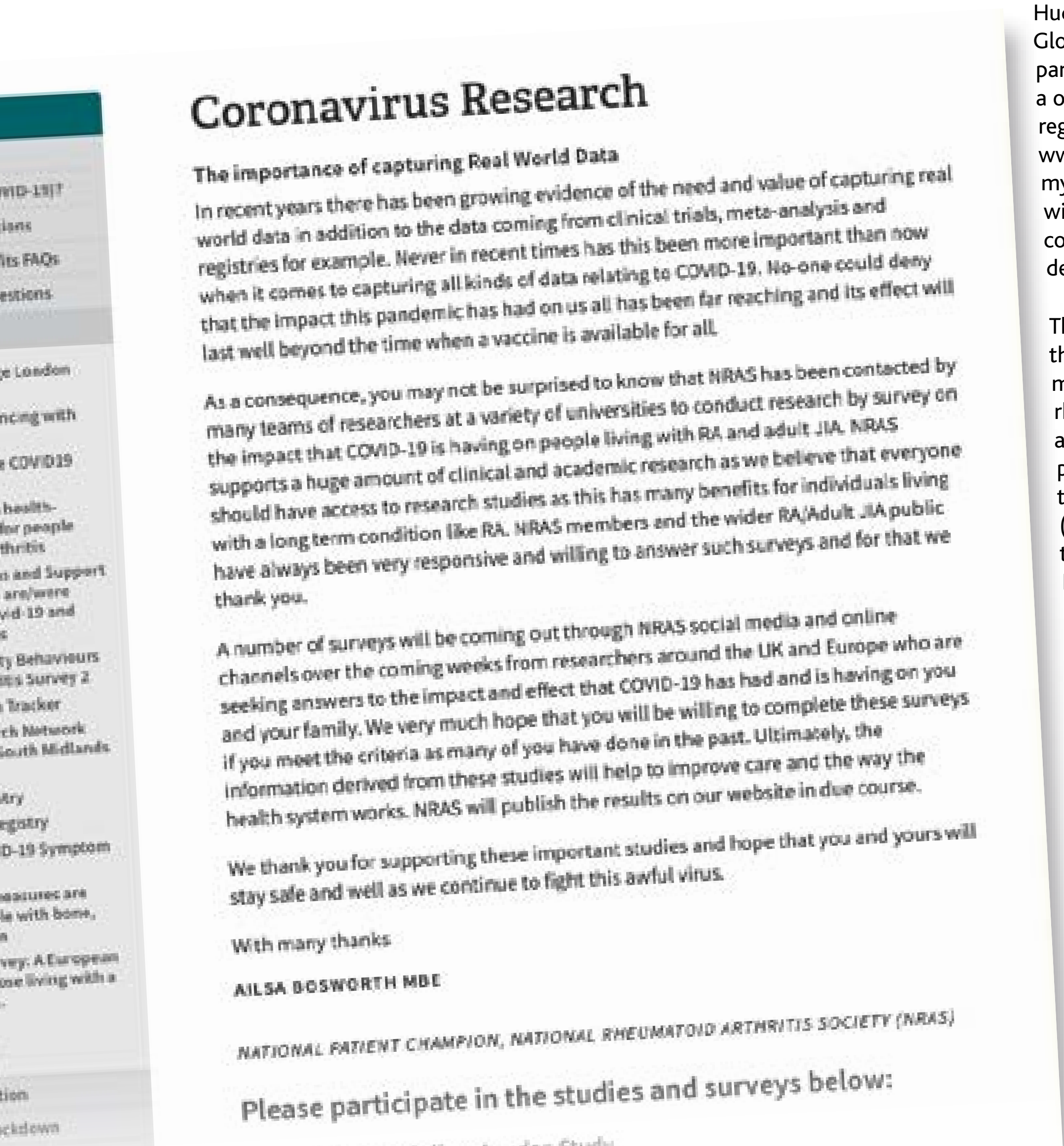
One of the first areas we tried to address is the frequently asked questions. Here you can see what sorts of questions our helpline staff were being asked on nearly every call and email.

We've also developed a section to address employment issues and another about emotional well-being during the crisis. There are links to information and many resources that are freely available.

The Facebook weekly live sessions proved incredibly popular, as Ailsa mentions in her piece, and from July, they have been reduced to monthly but we will continue to broadcast them as long as you find them helpful and informative.

Another area that many of you will want to participate in, I'm sure, is research into the impact of COVID19 on those with rheumatic diseases, including impact on emotional and mental well-being etc. As I write, we are supporting research from Kings College London, University of Seville, University of Birmingham, University of Southampton, University of Huddersfield as well as the European and Global COVID registries. You can all play your part in completing these surveys. Some are a one-off call for data, some require more regular input - full details can be found at www.nras.org.uk/coronavirus-research. It is my firm belief that the data being gathered will be what eventually give the scientific community the knowledge they need to defeat this virus.

The European EULAR COVID-19 registry that gathers clinician reported data, monitors the outcomes of people with rheumatic diseases who are confirmed as having COVID. As of 8th June, 2,149 patients' details had been entered with the UK contributing 18% of the data (378). The most common diagnosis of those in the registry was unsurprisingly RA - 37%, Spondyloarthritis -15% and PsA (Psoriatic Arthritis) -12%. Of the 2,149 patients with rheumatic diseases who were positive for the virus only 28% had no reported 'other condition' (comorbidity) and less than half required hospitalisation.



Coronavirus Research

The importance of capturing Real World Data

In recent years there has been growing evidence of the need and value of capturing real world data in addition to the data coming from clinical trials, meta-analysis and registries for example. Never in recent times has this been more important than now when it comes to capturing all kinds of data relating to COVID-19. No-one could deny that the impact this pandemic has had on us all has been far reaching and its effect will last well beyond the time when a vaccine is available for all.

As a consequence, you may not be surprised to know that NRAS has been contacted by many teams of researchers at a variety of universities to conduct research by survey on the impact that COVID-19 is having on people living with RA and adult JIA. NRAS supports a huge amount of clinical and academic research as we believe that everyone should have access to research studies as this has many benefits for individuals living with a long term condition like RA. NRAS members and the wider RA/Adult JIA public have always been very responsive and willing to answer such surveys and for that we thank you.

A number of surveys will be coming out through NRAS social media and online channels over the coming weeks from researchers around the UK and Europe who are seeking answers to the impact and effect that COVID-19 has had and is having on you and your family. We very much hope that you will be willing to complete these surveys if you meet the criteria as many of you have done in the past. Ultimately, the information derived from these studies will help to improve care and the way the health system works. NRAS will publish the results on our website in due course.

We thank you for supporting these important studies and hope that you and yours will stay safe and well as we continue to fight this awful virus.

With many thanks

AILSA BOSWORTH MBE

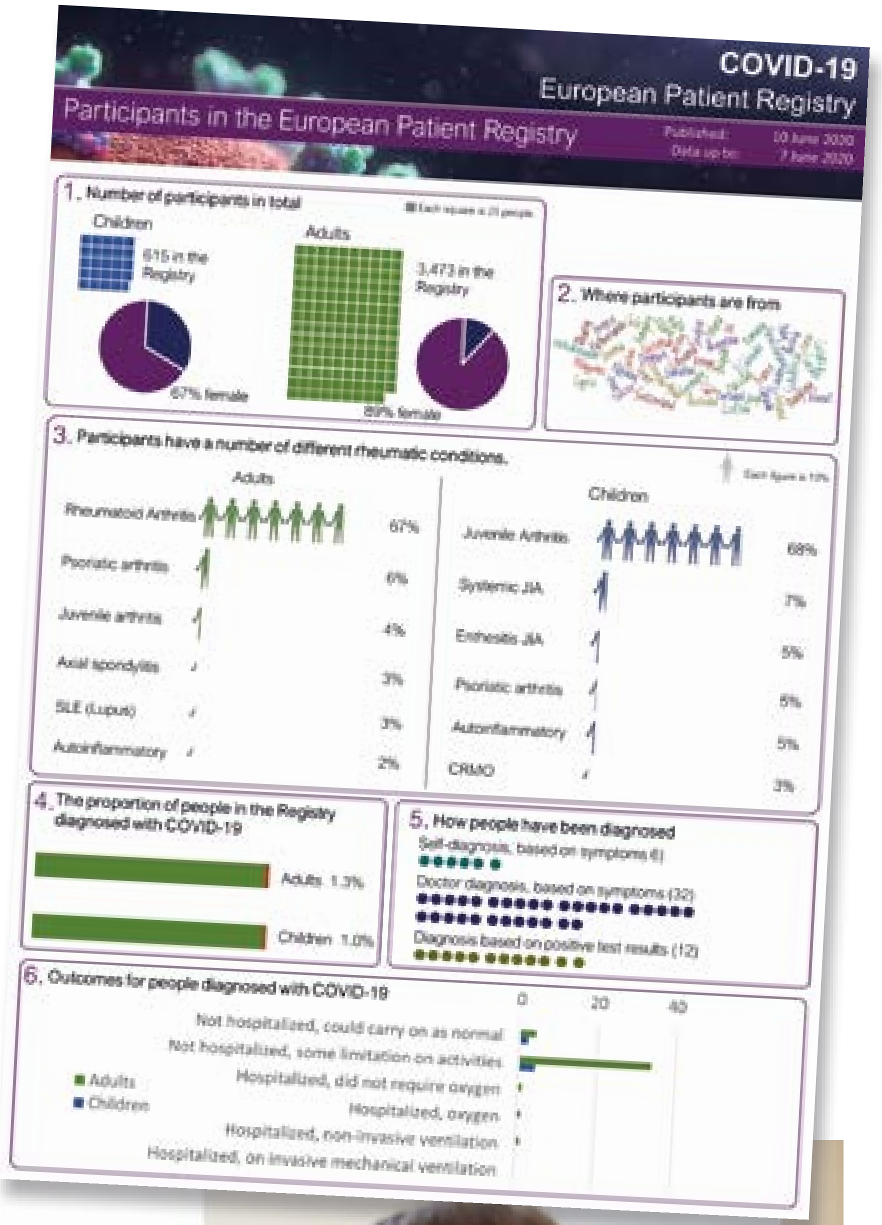
NATIONAL PATIENT CHAMPION, NATIONAL RHEUMATOID ARTHRITIS SOCIETY (NRAS)

Please participate in the studies and surveys below:

Many of you may have taken part in the European Patient Registry so I thought I would share with you some top-line findings.

As of 7 June 2020, there were 3,473 adults and 615 children included in the COVID-19 European Patient Registry. Of these, to date 44 adults (1.3%) and 6 children (1.0%) have been diagnosed with COVID-19 infection. You can still participate in this patient registry by visiting www.jarproject.org./covid.

All the above datasets are being shared with the Global data registry and will, in time, give us much clearer information on how those with immune-mediated conditions react to the virus and how the medications used to treat such diseases are playing a part in either reducing or increasing the severity of the virus if contracted. Early findings appear to indicate there may be an element of protection from serious consequences of the virus if someone is on certain advanced therapies. I hope by the time you are reading this we may well have more up to date and evidenced data which we will be able to share with you via our website and E-newsletters.



COVID-19
European Patient Registry

Participants in the European Patient Registry

Published: 10 June 2020
Data up to: 7 June 2020

1. Number of participants in total

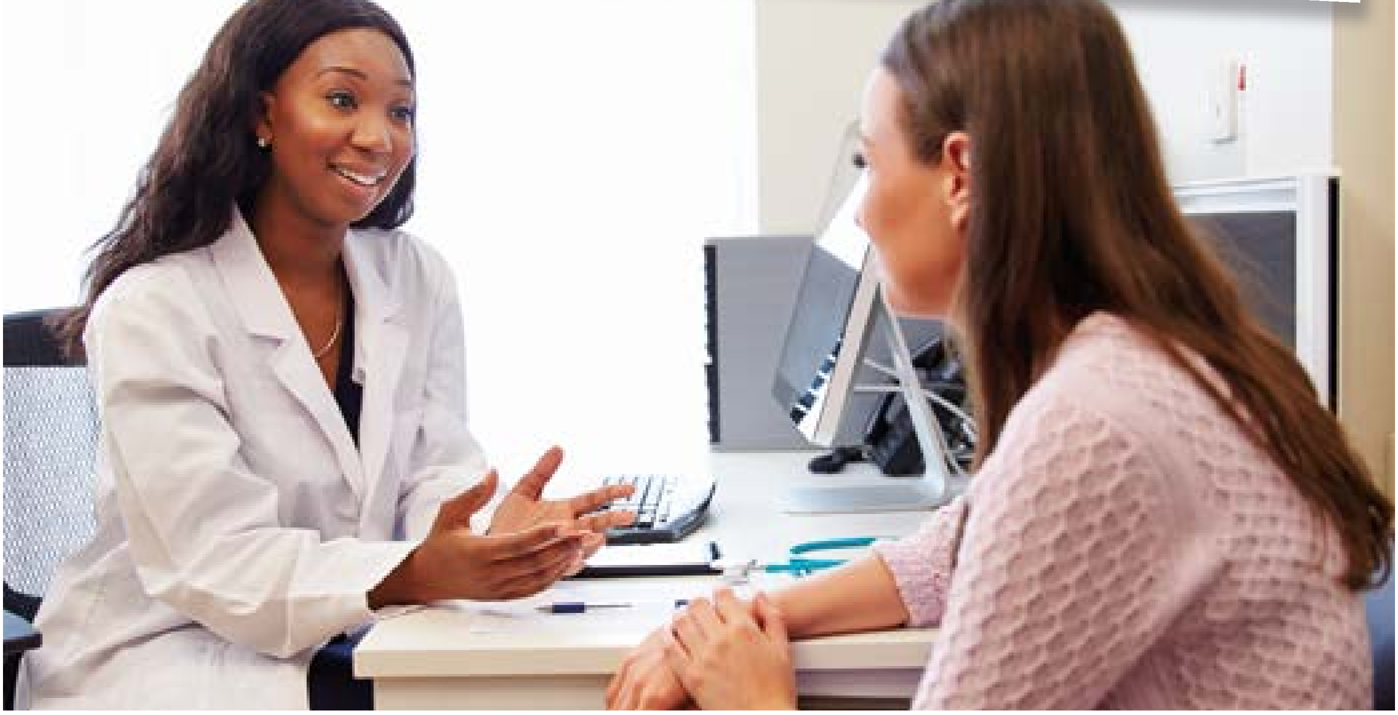
2. Where participants are from

3. Participants have a number of different rheumatic conditions.

4. The proportion of people in the Registry diagnosed with COVID-19

5. How people have been diagnosed

6. Outcomes for people diagnosed with COVID-19



By Di Finney

Progression in rheumatology nursing

Rheumatology Nursing has evolved so much since I started working in the specialty, it's hardly recognisable in some aspects yet the nursing components remain the same. We are all still here to support people with various forms of arthritis and related conditions. This year is also the Year of the Nurse and we all had loads of things lined up to celebrate and acknowledge the role of nursing. It's also the year we were hoping to launch the much-awaited Royal College of Nursing Rheumatology Nurse Competency Framework with a big bang.

> The main purpose of the framework document is to keep patients safe and support provision of the very best quality of care.

Then came COVID-19.....Lockdown happened a few days after we launched the ground breaking Competency Framework. We no longer had conferences to speak at, and very little exposure beyond virtual media. Also many of my colleagues and friends, rheumatology nurses, were redeployed to COVID wards or other areas to allow redeployment of other NHS colleagues so rheumatology services were cut back to skeleton crew. No time for them to think about downloading and using the new framework unfortunately so there is less awareness of this great resource. Uptake therefore has been slower quite understandably, however I am delighted to say despite all the unprecedented circumstances, a third of rheumatology nurses have downloaded it at the time of writing this article and we are continuing our awareness campaign via various publicity channels. We aim for at least 60% of rheumatology units to be using it by the end of 2020 and will be undertaking an evaluation process in due course.

The main purpose of the framework document is to keep patients safe and support provision of the very best quality of care. It supports our nurses' career progression as well as highlights the important and vital roles nurses in this field perform. I hope this is an empowering document.

I will now share with you some background as to the process by which the competency framework was designed, and how I think rheumatology nursing is progressing.

I began my career in rheumatology in the 1990s and followed in the footsteps of names rheumatology nurses and yourselves may be familiar with such as Sarah Hewlett, Jackie Hill, Candy McCabe, Sue Oliver and Sarah Ryan. Many of them who have contributed articles for this very magazine and NRAS resources over the years.

In my early days in rheumatology my role developed from the need for basic joint counts and my training was essentially on the job and informal. My role evolved based upon what was needed by the patients, and what new developments were occurring in the field of rheumatology. I quickly found I was assessing people, monitoring their progress, and supporting them to manage at home. My patient assessment was only required to be relatively basic, despite acquiring a huge amount of knowledge studying for a Masters in clinical science (which I had started in my previous role in intensive care). My role changed when biologics arrived on the scene in early 2000s. Whilst we did get a huge amount of paperwork there was also a need for standardised assessment which drove structured protocol development. Specialist nurses rapidly became essential members of the rheumatology team and developed more advanced skills such as joint injections and prescribing. My competency to do so was based on academic courses where other nurses underwent in-house training on joint injections for example, or trained within a network of sponsored events, or at training sessions not specifically designed for rheumatology nurses. The role and responsibilities of the rheumatology nurse varied depending on where you worked.

In 2017 the Royal College of Nurses (RCN) considered all of the changes and variety of roles that had happened over the years and we all agreed there needed to be clarity about the competency of those delivering care, at all levels in a modern health care system. This was supported by research that had been done and by a survey where rheumatology nurses all responded that they would like a national competency framework.

There are a wider range of training opportunities which have the potential to attract nurses into rheumatology nursing, but it is also true that the curriculums vary and are often medically led.

Nevertheless, I whole heartedly agree with Sue Oliver's statement in the foreword of the framework 'the future is bright for rheumatology nursing'. This is for several reasons; the number of specialist rheumatology nurses is growing and the demands of the services we work in are also increasing. With this in mind we, (nurses), have become a critical mass within the rheumatology specialism. We can no longer be viewed as a helpful addition to the units but pivotal to good patient care. This is supported now by evidence, and often quoted by third sector organisations representing patients, such as NRAS. We really value this support. We have learnt a lot from changes made during COVID-19 which will improve future services.


Royal College of Nursing
2020
A Competency Framework for Rheumatology Nurses
CLINICAL PROFESSIONAL RESOURCE

Having a competency framework for rheumatology specialist nursing will help everyone (including educators, employers and patients) to understand our roles, ensure centralisation of curriculums, define a high standard of skill and knowledge (and dare I say autonomy) to improve patient outcomes and support nurses' career development. I would like to acknowledge the hard work of the whole team in producing this framework and hope you all find it a reassuring fact that there is so much enthusiasm for it.

I would like to acknowledge the hard work of the team who put this together. Julie Begum, Lisa Howie, Polly Livermore, Louise Parker, Helen Smith and Ruth Wylie.

> The future is bright for rheumatology nursing

RheumZoom

East and West Sussex

NRAS runs a programme of Rheum for You conferences each year going to different parts of the country to meet as many of NRAS Members and people living with RA as possible and bring them presentations from expert speakers and of course some of the NRAS team. Our planned programme this year included a Rheum for You in Brighton in June and we were about to start promoting it in January when there began to be news of a potential global pandemic. We held off to see what happened, but it soon became apparent we would have to put all our plans for face to face meetings on hold for some time.

A new word to our vocabulary, Zoom! Who had even heard of Zoom in March but yet here we all are 5 months later and our work and social lives are largely conducted over Zoom!

So, the idea formed to try and bring the planned Brighton event to our service users in the area via Zoom instead. Our keynote speakers, Di Finney, Consultant Rheumatology Nurse at Sussex MSK Partnership Central and Stephanie Butler, Lead Specialist Pharmacist Rheumatology, Brighton and Sussex University Hospital Trust, gladly stepped up to the challenge of moving to a Zoom event.

We even managed to find a Tai Chi for Arthritis instructor, Sally Hemmings in West Sussex who was already holding her classes over Zoom and was willing to do a short exercise session to get everyone moving after the tea break.

We made the event really interactive to keep it interesting for everyone and we popped everyone into "Tea rooms" during the break so they had a chance to chat in small groups over a cuppa.

The feedback from the event was really positive and we received some great suggestions for improving future events. Everyone said that they would like to have a mixture of both face to face meetings and online events and also suggested Rheum Zooms should become a permanent fixture in our NRAS calendar! So, keep an eye on E-News for future Rheum Zooms!

Newsflash - Our next Rheum Zoom will be for Scotland on the 2nd September. Head over to our website www.nras.org.uk/rheum-for-you- for how to book your place

How NRAS groups transformed during lockdown

'It's so good to meet up with friends and exercise and keep sane.'

Julie Dickins – East Dorset

Before lockdown the East Dorset NRAS group provided weekly hydrotherapy and exercise groups and monthly coffee mornings. Luckily, many of us were already connected on social media and in a WhatsApp group.

At first we shared jokes to keep up our spirits but we all missed the camaraderie and support of our meetings and the motivation of our exercise sessions, so we set up two groups on Messenger to video call and exercise together. We go through a range of exercises from squats to stretches whilst we chat and laugh together.

These twice weekly calls have helped to add structure to our lives and keep us moving. The feedback has been great.

Sally said 'It's so good to meet up with friends and exercise and keep sane.' Jane added that she 'Loves the humour and support of this group - people who understand the pain, frustration and limitations but stay motivated, funny and supportive. Even when people can't join the video calls there are messages to read and news and advice to be swapped. Bernie said without these groups she would have become, 'Reclusive, unhealthy and lazy'.

We will continue to do this until we can all meet again.

Katy Pieris – Croydon

Dance can sound a little intimidating if it isn't something that you regularly do. There are many forms and for the Croydon NRAS group's June meeting they took part in a session run by SLiDE (https://slidedance.wordpress.com/), which is a local charity based in South London with a focus on running inclusive dance and movement experiences for the local community.

The session was run over Zoom with a group of ten and the focus of the session was gentle movement to music giving everyone the opportunity to move and express themselves to whatever level they were comfortable. It was a great way to see some regular faces and others who may find it hard to get to the normal regular meetings. Dance will definitely be featuring on future meetings.

A great way to see some regular faces

NRAS is *Here for You*

When the coronavirus pandemic began earlier this year and many Members living with RA found themselves shielding, NRAS called upon its amazing peer to peer support Volunteers asking them to sign up to a new telephone service supporting those isolating. The response was overwhelming and as a result, the "NRAS is Here for You" initiative launched at the end of March. By the end of June, NRAS is Here for You Volunteers had responded to almost 80 requests for support across the UK. We would like to thank every one of these Volunteers who have supported others with RA whilst living with the condition themselves. Here are a few of their stories

Here for You Volunteer Nadia Shaw

My name is Nadia and I am a Telephone Support Volunteer for NRAS. My reason for volunteering was because I have used the Helpline service myself when I did not know what to do. When I was given the diagnosis of RA the consultant told me there was nothing he could do. This was thirty odd years ago. I was never told how to gain support in any way.

When I realised that I had to find things out for myself I came across NRAS and phoned for advice and help. Even if I was in tears the person on the end of the phone was there for me and I knew it by the way they listened to me. I got amazing advice from them and was told about a consultant to help me. It also made me realise what all my symptoms were and that there could be ways of helping myself.

Enough of me, but I really wanted you to know that the NRAS Here for You telephone support service is definitely worth contacting. You may want someone to listen, cry, scream or ask for help. Although no medical information can be given, the fact that there is someone giving you time means everything.

I really feel that being an NRAS 'Here for You' Volunteer also helps me to try and understand how we all have to deal with life around the many issues RA can bring.

Here for You Volunteer Annmarie Bell

From the moment I was contacted by Janet at NRAS I knew I was going to volunteer for 'NRAS is Here for You!'

I already have a positive experience as a Volunteer and with the ever-changing situation of COVID-19 I wanted to be part of the solution.

If I'm honest, I felt a little nervous making my first call as unlike my usual peer to peer to calls, I did not have a list of specific concerns that the call recipient wanted to talk about. This was much more of an informal chat with someone struggling with the challenges of the pandemic situation. However as soon as the conversation began I felt more at ease and was once again reminded of the fantastic community which NRAS is.

Speaking with others who have RA is a truly uplifting experience. From those newly diagnosed, to those who have lived with the condition for many years, listening to the journey of others and being able to share my own experiences to help and support them is a privilege. As long as people want support I am here to listen.

Here for You Volunteer Katy Pieris

I became an NRAS 'Here For You' Volunteer because having RA is a debilitating and isolating disease and like me, sufferers are shielding due to the medication compromising our immunity. Whether you live alone or within a busy household, it can often be difficult to talk about your condition as only you are experiencing the unique challenges that come with it. By sharing my experiences and being a friendly voice at the end of the phone I hope I can have a positive impact to those in need.

So far, I have spoken to a wide variety of people, ranging from those newly diagnosed, long term RA warriors and everything in between. The regular social interaction and the knowledge I am not alone is really helping me through this mentally and physically challenging time.

COMMUNITY FUND

[illegible]

> *'As long as people want support I am here to listen'*

Gifts in Wills

A considerable amount of the services NRAS delivers are funded by generous gifts in Wills.

These wonderful gifts have helped NRAS provide vital services, and develop new services, to those living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) across the UK.

Gifts in Wills have helped NRAS:

- Provide our vital information and support services including the NRAS helpline, peer to peer support services, webinars, patient information events and educational booklets.
- Start the planning and development of a Digital Self-Management Programme. This programme will be designed to build the knowledge, skills and understanding around supported self-management of RA. Modules will include expert talks, animations, videos and interactive content.
- Begin the planning and development of new booklets for children and young people with JIA as well as their parents, carers and healthcare professionals. These resources will provide information around medications and treatments and practical support towards effective management of pain and fatigue.

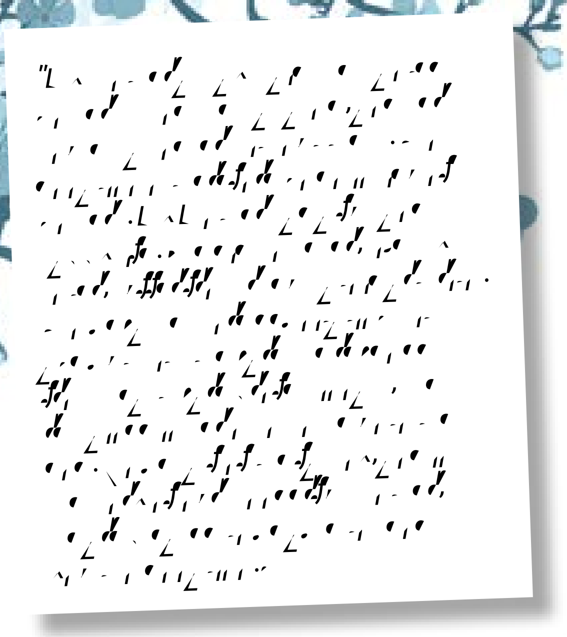
If you have any questions about leaving a gift in your Will please contact Emma Spicer. Emma would be more than happy to answer any of your questions.

Contact Emma on espicer@nras.org.uk or 01628 823112

Remember a Charity week will take place on 7th - 13th September in 2020. For more information visit our website.

A lasting gift...

In October we received a wonderful letter from Deborah Mason who had chosen NRAS to receive donations in lieu of flowers in memory of her mother, Marina Roche. In her letter she wrote:



Donations made in this way make a huge difference to our work. In 2019, funds raised though gifts in Wills or donated in memory of a loved one have contributed to the development of new RA and JIA NRAS websites. The JIA website was launched in July of this year, with the NRAS website launch due to follow later in 2020. These new digital platforms will be easy to use and capable of delivering a wider range of interactive patient support, e-learning videos and video learning programmes. Making useful and practical information as accessible as possible to RA and JIA patients, now and in the future.

NRAS is truly grateful to all the individuals, friends and family members, who lost a loved one and chose to honour their memory with a donation to the charity. You have supported others living with RA and JIA in an invaluable way – thank you.

If you would like any further information please contact fundraising at 01628 823524 or fundraising@nras.org.uk

Good Boost moves on to dry land in response to Coronavirus

By Ben Wilkins

CEO, Good Boost

Good Boost is a social enterprise that uses clinical technology to transform public swimming pools into therapeutic spaces for people living with musculoskeletal (MSK) conditions. In response to COVID-19, they're adapting their world-leading technology into a solution that supports people at home. Previously, the artificial intelligence (AI) powered software created an aquatic rehabilitation program on waterproof tablets in pools. This AI has now been 're-trained' to support participants on land, using their own phone to follow individually tailored exercises at home.

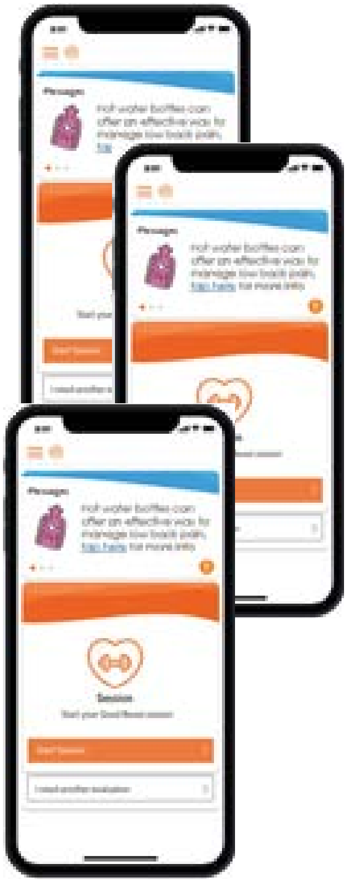
Good Boost, who champion the phrase, 'Move More, Have Fun, Feel Better', started out as a community health research project in 2015 and have now grown into an established social enterprise, working across the UK from 2018. Their mission is to create more affordable and accessible options for MSK community health services. Good Boost uses technology at the forefront for change.

With MSK conditions affecting over 18 million people across the UK, and with millions of physiotherapy and joint surgery appointments postponed due to COVID-19, there is an ever-growing need for solutions that provide personalised support at home. In response, Good Boost's team of physiotherapists, osteopaths, MSK researchers, software engineers and AI specialists have been working around the clock since March, to redevelop their validated software to provide home-exercise programs. The team have also been running 'virtual focus groups,' inviting people living with a wide range of arthritis and pain conditions to offer their thoughts and feedback on the features, function and design of the app to make sure that it's fit for purpose and easy to use ahead of the summer release. Thank you to the NRAS Croydon and East Dorset groups for participating in this feedback.

Using the Good Boost app starts with an initial registration just like the consultation you would complete with a Physiotherapist. You provide information on your movements, overall health, your conditions and where you have difficulty or experience pain. This information is used to calculate the most suitable exercises for you based on research evidence and clinical best practice. These exercises are demonstrated on the app using easy to follow videos. After your session, you can provide more feedback so that the software continues adapting and evolving your exercises week-to-week, personalised to you.

Good Boost has been funded by Innovate UK to complete all the clinical and technical developments to make this possible, as part of Innovate's 'business lead response to COVID-19.' They have won multiple awards, been selected as one of twelve organisations on Microsoft's 'AI for Good' accelerator and been independently reviewed by Physiotherapists and medical-app specialists. They have also been recognised for their technology's ability to cut through health inequalities by aiding accessibility and affordability, encouraging everyone to 'love looking after your health'.

The Good Boost app is due to be released on the 14th August and will be available for download on Android and Apple phones. For the first two months it's free to use, followed by a £3.99 monthly subscription thereafter. You can expect to find an intelligent, individually tailored app which adapts to your needs and revises your exercises based on your feedback, just like a human therapist would. It allows for self-management of many MSK and pain conditions and is particularly beneficial for those unable to access their usual therapy sessions due to the pandemic.



More information on Good Boost can be found at: www.goodboost.org

COVID-19 and Ethnicity: Challenges in Rheumatology

By Kanta Kumar, Shirish Dubey, Ash Samanta, Ailsa Bosworth, Arumugam Moorthy

The coronavirus disease 2019 (COVID-19) pandemic has impacted internationally since March 2020. Data from Office of National Statistics in UK and Centre for Disease Control in USA suggest people from Black Asian minority ethnic (BAME) backgrounds have been disproportionately affected by COVID-19. Reviews have highlighted the huge inequalities that are apparent despite the valiant national and international efforts to fight this global pandemic. The rise of COVID-19 among BAME communities can be due to the increased rates of existing co-morbidities, deprivation and other social and cultural factor. Current ongoing studies indicate the possibility of genetic link to increase predisposition of COVID-19 among BAME. However, mortality rates with COVID-19 in both India and Pakistan remain low at ~3-4% (data sourced 10th May 2020). Vitamin D deficiency and obesity which are common among BAME patient groups make this group more susceptible. People living with rheumatological conditions who are on immuno-modulatory or immuno-suppressive medications are also at greater risk of infections. Health Foundation data suggest that key workers in London are more likely to be from a BAME background thereby resulting in greater exposure. Moreover, insurance charges and lack of universal healthcare provision in USA may be barriers for this group in terms of accessing high quality healthcare.

Previous research has shown that healthcare provision in chronic diseases in BAME populations is generally inferior to that experienced by White British population or local population. Delay in help seeking behaviour noted among BAME communities and to adhere to self-management programmes makes this worse. We have previously identified several barriers to treatment access and adherence and their impact on poor medication adherence. Cultural and illness beliefs were noted to play an important role in how these communities approach healthcare. In rheumatology practice, colleagues acting as Ambassadors for Ethnicity Health in Rheumatology have lobbied for national data sets to be collected including infection and death data by age, region, gender, ethnicity, social deprivation and co morbidities. We are aware that local and global registries in rheumatology still lack detail, control arm and often have very small number of patients from BAME backgrounds, hence are unable to provide any meaningful outcomes in this context. More granular data needs to be made available within the healthcare context in order to understand these discrepancies.

There has been a growing concern about the actual level of shielding and self-isolation amongst BAME communities and how strictly or well these communities may be adhering to the Government's guidelines. In the UK, the National Rheumatoid Arthritis Society (NRAS) report that their helpline has been deluged with enquiries from worried and anxious people with RA but very few of these are from BAME communities. Although our group has produced some educational videos to try and explain the current situation to patients, accessing this has been patchy. It does appear that culturally and linguistically appropriate advice has still not reached BAME patients. There are no clear data to demonstrate whether people are following advice or stopping their medications and how they are coping with 'shielding' or feeling supported during this challenging period. In the UK, this anxiety has led the authors to devise a short survey between hospitals serving large numbers of people from BAME communities.

As we progress over the next 12 months with this pandemic there is an essential requirement for additional in-depth understanding from local, national and international data on health-seeking behaviours and the clinical experiences of different ethnic groups during COVID-19. What are the social, cultural and psychological implications of COVID-19 on these communities Globally? How are current beliefs and attitudes being accommodated in situations of quarantine, isolation and shielding? Might these views contrast or align across or within different ethnic groups? How does population density and overcrowded housing fit into this equation? Are

> In the UK, the NRAS helpline has been deluged with enquiries from worried and anxious people with RA but very few of these are from BAME communities

these groups getting access to the same level of care as other groups? These fundamental questions require serious consideration.

Trials comparing outcomes between groups need to be large with strategies for recruitment and funders need to understand the necessity of inclusiveness when designing such trials. Participation of other stake holders such as general practices, pharmacists, Social Care workers in socially deprived areas should be involved in this proposed work. Having a suitable range of culturally, linguistically adapted and validated instruments which assess outcomes is essential in comparing outcomes that go beyond the COVID-19 phase. Although ethnic inequalities in rheumatology outcomes had been identified more than a decade ago there has, regrettably, been very little progress. The current crisis is exacerbating this long standing unacceptable health inequality in our society.

We believe the lessons learnt during COVID-19 may shine a crucial light on these issues and thus gain the attention required from clinicians, policy makers, national and international society, patient charities to work harder to reduce the health inequalities. This is the ideal time for us to reflect, share our challenges and experience and learn from our international counterpart facing similar challenges. This will help us to develop clear evidence bases risk stratification criteria for BAME patients which can be shared internationally. Research around ethnicity must be prioritised and collaborated by health care providers around the world to tackle the biggest healthcare challenge we have all seen in our lifetimes. Whilst we may be over the peak, there is likely to be a lower level of prevalence of COVID-19 that we will have to live with (until there is a vaccine or definitive treatment). The choices we make now will live with us for a long period of time.

This article was published in Rheumatology, Volume 59, Issue 8, August 2020, Pages 1802–1803, https://academic.oup.com/rheumatology/article/59/8/1802/5858930.

For references, please contact enquiries@nras.org.uk.

Research around ethnicity must be prioritised

By Ailsa Bosworth, MBE

National Patient Champion for NRAS

Have you seen our COVID-19 video in Hindi?

In April, rheumatology health professionals from the Universities of Birmingham and Oxford joined the National Rheumatoid Arthritis Society (NRAS) in reaching out to Asian people living with inflammatory forms of arthritis (IA) (in particular, rheumatoid arthritis (RA)) with information on how to keep themselves and their families safe from coronavirus. Dr. Kanta Kumar and Dr Shirish Dubey recorded a special video – in Hindi – aimed at helping Asian people with IA/RA, who do not speak English as a first language, protect themselves from the threat of COVID-19.

The video is available on the Apni Jung अपनी जंग area of the NRAS website (www.nras.org.uk/apnijung) – a unique resource for South Asian people living with inflammatory arthritis/rheumatoid arthritis who would prefer to access information about their disease in Hindi. Dr Kumar is an experienced researcher at the University of Birmingham who has published many papers on the subject of ethnicity and its impact on musculoskeletal practice. She commented: "Many people in Asian communities – particularly elderly family members – do not speak English and some may have difficulty reading information on Public Health England websites, even if it's written in their own language. More importantly, the terminology used in the government's COVID-19 guidelines requires clarification when applied to the cultural beliefs and traditions of the BAME (black, Asian and minority ethnic) communities."

It was very clear to NRAS from early March that everyone with RA would need information and guidance about how COVID-19 might impact on their condition and the steps they needed to take to protect themselves and their families. Consequently, we quickly developed a new section on the website to address everything related to COVID-19 as well as starting weekly Facebook Live sessions. Our university partners recorded this video in Hindi to enable NRAS also to reach as many people as possible in the South Asian communities across the UK and of course, we are now all too aware, how COVID-19 has disproportionately affected people from BAME communities.

The video explains what COVID-19 is and how people can spot symptoms, detailing how to isolate if symptoms present. The experts cover the importance of hygiene and social distancing, as well as giving advice about what to do if living in an extended family.

Dr Shirish Dubey, Consultant Rheumatologist based within Oxford University Hospitals NHS Foundation Trust, who features in the video with Dr. Kumar, said: "COVID-19 represents a serious threat to everyone's health – we must all stay at home and look after ourselves and our families. We are in this together and working hard to fight the virus."

He went on to say:

> "It is particularly important that people living in extended families do everything they can to protect themselves against the virus. I would urge people across the Asian community to watch our video and then share it – in a safe manner – with their families."

We would hope by the time you are reading this article there will be a lot fewer cases of COVID-19 than when we launched the video in April. We hope that it will have enabled and continue to enable South Asian communities across the UK get the right information in their own language and protect themselves from COVID-19 as long as the virus remains in the UK population.

NRAS formed a new Advisory Board to work with us to help us to develop our Apni Jung resources so that we can continue to support South Asian communities everywhere.

For more information about NRAS Apni Jung, or to get involved, please contact Ailsa@nras.org.uk

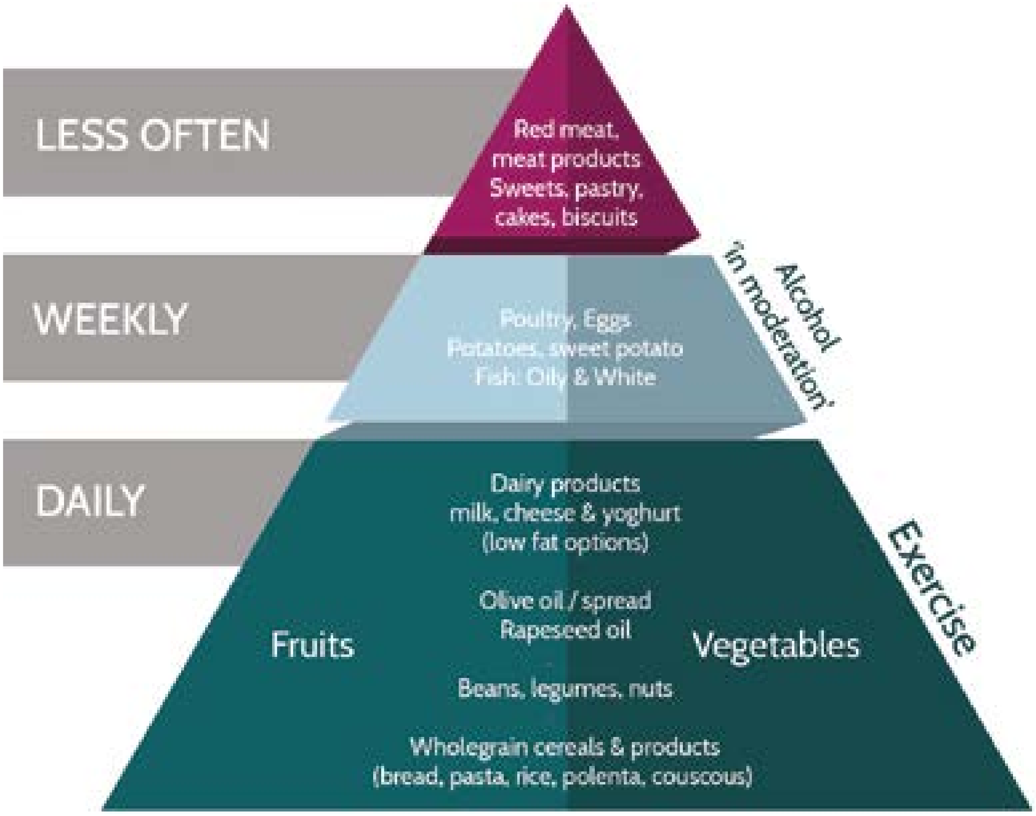
RA and diet – What we know

There has long been a suggestion that diet could play an important role in the self-management of rheumatoid arthritis. A variety of different diets have been commonly used by people with RA over the years, to varying levels of success. This topic continues to be an area of interest to patients and is commonly discussed on our forum and in our helpline calls.

A recent review by researchers at King's College, London investigated the findings of 70 studies in total. Looking for common themes, the researchers found a number of key areas where dietary changes were beneficial to patients with RA, including:

- High dose Omega-3 supplements reduced RA disease activity and resulted in lower failure rates for medications.
- Vitamin D supplements and restrictions of sodium in the diet were beneficial on some RA outcomes.
- Fasting could cause significant improvements, but was transient and these improvements were subjective.
- The Mediterranean diet showed some improvements in disease activity measures.
- Outcomes from vegetarian, elimination and elemental diets were very individual.

These findings provide a useful summary of the benefits certain dietary changes can have on RA. The level of improvements these different dietary changes can make can vary between individuals. Dietary changes will also not occur in isolation and it can be hard for patients to know whether a change of diet is helping them. Other factors contributing to an improvement in symptoms may occur at the same time as dietary adjustments, such as changes to medication or lifestyle factors such as stress levels, level of exercise etc. It can therefore take time, perseverance and a certain level of scientific approach to see which changes offer the most benefit to an individual with RA. This can entail keeping a food diary for a while, where changes to diet are monitored alongside symptoms. When it comes to cutting out certain foods from the diet, they may also need to be reintroduced a couple of times to be certain whether or not cutting them out is actually making a difference.



For more information on diet, see our newly updated article on the NRAS website:
www.nras.org.uk/diet-rheumatoid-arthritis

UPDATE

NRAS Policy and Campaigning Work

By Samuel Lawes

Policy and Communications Manager

We have been busy here at NRAS, responding to the flood of requests from the clinical and academic rheumatology community, to support COVID-19 related surveys, by getting these out to our Members and the wider RA and JIA public. As always, you have been brilliant in your support of surveys and studies.

Despite the above workload, we have continued our policy, communications and campaigning activity, albeit temporarily at a lower key, and so here is a brief update on some of the work we've been undertaking on your behalf.

[illegible]

In collaboration with the DBC (Disability Benefits Consortium) we are campaigning for all those receiving legacy out-of-work benefits to receive the same £20 uplift as those claiming universal credit. As Policy and Communications Manager, I regularly attend meetings with the DBC and will be adding updates to the campaigns area of the website on this as it progresses.

We've been working with the Prescription Charges Coaliton (PCC) and advocating for people with RA and other long-term conditions to be able to get free prescriptions for many years. Recently we were part of a group of 50 charities on behalf of the coalition calling for the £9 prescription charge in England to be suspended for people with long-term health conditions during the present pandemic. A letter outlining the coalition's call for a suspension was sent to Lord Bethell of Romford, parliamentary Under Secretary of State at the Department of Health and Social Care at the end of March.

Both I and our CEO, Clare Jacklin, have been meeting with other members of the Arthritis and Musculoskeletal Alliance (ARMA) on a weekly basis throughout the lockdown, to discuss issues relating to COVID-19 which have been highlighted through our helpline. NRAS National Patient Champion, Ailsa Bosworth, recently attended a meeting on Shielding on behalf of ARMA, with officials from the Shielding Teams from the Department of Health and Social Care and the Department of Work and Pensions to specifically report the community's concerns around employment issues for the clinically extremely vulnerable group. .

DBC Disability Benefits Consortium ARMA National Voices

NRAS is an active member of the above organisations who work on behalf of disabled people and people with long term conditions.

Work with NICE (National Institute for Health and Care Excellence), NHS England

We continue to work with NICE, NHS England and the BSR on our campaign to widen access to biologics for people with 'moderate' disease (i.e. a disease activity score of between 3.2 and 5.1 where prognostic factors are poor). With NICE, we are also addressing the fact that in some areas the commissioners are arbitrarily limiting the number of biologics a patient can have. Both projects are complex and will take time to conclude but we will keep you updated as they progress. We will be publishing the results of our survey of people with moderate disease in the autumn and will also be reporting later in the summer on the survey on patient experiences of switching to a biosimilar which we did jointly with the National Axial Spondyloarthritis Society, the Psoriasis Association and Crohns and Colitis UK.

The challenges for many thousands of people on universal credit and other benefits have been highlighted on many occasions during the pandemic. Jobs have been lost and people furloughed and just as a reminder, we have the following publications available which you can download from our website, **nras.org.uk/publications,** or contact us for a hard copy to be sent by post.

How to Claim PIP

We support individuals in how to prepare for assessment and how to claim and we provide health professionals across the UK with free copies of this booklet for their patients.

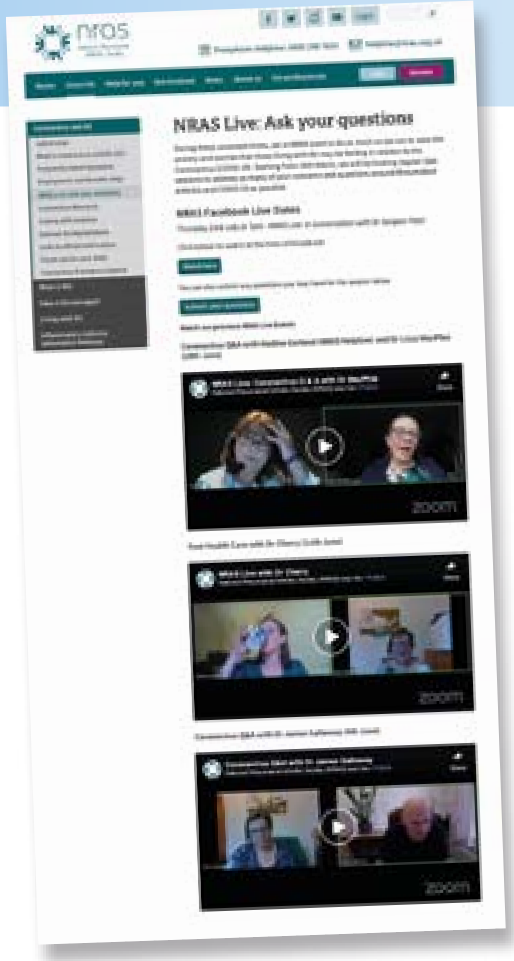
Benefits in Rheumatoid Arthritis

We commissioned this booklet to be written by an expert with a particular emphasis on helping those with RA and It includes information on Universal Credit.

nras National Rheumatoid Arthritis Society

How to claim
Personal Independence Payment
July 2017

A self-help guide to claiming Personal Independence Payment for adults with Rheumatoid Arthritis



NRAS Live: Ask your questions

Individual Advocacy and keeping you informed

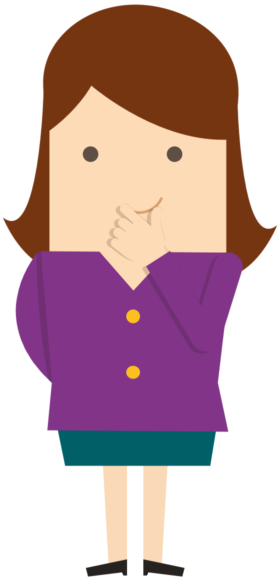
We have advocated on behalf of quite a number of individual people during recent months who have had major issues in getting the treatment and care they needed during the period when the COVID-19 curve was increasing and rheumatology teams were re-deployed onto COVID-19 wards. Some are still having difficulty getting the help they need. Many of you will have seen the Facebook Live interviews on COVID-19 with key health professionals, hosted by our CEO Clare, and our Support Services Manager, Nadine – these have now gone from weekly to monthly and have had well over 120,000 views.

We invited the new President of the British Society for Rheumatology, Dr. Sanjeev Patel, to be live with us on the 23rd July. He discussed how rheumatology is managing under the new COVID-19 norm and how rheumatology teams across the UK will be delivering services and responding to the need to treat people whilst keeping them and the NHS staff safe. You can watch this back by visiting our Facebook page.

Supermarkets

At the end of July we wrote to major British supermarkets, asking them to pledge two things: to continue to offer priority delivery slots to people who have been shielding; and to ensure people in this group are offered priority delivery slots regardless of whether or not they are regular customers. The letter was co-signed by seven other patient organisations, including ARMA.

For further information on any of our campaigning activities, please contact samuel@nras.org.uk.



Why do more women get RA than men?

RA affects roughly two-three times more women than men and this isn't the only difference. The average age of onset for RA is around 40-60 in women, whilst the average age for men to get diagnosed is slightly later in life.

We still don't fully understand what causes RA and why it occurs at the particular time that it does in each individual, and this is because there are likely to be multiple factors that influence this in each person. However, there is still a lot we do know. For example, we know that genes play a role in susceptibility to RA and that certain environmental factors can increase the risk of developing RA, for example smoking, which is known to be a major risk factor.

The very fact that RA affects more women than men points towards the possibility that hormones play a role and it is commonly reported that the onset of the condition comes during periods of hormonal change, such as the start of the menopause or just after having a baby. However, if a woman develops RA within 6 months of having her 2nd or 3rd baby, we still do not fully understand why it wasn't triggered by her 1st. What we do know from studies is that women who have given birth to two or more children are nearly 3 times more likely to develop RA than women who have had no children. We also know that the number of women to develop RA who have ever been on the contraceptive pill is around half that of women who have never taken it.

There is still much more to be understood about the reasons for this gender difference and not just for RA. Autoimmune diseases as a whole effect around 8% of the population and 78% of those affected are women. This means, therefore, that this gender difference will continue to be an area of interest for research into all auto-immune conditions, and so will further help to improve our levels of understanding about the gender difference and causes of RA as a whole.

There is still much more to be understood about the reasons for this gender difference

Young People and Anxiety

Research from a team based in Australia and the Netherlands has found that the prevalence of anxiety disorders in youths with long term conditions is significantly higher than that age group in the general population.

The researchers reviewed 53 studies. 29 of these studies investigated the occurrence of anxiety disorders, whilst the other 24 looked at the impact of anxiety on disease-related outcomes.

This review found that approximately 20-50% of young people with a chronic disease suffered from anxiety, compared to a global rate of around 6.5%. Added to this, those experiencing anxiety had poorer disease outcomes, including increased pain among children and young people with JIA.

It is therefore important for parents, young people with JIA and healthcare professionals alike to be aware of both the increased risk of anxiety and the impact that this can have on mental and physical health. Early support with getting an anxiety disorder under better control could also play an important role in improving the management of JIA symptoms.

Women with RA less likely to develop breast cancer

A recent study of Swedish registers, looking at women with a new-onset RA diagnosis between 2006-2016 has found that the women were less likely to have a diagnosis of breast cancer and that women with a history of breast cancer were also less likely to develop RA.

The lifetime risk of developing breast cancer in the general population is 1 in 10, whilst the risk to patients with a diagnosis of RA reduced to 1 in 12.5, pointing to around a 20% decrease in risk. The reduced risk of those with a history of breast cancer in developing RA fell by a similar amount.

The researchers were unable to explain why this decreased risk exists, but said that it was not explained by hormonal risk factors. The deceased risk in the occurrence of breast cancer in RA patients was already present before RA diagnosis.

Benefits and Barriers to Exercising with Rheumatoid Arthritis

By Xiang Li Tan

Centre for Sports and Exercise Medicine, William Harvey Research Institute, Barts and the London School of Medicine and Dentistry, Queen Mary University of London

It is widely known that physical activity has numerous benefits for people living with rheumatoid arthritis (RA). Physical activity has been identified as a viable nonpharmacological strategy to manage RA symptoms and is recognised as a core element of disease management. The American College of Sports Medicine guideline recommends people with RA to participate in 150 minutes a week of moderate intensity, low-impact aerobic activity. Benefits of physical activity include improvements in cardiovascular health, body composition, functional ability, and psychological well-being. However, those with RA are more physically inactive than the general population, most often limited by arthritis specific factors.

We conducted a questionnaire study investigating factors associated with physical activity engagement among adults with RA in order to assist future exercise intervention development targeted at RA to facilitate an increase in physical activity uptake and improve engagement and adherence to physical activity interventions. In our study, we analysed the baseline health status and physical activity levels, along with the participants' perceived benefits and barriers to exercise. In addition, we established exercise preferences to provide direct insight from the perspective of RA participants about optimal tailored exercise interventions.

Those with high physical activity levels were significantly associated with lower functional disability and pain, with better cardiovascular risk profile. In contrast, the low physical activity group generally had higher cardiovascular risk, worse functional disability and higher reported pain. However, we found that regardless of the baseline physical activity levels, there was high awareness of the benefits of physical activity. Nevertheless, participants experienced numerous barriers, with the low baseline physical activity group reporting greater degrees of general and arthritis-specific barriers. These barriers include general barriers, such as not feeling athletic enough to be part of an exercise group; and arthritis-specific barriers, such as pain and limitation of body caused by RA. Other barriers include situational barriers such as the lack of free exercise facilities and arthritis-specific programmes locally, and the lack of suitably qualified exercise class instructors with RA-specific knowledge. Preference of physical activity was varied but most commonly reported preferences were unsupervised indoor home exercises, with exercise of low intensity preferred by the lower baseline physical activity group.

Our study identified the importance of addressing these specific barriers in the development of future exercise interventions. Furthermore, these findings highlight the importance of identifying coping strategies to overcome barriers to physical activity. Confidence to overcome exercise barriers is also key to regular engagement in physical activity and is a significant predictor of physical activity. Incorporating exercise preferences and RA-specific needs in exercises tailored to baseline physical activity level when developing exercise interventions, may help increase uptake and adherence to physical activity.

We would like to thank the National Rheumatoid Arthritis Society and Clare Jacklin for their assistance with this study and participant recruitment, and all the participants who took their time to take part in this study.

2.6 Challenges

The 2.6 Challenges took place on the day which would have been the London Marathon this year, which was postponed. It was an opportunity for people to raise money for charity and here are a few of their stories

[illegible]

Helen Hubback and Edward

Edward was diagnosed with JIA in November 2019 (when he was 6 years old). Edward has endured injections of steroids to multiple joints, numerous blood tests, weekly injections and lots of eye drops. As part of his condition Edward also has on-going uveitis which if not treated can lead to loss of vision. Throughout all his treatment so far, Edward has been amazing and takes it all in his stride. One thing that will always stick in my mind was when he announced at the dinner table that he could run again in school that day, following an injection of steroids into his knee, as he could barely walk prior to this.

We decided to take part in the 2.6 Challenge to raise money and it was a real family affair. Nanny (Sue Morris) walked up and down the garden path for 26 minutes. I (Helen) ran 2.6 miles around the garden. Esme baked 26 cookies and Freya did a handstand for 26 seconds. Beatrice performed 26 Tik Tok dances and of course not forgetting Edward who rode his bike around the garden 26 times! We raised a total of £547 – thank you so much for all the support for a cause that is so close to our hearts.

Jean and Heather Yeadon

Jean said, [illegible]

Heather said, [illegible]

[illegible]

[illegible]

[illegible]

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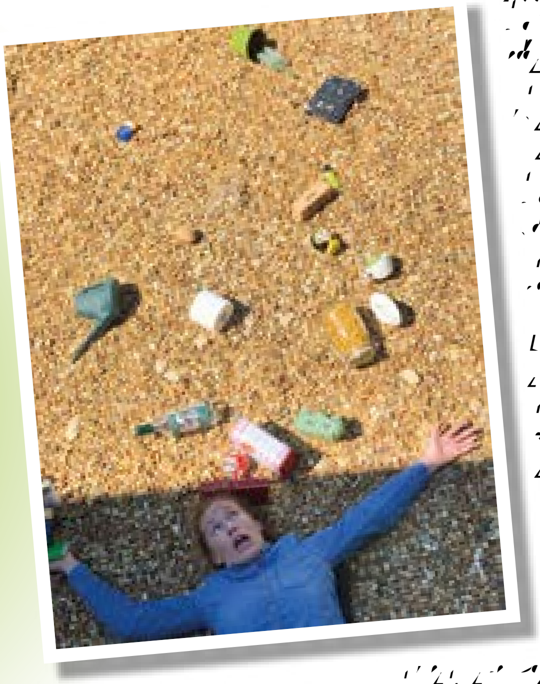

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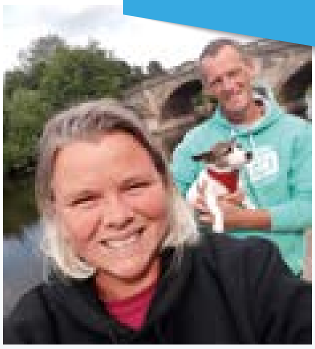
2.6 Challenges



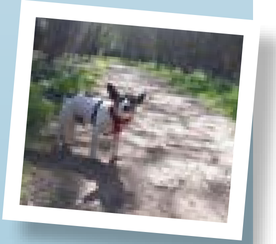
Katherine Alker

I decided to take part in the 2.6 Challenge and raise funds for NRAS as they have been a source of information and support for my partner Rob and me over the past few years. Rob was diagnosed with RA in June 2015 after a rapid decline in his health. He had agonising pain in his joints and went from being relatively active to being unable to walk more than about 10 metres in a matter of weeks. Rob's GP took a blood test and quickly diagnosed RA. Rob was then referred to the Rheumatology department at Worcester Royal Hospital, where the staff have been great, particularly Specialist Nurse Teresa Ford.

After receiving several steroid injections early on, Rob is now on triple therapy of high dosage methotrexate, sulfasalazine and hydroxychloroquine, as well as omeprazole and folic acid. Rob gets flare-ups if he's been over-doing it or feeling particularly stressed about something, but generally speaking the medication is working well and he is able to do most things that he was able to do pre-RA although he does get worn out much more quickly.

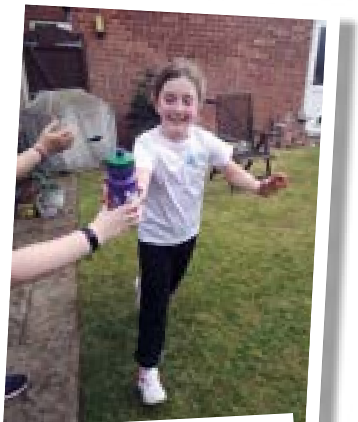
We have found the NRAS Facebook page and magazine a really useful source of health tips and information, as well as hearing about other people's experiences.

For my 2.6 Challenge I decided to walk 5.2 miles (that's 2 x 2.6 to fit in with the challenge) every day for 8 days. Some days Billy our Jack Russell walked too, but not if it was raining – he won't walk far in the wet! Due to lockdown it was very quiet, and I barely saw a soul. I enjoyed the chance to watch wildlife, listen to the birds, and see the spring flowers as well as have some time on my own to free my mind. My fundraising efforts were supported by wonderful friends and work colleagues, and I am delighted to have raised a total of £740 for NRAS.



Collis family

On Sunday the 26th of April the London marathon should have been run. Anyone who sees big running events like this thinks of the costumes and the variety of charity shirts and vests being worn all raising money for their favoured cause. In the current Pandemic we like so many more have been stuck in the house, worried and looking to the organisations like NRAS for advice, we had seen the 2.6 Challenge setup to keep a bit of the magic alive and raise money for the charities that have been starved of funds through the crisis but are more important than ever.



Our daughter Kate was diagnosed with Polyarticular JIA at 4 and later uveitis. Since then she has been through lots of treatments, there have been lots of bad times, lots of medicine and lots of needles, but we have also met lots of fantastic people. JIA-at-NRAS have been a great source of information and advice through all this, we have been to the family days where the grownups learn, and the kids explore and play. We have supported Wear Purple For JIA since 2017, that is when "Team Kate" started, we have raised money for all the charities that have helped so much and more importantly tried to raise awareness of this so little known affliction.

Kate is now 8 and has been doing great, she has been in medical remission for over 2 years now, she has dance lessons twice a week, she is so full of drive and energy, she does PE with Joe and doesn't let anything stop her.

When the idea of a 2.6 mile family relay for JIA-at-NRAS was suggested Kate and her brother James jumped on it, so, we got out our JIA t-shirts and Kate being Kate she pushed herself the hardest, ran the furthest and the fastest!

The Collis family raised a fantastic £269 through sharing their fundraising story on Facebook!

My Arthritis App

Making the transition to virtual easier for patients and clinicians.

AMPERSAND

Improve Out of Hospital Care for the At Risk

Monitor immune-suppressed patients remotely

Manage their care in a IMID-specific digital framework

Minimise clinic attendance and focus on the most pressing cases

Get up and running in 48 hours - streamlined implementation, ready to go

Free, no strings attached, till January 2021

You may be aware of the My Arthritis App, a self management and remote monitoring platform developed by Ampersand Health, in partnership with NRAS and King's College Hospital.

To support the NHS's COVID-19 response, the My Arthritis platform is being offered to the NHS for free until 2021. Ampersand is offering a streamlined onboarding process and, because the system relies on explicit patient consent captured in the app, NHS Trusts can get started straight away.

The platform comprises a patient app that is already available in the App Store and Google Play (and which includes a good deal of NRAS self-management resources); and a web-based monitoring and messaging platform for rheumatology professionals. It is CE marked, regulated by the MHRA, reviewed by NICE and was included in ORCHA's COVID-19 Formulary and selected for NHSX's (NHS Digital) Techforce 19.

For Trusts, the platform enables remote monitoring and intervention and improves clinical efficiency: it is shown in studies to facilitate a safe 47% reduction in overall outpatient appointments and is linked to a 50% reduction in out of hours A&E visits. Moreover, 85% of patients expressed a preference for managing their hospital care through the app instead of in person.

"As clinicians on the front line of COVID-19, we're pleased to be able to do our bit to help the NHS at this unprecedented time", said Bu Hayee, co-founder at Ampersand and consultant at King's College Hospital. "The move to virtual outpatient care has been on the cards for a long time and tools like these could be an important part of making this swifter-than-anticipated transition work for patients and the NHS."

If you are a clinician within rheumatology and want to find our more about embedding this resource into your COVID-19 recovery plan do please contact Ampersand (contact@ampersand.health) My Arthritis is available for free, with no strings, until January 2021.

Information for people living with RA about the My Arthritis App

Even if your rheumatology department are not yet utilising the platform you can still download the app to help you keep track of your disease and improve your self-management techniques.

We are all aware that COVID-19 is having a significant impact on the way hospitals look after people living with inflammatory arthritis. Many hospitals are moving to doing more virtual appointments – to not only reduce the risk of infection to those considered at higher risk but also to maximise the capacity available to Trusts to deal with emergency cases and reduce waiting times etc. The My Arthritis App is a great way of having all the information to hand when you are about to go on a virtual consultation with your nurse or physician. To download the App you can find out more at www.nras.org.uk/my-arthritis.

AMPERSAND

#OurMindsRAPriority #WeRAPriority #mentalwellbeing #NRAS #RAAW

RA Awareness Week

7th - 13th September 2020

#OurMindsRAPriority

RA Awareness Week has always been about raising awareness of RA and its impacts on all aspects of life. This year, especially taking into account recent events, the focus for NRAS RAAW will be on Physical and Mental Wellbeing.

Some key areas that will be focused on during the week will be:
Mindfulness, physical activity, movement, connecting with others, kindness, giving and learning.

Throughout the week we will also share some personal stories, raise awareness, and fundraise to support those living with RA.

We will share more details on RAAW and the programme for the week very soon so be sure to sign up for E-Newsletters and keep an eye on our RA Awareness Week webpages.

To register your interest in RAAW please contact the fundraising team:
fundraising@nras.org.uk

#RAAW

"I am feeling anxious"

"Who can I talk to?"

"I wish someone could help me"

"I would like to try something new to help my mental wellbeing"

"I want to connect with people"

From Oz to NRAS

By Nadine Garland

Support Services Manager

> Travelling overseas with RA takes a bit of planning but is something I love to do.

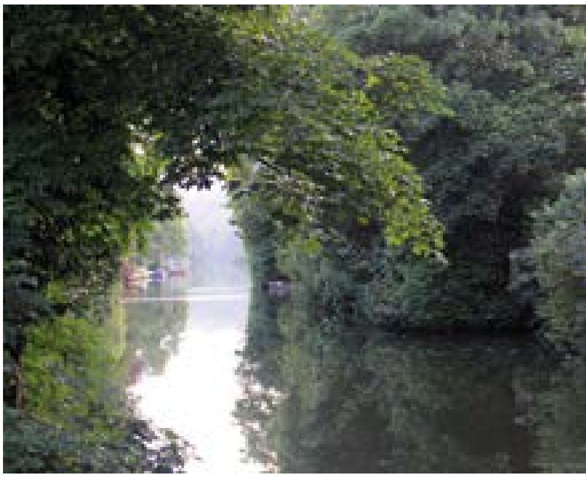
Hi, my name is Nadine Garland, I am the new Support Services Manager here at NRAS. I am from Australia, but I have dual nationality. I was diagnosed with RA in 1987, and despite being told I would never be able to do so, I have been working as a nurse most of my life, although I have not completed my UK registration as yet. My husband and I decided about 2 years ago to embark on a mid-life adventure throughout England and Europe. We arrived in the UK in mid December and had the opportunity to spend Christmas with my aunt and uncle, catch up with old friends and family and see a bit of the UK before my husband returned to Australia in February to begin his visa application process.

Conversations with my aunt made me reassess the important things in life, including work. Whilst I enjoyed my recent roles of Clinical Nurse Educator and college tutor, the job that really made my heart sing, was working for an arthritis charity in Australia. I worked, mostly, with children with JIA and their families as well as working aged adults with RA. I went looking for a similar role and found this position with NRAS. I started work in early March, but I was only in the office about a week before I had to start working from home.

Travelling overseas with RA takes a bit of planning but is something I love to do. As soon as I arrived in the UK I got into the NHS system so I could make sure I was able to continue the only medication that has ever actually brought me into remission, tocilizumab. My appointment with a rheumatologist was cancelled at the last minute and I had to move for my new job. Then COVID-19 led to lockdowns and it meant things had to change. Rheumatologists were called to the front line, appointments went to phone calls, new people were not started on biologics and supply looked threatened. I was about to book my ticket home when I got the call to say I would be able to get my medication for 16 weeks and they would write a referral to a rheumatologist near me.

So here I am, in a new job, in a new house, in a new town and country for that matter, with none of my usual support people, having to hit the ground running with one artificial knee and several wonky joints that make running difficult (I do love a good metaphor). I can't say it's been easy, or always fun, but I was reminded early on in this pandemic about the importance of gratitude, so I take my daily walks, keeping my eyes and camera ready to keep my focus on the things in nature that bring me joy. Regular contact with friends and family and my obsession with sharing a love of music, has also kept some sanity in my crazy world.

NRAS isn't just my employer, but they have become my family. The helpline has been a lifeline to many people struggling with the management of their RA during a pandemic, a struggle I empathise with completely. My team have not just stepped up to the challenge of a 600% increase in calls but done it with compassion and a sense of teamwork, that is exemplary. They have been generous with their time and patient as I learn the ropes in the middle of this maelstrom. I am looking forward to seeing where this crazy adventure takes me next.



Assistive equipment in the kitchen

Are there any devices that will help me cook and eat with hands severely affected by RA and where can I get them?

There is a wide variety of kitchen aids available from a number of places, they range in price, however the quality is consistent across the board.

Bottle, jar and tin openers come in many shapes and sizes and are a good basic piece of equipment that make a huge difference. You can get ones that come in a variety of sizes and others that are adjustable. There are also grip mats that are useful if you still have some mobility but lack strength, these can be used with jar openers that pop the seal on jars. Everyone's needs are different, but many people find the adjustable ones or multi tools take up less room in the kitchen drawers.

Kettle tippers and multi handled teapots ensure you can make a cuppa without the risk of spilling hot water.

One of the most important pieces of equipment in the kitchen is a good knife or two. You can get easy grip handles and angled handles that make carving and slicing easy. Rocker knives help with chopping without chopping yourself.

Cutlery with thick handles or easy grip tubing that makes holding cutlery more stable and comfortable are very good and have become a bit more aesthetically pleasing over the years.

Useful links to websites on aids for daily living

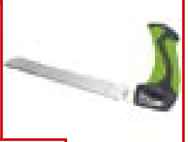
www.completecareshop.co.uk

www.livingmadeeasy.org.uk

www.careco.co.uk

www.nrshealthcare.co.uk

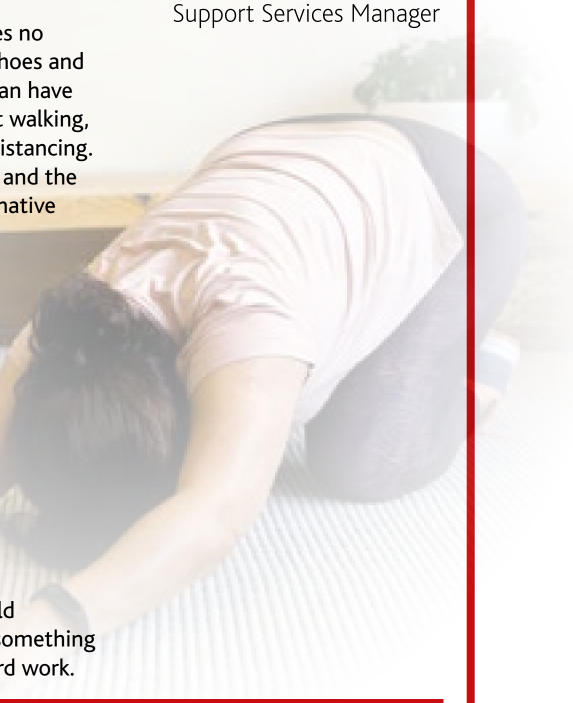
Disabled living www.disabledliving.co.uk offer a helpline with a variety of allied health professionals who can respond to requests for information, they also offer a supplier directory for all assistive equipment.



Which exercise videos are safe for people with RA?

By Nadine Garland

Support Services Manager



During lockdown a plethora of exercise gurus sprung up on the internet, but it can be hard to know which ones are safest for people with RA. When managing your health conditions, the best advice you can get is personalised information from your own health teams, however many people have had limited access to them recently.

Exercise programmes and videos from physiotherapists, occupational therapists and exercise physiologists have the most medically sound advice. You are also the best source of what works for you, if you have not exercised in a while, you may experience stiffness and possibly some discomfort, however, you should never ignore pain as its your body's way of saying it's not happy. The NHS has some very good programmes that are easy to follow and can be found at www.nhs.uk/conditions/nhs-fitness-studio/

Walking is a good exercise that requires no more equipment than a good pair of shoes and somewhere to walk. Walking outside can have its problems such as lots of people out walking, making it difficult to maintain social distancing. Other factors such as uneven surfaces and the weather make it problematic. An alternative might be to stay inside, put on your favourite music and march on the spot, you can hold onto a chair if you need extra support, or even sit in a chair and march. If you want to challenge yourself add in your arms and conduct that marching band as you go.

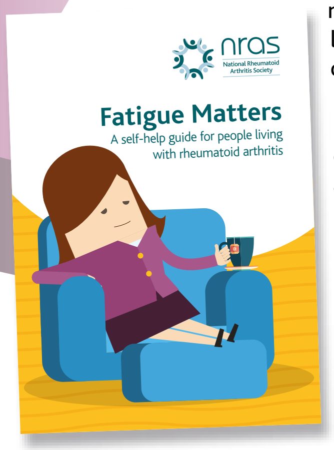
The old adage of move it or lose it rings very true when applied to your mobility, however my personal favourite is exercise should be taken regularly, not seriously. Find something you enjoy and it will never feel like hard work.

For safe and effective exercises you can do in your own home take a look at the exercise videos on our website www.nras.org.uk/exercise-videos.

Feeling tired? RA and Fatigue

Fatigue has long been recognised as one of the most common and severe symptoms of rheumatoid arthritis (reported in up to 90% of people living with RA).

Fatigue as a result of a health condition such as rheumatoid arthritis is very different to the kind of fatigue experienced periodically in healthy individuals, for example through over-exertion or lack of sleep, in that rest does little to manage the fatigue and it can be present for long time periods, as a result of the processes occurring in the body due to disease activity.



nras
National Rheumatoid Arthritis Society

Fatigue Matters

A self-help guide for people living with rheumatoid arthritis

People with RA will know that fatigue can be one of the most debilitating of symptoms, as it can be harder to control in some instances than pain and swelling, which can be treated with medication and other therapies. However, patients will commonly report that healthcare professionals pay less attention to their fatigue, perhaps feeling that it is less within their control to help manage than symptoms such as pain.

A recently completed 2 year study in Belgium investigated the effects of early intensive treatment on fatigue levels. Eighty patients considered to be at a low risk for severe disease progression were split into 2 groups of 38 and 42 at random. One group received a weekly dose of 15mg methotrexate while the others received the same dose, but with the addition of cortisone steroid tablets, starting at 30mg and gradually tapering down to 5mg. Whilst the levels of disease activity were comparable between the 2 groups, those receiving the more intensive treatment experienced less fatigue than those on methotrexate alone and this difference in fatigue levels increased over time.

The findings of this study are important, as they show that fatigue can be more manageable, if the right treatment is used at an early stage. They also highlight that even for those considered to be at a low risk for high disease progression, this more intensive treatment in the early stages might be the best option. As a result, the European League against Rheumatism (EULAR) therefore recommends that even in so-called low-risk patients, early consideration should be given to whether intensive treatment should be initiated.

Autism and JIA

According to study results presented at the European League Against Rheumatism (EULAR) 2020 E-Congress in June, children with juvenile idiopathic arthritis (JIA) and those without JIA, but who have at least one first-degree relative who has JIA are more likely to be diagnosed with autism spectrum condition (ASC), sometimes referred to as 'autism'.

The study took the form of an online survey, conducted with parents of children with JIA. They were asked questions about each member of their family, including whether they had been given a diagnosis of JIA or ASC and the age of that diagnosis.

202 patients had a diagnosis of JIA among 197 families. In studying information on the eldest child with a JIA diagnosis from each of these families, a significant number were found to have a diagnosis of ASC.

This increased susceptibility does not mean that a child with JIA should expect to also be diagnosed with ASC and more will need to be understood about other possible factors in why some have both conditions. However, these findings do mean that parents of children with JIA should be mindful of this link. More information on ASC, including signs and symptoms can be found on the National Autistic Society website: www.autism.org.uk.

Making a difference on YouTube

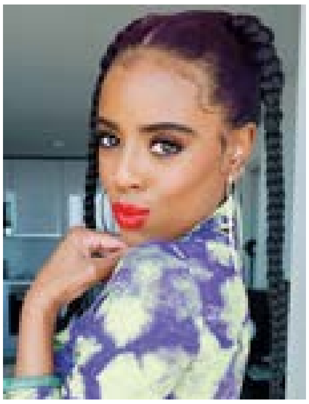
Many young people living with RA and JIA are achieving amazing things whilst dealing with the challenges the condition brings. When first diagnosed, it can be a confusing and scary time and finding others of a similar age who can relate to what you are going through, is not always easy. "Youtubers" like Yulanda and Magda below are reaching out to the young RA and JIA community, letting them know they are not alone and showing them that they don't have to let RA define them.

Magda Weronika, 19

Hey, my name is Magda and I'm currently a 2nd year medical student at the University of Cambridge. I properly started my YouTube channel during my A-levels and I mainly film academia-focused videos such as study with me's, university vlogs and advice for A-level candidates or uni applicants. I have spoken about my inflammatory arthritis a few times on my channel, as whilst I don't like to make it the sole focus on there since I'm still working to accept that my JIA doesn't define me, I think raising awareness of the condition using my platform is really important. I was diagnosed with JIA when I was 6 years old, yet a lot of people are still quite shocked to hear a young person saying they have arthritis. One particular video I made was entirely talking about my experience of living with this disease, in order to address not only this point but also to reiterate that the condition can have major effects on many aspects of someone's life. I hope it might also make young people also living with RA or JIA who watched it feel less alone, hearing about others with similar experiences. Besides this, I have tried to make my channel as open and honest as possible, so I occasionally talk briefly about the impact my condition has on my life at university in my vlogs too, as realistically flare-ups, medications, etc can mean your university experience may be quite different to other people's. Although my main aim with my channel is helping students, I'm really pleased that I have the opportunity to spread the word about arthritis in young people – even just mentioning it might encourage people to look it up and discard any misconceptions. The internet is a really powerful tool nowadays – it's the most efficient way to reach people, whether in support or to educate.

Yulanda Sabrina, 33

My name is Yulanda Sabrina, I'm 33 and live in Croydon, Surrey. I'm a professional singer-songwriter, jewellery designer and Youtuber with nearly 10k subscribers. I started my YouTube channel in April 2014 shortly after I was diagnosed age 28 with severe rheumatoid arthritis and Sjogren's. My intention for launching my YouTube channel was to showcase myself as an example of somebody relatively young, in their late 20s suffering with this debilitating and in some cases, life threatening disease. In the beginning I found it very difficult to find others online who I could relate to who were also suffering with the same disease as me. It was a frightening time and I was searching for guidance, support and a community to join but unfortunately I couldn't find that many people sharing their stories online. My very first YouTube video - entitled my story living with an autoimmune disease - began to gain traction and I received a really amazing and positive response from the autoimmune community on YouTube. I was surprised to learn that so many others could relate to me and my story. I was equally as shocked to see that my subscribers suffered with a range of different types of autoimmune diseases ranging from RA to lupus to fibromyalgia. It was such a comforting feeling knowing that by just having the confidence to share my story, I had been able to connect with so many awesome people all over the world that I otherwise would never have connected with. During my career so far on Youtube I have uploaded a series of videos dedicated to speaking about and bringing awareness to my disease, RA. It has been the most incredible life changing work, it has brought me so much joy and introduced me to thousands of people all over the world who I now have a special bond with. I love my subscribers and I love my channel... but don't get me wrong it's extremely difficult doing Youtube full time as a person with RA but the reward is in pushing and challenging myself to maintain my presence - every upload feels like a real achievement.



> I received a really amazing and positive response from the autoimmune community on YouTube

S M T W T F S

The Covid Chronicles

By Christine Lowe

Manchester NRAS
Ambassador

MARCH

Early March was spent mostly in shock watching events unfold around the world and thinking, 'is this really happening?'. We went into our own personal lockdown on the 12th March as the news got worse. We had tickets for performances at the theatres which were still open but we decided not to go and I'm really grateful we made that decision.

21 March: Here we are fully shielding as I received the letter advising that I had been identified as a person at risk of severe illness if I contracted COVID 19. A sobering day and frightening prospect.

The country went into lockdown around 23 March but by that time we had arranged for the supermarket to deliver food and pharmacist to deliver meds to be as self-sufficient as possible.

The hardest thing has been the separation from our family. We have four children and five grandchildren and one baby who was just four weeks old at the time. The thought of not seeing our little ones and not being able to support my daughter with our new grandchild was unbearable.

MAY, JUNE, JULY

Reality kicks in. These have been months of making adjustments. Finding things to keep us occupied; there's a permanent jigsaw on the dining room table, I'm reading more, we are hammering through TV box sets. We watched the whole of Game of Thrones AGAIN whilst in lockdown!

We try and have a purpose. Thursday is known as mopping and shopping day in our house where bits of cleaning are attempted, and we await the mystery of the supermarket order and their puzzling substitutions.

- Instead of hand cream they sent shower gel!
- Instead of courgettes we got cucumbers! (to be fair they are green!!)
- Instead of cream cheese, a strange tub of this thing called Quark which neither of us recognised which found its way swiftly into the bin.

The funniest of thing was my daughter dropping off a bag of self-raising flour at my front door and how excited I was ... ridiculous!!

Andy has built his COVID Pond which is a joy to see from our garden room and watch the wildlife.

We still 'go' to church on Sunday through an online service which is tremendously uplifting and helps us during these awful times.

S M T W T F S

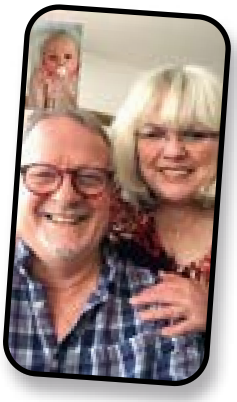
☐ ☐ ☐ ☐ ☐ ☐ ☐

WHAT NOW?

Frustration is setting in, but we are having a walk daily when the arthritis allows and that has been great to help with the blues and clearing away the cobwebs.

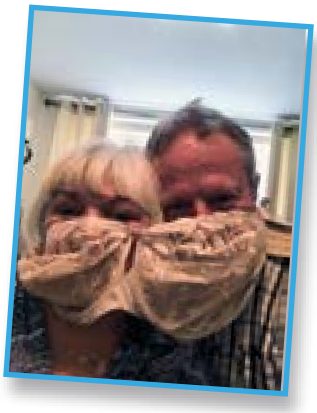
As a member of the Women's Institute we've been helping to keep members spirits up with a messenger chat and quizzes, bingo sessions etc. We've also had a few messenger online auctions comprising of stuff hanging around our houses that we no longer want. These have been hugely popular and very much enjoyed by our members and been surprisingly competitive too. These auctions have raised over £700 which has gone to the Foodbank and also Royal Oldham Hospital. We've sent loads of chocolate, crisps, fizzy drinks, hand creams and lip balms for their 'wobble rooms'. These rooms are where the staff can chill and have a bit of peace away from their workplace and some of the awful things they are dealing with.

One of the positives of the lockdown is our increasing IT skills: 'Zoom' meetings, FaceTime quizzes, FaceTime catch ups with my children and our little ones. These have made things more bearable.



I will always remember clapping and banging pots and pans for the NHS with all our neighbours in a great sense of community. Honouring my daughter in law who is a nurse and a cousin's son who is an ambulance man.

The Government guidance has also been frustrating at times as it's been sketchy and open to interpretation [or misinterpretation] equally frustrating has been the lack of local news with local COVID figures.



In all of this the British sense of humour has stood steadfastly and continued to make me laugh including:

'Now that I've lived during a plague, I understand why most renaissance paintings are of the larger lady lying around without a bra'

Sentiments many of us will associate with.

The other drawback has been the absence of a hairdresser. As they say we are all a month away from knowing everyone's true hair colour!!

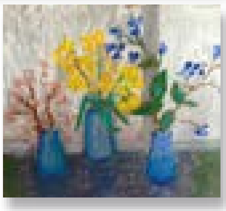
As for me and Andy we have been cutting each other's hair and apart from a couple of minor incidents, a slight stabbing in the eye and a chunk being taken out of the back with the clippers (no one can see it), we are doing swimmingly. After all there's only two weeks between a good and bad haircut!

My brother said we will forget all of this in another year or so. My assertion is we shouldn't. This has reiterated to me what is important in our lives. It's not material things, money, shopping, wealth, celebrity or stuff. Its family, faith, connection, community and love. I only hope these experiences stay with us for a very long time and make our lives all the richer.

Pace, Prioritise, Paint

Positive vibes

Before the hideous virus struck, I had been painting calm, subtle abstracts but felt with the grim Coronavirus and lockdown it was time to break out into COLOUR. I wanted the freedom of being light-hearted as an antidote to the stifling cocoon of lockdown. Pre-virus I saw some intriguing collages by Marzia Colonna, they influenced the first piece (vases with anemones). The second (window sill spring) and third (3 blue vases) were about having fun with colour and shapes. Loose, fresh and lively!



[illegible]

During Lockdown

"Avoiding anxiety" is one of the gems to help with arthritis, millions of other health conditions and basically being human. Hey, in the middle of a pandemic just chill. What else is there to do?

Enjoy the lessening traffic noise, the quieter garden. Positive thoughts and actions take the edge off the negative. FaceTime helps but I miss 'the cuddles if you can catch them' with the grandkids, miss friends and family, miss having a day out and miss the proposed new wet room, as I can't use the bath anymore. Thinking positively, there's time to do all the things I've put off. Choose the fun stuff. Do the things I want to do, after the washing up of course. Plan, Prioritise and Paint.

Sanity Saving Solutions

Phone friends and family, read, I recommend these three books: [illegible] by Margaret Forster; [illegible] by David Nichols and [illegible] by Tracy Chevalier. The last was serialised on Woman's Hour, radio being another good resource if listening (dancing carefully) to music and minimal news. Appreciating neighbours, home deliveries of food, milk and medicines. Making a banner for the NHS and key workers with oil pastels on canvas (so it was rain proof). Being inspired by Grayson Perry's Art Club on TV. Drawing a self-portrait in charcoal. Being absorbed in whatever activity, whether cooking, watching the weeds grow, making cards.

Short walks, exercises and stretches all help.

I'm now upgraded to "shielded", lucky me, and due to long steroid use and a new diagnosis of diabetes I have another hurdle to leap over.

By Catherine Gow

A Reel Good Time

Organised by
George Hancock

The Burns Night ball was held on the 1st February 2020 at the London Scottish House where there was a raffle and an auction to raise funds for NRAS.

The Burns Night Ball managed to raise a fantastic **£2050.00** so a big thank you to George! Slàinte!

'The night was a fantastic laugh and attended by 140 people'

[illegible]

Lockdown moments in Manchester

By Ralph Bell

NRAS Ambassador
in Manchester

March

Work starts to give people the option to work from home and since I love the banter and city centre experience, I am very reluctant.

Later, I see I am in the work at-risk category and decide because of the unknown risk, I will work from home as a precaution. Within a week the whole office is basically working from home.

April

I am one of the very lucky ones and despite having a virulent aggressive form of RA, like my late father, the biologics have transformed my experience from needing to walk with a stick to being fully active and to all intents and purposes in remission. I also don't really suffer from low immunity with colds and flu.

The main changes have been the queuing and being more aware of people around you. Some say it suits a lot of people to keep their distance from others, but it has also led to some spontaneous conversations. I noticed much more of a community spirit locally, with lots more people out and about, even some younger people away from their PCs.

May

One of the great things has been the increase in cycling by everyone, especially families, making the streets much quieter, safer and so much easier to hear the birds singing. I cannot believe the amount of people jogging, from very early until sundown.

June

I do really feel for people in flats who live alone. Many people have been very stoic, and incredibly kind.

My RA appointment was postponed. Although more of a check-up for me, I was mindful of those who needed medical support, and the effects this would cause. I received the Government NHS letter about risk category and shielding, which was a bit un-nerving, but the information was fairly clear.

July

Now the country appears to be fast getting back to normal with lots of traffic and noise, but also people finding a routine and starting to be able to enjoy activities, whether sport or even a beer now, and that certainly feels so good.

I have found the NRAS Facebook live sessions and website information invaluable and I've been thankful for these. I am not sure how all this will pan out in changes to social habits or activities, but certainly hope that others are able to reach a balance of risk, that enables them to enjoy relationships and activities and make life fulfilling.

Reflections on the Welsh lockdown

By Carl Harrison

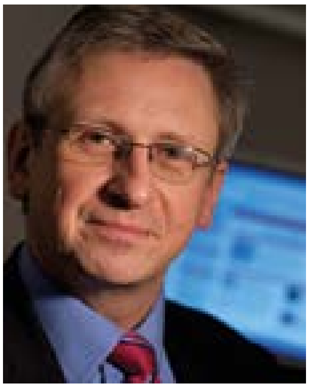
NRAS Ambassador in Wales

I live in Wales where the Welsh Government has been responsible for lockdown and its easing. Although I think we went into lockdown much later than we should have done, I have found the more cautious approach to easing lockdown in Wales reassuring. I have been required to shield.

After a bit of a slow start (it took the Welsh Government longer that the UK Government to provide supermarkets with a shielding list) I found food deliveries and prescription deliveries (free in Wales) worked very well. I was contacted by my local authority to check on my wellbeing and received calls from my GP and local rheumatology department. I think on balance they have done a good job. As has always been the case, I am very grateful to live on the right side of Offa's Dyke.

What has lockdown been like for me? Quite a question to answer. I write this very much aware that COVID-19 is far from over and there might be many difficult days ahead. It has given me time to reflect, slow down my pace of life and appreciate many aspects of life that I had previously taken for granted. I plan to keep jogging regularly (and in more interesting places than my drive) once I return to a more normal existence.

On day 100 of shielding I realised that out of the last 2400 hours I had spent 2399 at home. For someone who normally goes out to work and enjoys meeting up regularly with family and friends, this was a real shock to the system. The pandemic has without doubt been a very stressful and uncertain time, particularly those early days in March. It was during this time that I was most thankful for the NRAS COVID-19 information page, and the webinars presented by Clare Jacklin and various guests. They made a difficult time more bearable. For that I am very grateful.



Prediction and prevention: are we getting any closer?

By Prof Andrew Cope

with the support of
Marianna Jasenecova,
Eirini Kasapidou and
Mariam Al-Laith

[illegible] explains a young mum, who looks a bit washed out.

[illegible] says the GP some moments later. [illegible]

This is a familiar scenario, and one that commonly triggers a referral to a local specialist unit for further assessment. In the absence of joint swelling it can be really difficult to distinguish non-specific aches and pains from the very earliest phase of an inflammatory arthritis such as rheumatoid arthritis (RA) which needs careful assessment by experienced doctors.

In the same way that we recognise that high blood pressure and raised blood cholesterol levels are risk factors for a heart attack and stroke, we are beginning to recognise a complex of symptoms and signs that herald an "at risk" state for the development of RA.

This is really important, because we all know that early treatment can mean better outcomes. But in fact it's not that complicated. For example, when someone with joint pains pitches up to a hospital early arthritis clinic for the first time the rheumatologist will focus on the duration of symptoms, the distribution and symmetry of joint pains (especially those in the wrists and hands), the duration of morning stiffness in symptomatic joints, and whether there is a family history of RA. As part of the clinical assessment, a specialist will also be interested to establish if hand grip is more difficult and whether pain can be elicited when the knuckles of the hands are squeezed. If such symptoms and signs are confirmed then this raises the suspicion of an at risk state, which rheumatologists now call a state of "clinically suspicious arthralgia (or joint pain)". This state invariably prompts some additional investigations. The presence in blood serum of antibodies associated with RA (in particular anti-CCP antibodies) and a raised CRP or ESR (a marker of inflammation) would suggest that an individual is at higher risk. X-rays of painful joints are not that helpful at this very early stage, but imaging joints by ultrasound (similar to the scans used to monitor foetal growth in pregnancy) or by magnetic resonance imaging (MRI) can detect early signs of inflammation even when swelling is absent upon clinical examination.

Experts in many centres in Europe and the US now have a much better feel for the level of risk, based on these and other assessments. By close observation of at risk individuals over time to see who goes on to develop swollen joints (i.e. clinical arthritis) and those who do not, it is now possible to quantify this risk. For example, approximately 50% of individuals with the symptom complex of "clinically suspicious arthralgia" described above, plus the presence of anti-CCP in blood, will progress to inflammatory arthritis or RA within 2 years. This percent is much higher, approaching 80%, for those who have clear evidence of inflammation by US or MRI scanning.

Whilst being able to predict those at highest risk is a very exciting development, it also presents a challenge. Currently, there are no guidelines for the treatment of at risk individuals. Furthermore, approaches to treatment are unlikely to be uniform because the type of therapy should be appropriate for the level of risk – the higher the risk, the more intense the therapy.

When there is no evidence to guide therapy, there is only one thing for it. Generate the evidence! And in medicine, one common way to achieve this is to undertake clinical trials. In 2009, and with the support of many experts across UK and Europe, we conceived such a trial, selecting to test the drug abatacept because we felt that this drug might stand the best chance of having an impact at this very early at risk phase.

Early treatment can mean better outcomes

This choice was also influenced by the fact that the drug – one of the class of drugs known as a biologic – was already licensed for use in established RA, had an acceptable safety profile, and had also been tested in people at high risk of developing diabetes. The Arthritis Prevention in the Pre-Clinical Phase of RA with Abatacept (APIPPRA) trial received ethical approval at the end of 2014 and the first at risk subject was enrolled in early 2015. This was a milestone moment for RA prevention studies, and one that would not have been possible without the input and advice from patients, who helped us to design and monitor the trial, as well as NRAS executives Ailsa Bosworth and Clare Jacklin, who helped coordinate the patient focus group.

Recruitment of our target population of 206 at risk individuals is now complete, and all study participants have completed the 12 months of therapy (active drug or placebo). Follow up will be completed at the end of this year, and so we will know the outcome of the study in early 2021. We are also very excited that the follow up period for this study has been extended for a few more years, so that we can realise the true benefit of treating at risk subjects and be absolutely certain that is does not cause harm. This will allow us to examine whether the onset of RA is merely delayed, or whether there are subsets of individuals for whom the disease process can be stopped in its tracks. We also look forward to seeing the outcome of similar prevention studies that have been initiated since our study began. These studies are testing the effects of familiar drugs such as hydroxychloroquine and methotrexate in at risk subjects to see whether they delay or prevent RA.

As we get better at defining the at risk state, and gain more experience in studying the impact of different therapies, it is likely that interventions can be considered for those who carry risk factors but have not developed symptoms. This approach would be more in keeping with treatment of high blood pressure and high cholesterol. For those at risk individuals who have yet to develop symptoms, interventions may target life style factors such as diet, smoking and dental hygiene. Regardless of the approach, we have been struck by the enthusiasm of participants who have contributed to our study, and are hugely grateful for the commitment of so many patients who have supported our work over the years. Thank you NRAS!

The best treatments can lead to cure. But the best way to cure is to prevent. We promise to keep you posted!

> We have been struck by the enthusiasm of participants who have contributed to our study

Become a friend of NRAS!

We are often asked by friends, family members and colleagues of those living with RA or JIA, is there a way in which they can support them? You can support all those living with these debilitating conditions by becoming a 'Friend of NRAS' and setting up a monthly Direct Debit today.

This dedicated group of supporters provide NRAS with a steady and reliable income we need to carry on providing key services including our Helpline and free publications and the essential confidence to commit to new projects that will improve the lives of those living with RA and JIA.

In return, we keep the Friends of NRAS informed, through bi-annual updates, of how their donations are making a difference and one of our lapel badges to thank them for their support.

A monthly donation makes a big difference whatever the amount.

Direct Debits can be set up online at www.nras.org.uk/donate, over the phone (01628 823 524) or email fundraising@nras.org.uk to request one of our forms by post.

We know that many of our Members have already kindly set up a Direct Debit in addition to their annual subscription or choose to support us in other ways and for this we thank you sincerely.

> ***"You have been inspirational for the information and comfort.***
>
> ***Thank you, and please carry on!"***
>
> NRAS Helpline caller

NRAS Ambassadors Stories in Scotland

NRAS Ambassador Allison Elder shares her experience of lockdown as a person living with RA in rural Scotland.

Since the end of March, our government has acted on its own scientific advice when First Minister (FM) Nicola Sturgeon started to make decisions independently of the rest of the UK.

As a result, Scotland has been slower to relax lockdown conditions than England, with us only moving to Phase 3 on 10th July.

This means that as this article was written, the 2m rule still applied; cleaning hands and surfaces remained paramount and wearing face coverings on public transport and in shops (unless exempt) was mandatory. Which may seem a touch severe to some of you, but actually there has been little by way of protest around these decisions.

When Scotland entered lockdown on 23rd March 2020, I considered myself extremely lucky as only 7 weeks earlier I had received a new hip and was now well my way to recovery. I cannot imagine how people have coped having their surgery delayed for months due to the COVID-19 situation.

In the Highlands online learning and working remotely are commonplace and we already have a video consulting service (Telehealth) where virtual appointments are made with health professionals.

This works well for our outlying islands and remote areas and has also proved very useful during lockdown as patients could still arrange an appointment without risk to themselves or the health professional.

The support I received, personally, from NHS Highland was excellent during lockdown. I was advised of blood test appointments by text, had phone call appointments with a GP and discussions with our Specialised Rheumatology Nurse. Further, when I enquired about my exercise programme a Telehealth appointment was arranged with the physio I usually see.

This was a great help as she was able to see how I am walking and advise of the next phase of post-surgery exercises and has continued to keep in touch by email asking about my progress.

I have found this very encouraging and it has helped to keep me focused on my recovery and recuperation. Which could so easily have gone astray if I was left with no input from health professionals during this long road to recovery and without the usual follow up appointments.

My personal experience of the lockdown has been mainly positive with probably the hardest part, as for many, was not seeing my family (especially grandchildren).

Like others, this period of social isolation has been an opportunity for learning and I now attend an online yoga class, have added several new recipes to my repertoire and can knit daffodils (excess of yellow wool). However, I am also rather too familiar with the neighbouring pavements having walked them daily for 113 days and have run out of episodes of 'Homes Under the Hammer' to watch.

Although I was not shielding, I did self-isolate for many weeks, but this was not an issue for me as I work part-time from home and continued doing so.

However, I do know that for those that required shielding letters for work, the haphazardness of the issue of the letters has caused quite a lot of distress for people who felt they could not attend work for health reasons, and without these letters many would not receive any money.

From a Scottish perspective, I believe that it is the strident approach taken by our First Minister (FM) that has helped prevent the virus rate from escalating as in other areas and this appears to have worked fairly well to date. However, I am not involved in the tourist industry or the

> When I enquired about my exercise programme a Telehealth appointment was arranged with the physio I usually see

hospitality sector and I think these people have a very different view of the delay in opening Scotland up to tourists.

There is no doubt that the impact on businesses and workers will be immense and, in the Highlands, where tourism is a large part of our economy there is likely to be serious consequences for many and possibly for years to come.

Of course, there are lessons to be learned, such as the issuing of shielding letters and the importance of these to people's livelihood. This would need to be addressed if required at any time in the future. Also, many believe the government should have taken more control of people entering the country as, even now, there is little by way of tracking visitors to monitor any spread of the virus.

Already the Scottish Government is seeking responses from the public on various aspects of the lockdown about how they were affected and what could be done differently and better should the need arise again. This feels like they are at least listening to us and are trying to learn from our collective experiences.

Protection of life has been our governments overriding objective since the onset of this situation and I believe it has been the right approach for Scotland.

There may be many reasons, political and otherwise, for the decision to act independently from the rest of the UK, but suffice to say that, I think, most people in Scotland are happy that the FM has remained steadfast in her approach of focusing on the health and wellbeing of the population above all else.

> This period of social isolation has been an opportunity for learning

Reflections on the COVID-19 lockdown in Scotland

By John Paton

NRAS Ambassador

The experience of people with RA in Scotland mirrors that in other parts of the world. Since the initial case in Scotland on 1st March, it has been one of grave concern. People have reported fear about personal risk from the unknown virus, frustration at the confused and conflicting public information about how to protect ourselves, and dismay at what the shopping, medical and economic changes meant for those of us with financial, mobility, and chronic health issues.

Scotland has followed a different approach to protect its population. That this has often been overlooked at each change in policy by UK media, public bodies, and professional associations has led to confusion and anger from NRAS members. Four months on, there are now no new deaths from COVID-19 being recorded in Scotland. The clarity and consistency of Scottish government health information has much to do with that. NRAS' excellent weekly live Facebook live events have also contributed.

Messaging and communication about shielding has varied between Scottish NHS Health Boards, and this - and the delay in provision of supplies to those isolating with no personal support - is still an issue. That said, new GP referrals for early RA treatment seem to be hitting 12-week targets, and GP surgeries are safely set up for bloods and other procedures. But infusions, injections and other hospital treatments have been another matter, and some Rheumatology clinicians have been on the COVID-19 frontline.

Fifty-five COVID-19 research projects are underway in Scotland, some specific to the interests of people with inflammatory arthritis, and some around the serious mental health effects of this continuing pandemic.

[illegible]

Addressing RA after lockdown: a mini manifesto

The Scottish Parliament's Cross-Party Group for Arthritis and Musculoskeletal Conditions had been due to meet in Edinburgh on 8th July. Like so many other long-planned events around the UK, the COVID-19 pandemic meant the meeting had to be held via Zoom instead.

NRAS recommends that rheumatology units ask every patient about their mental/emotional wellbeing as a matter of course

People shared evidence from kitchens and sitting rooms, including NRAS Ambassador John Paton (see article, page 35). Much of this experience was common to all four nations of the UK: routine health care put on hold because of COVID-19; experiences of shielding; worries about mental wellbeing; the urgency of unaddressed health care concerns building up during lockdown.

In May, NRAS surveyed our members and produced recommendations for the House of Commons Health and Social Care Committee. We asked about people's experiences of rheumatology services through the pandemic, and for thoughts about what would come next. Our thanks to everyone who responded.

Gathering together all that the NRAS policy team have learned through the pandemic, we have brought together a mini-manifesto of some of the issues rheumatology services and the government will need to address in the months ahead.

Mental wellbeing

In our May survey, NRAS asked respondents to rate the impact of COVID-19 on their mental wellbeing out of ten. The average response was five and a half. Half of people who have been shielding told us the experience had had a 'significant impact on their mental wellbeing' and one third told us shielding 'will lead to additional health and/or social care needs as we come out of lockdown'.

Various things should happen to address this. In the longer term, NRAS recommends that rheumatology units ask every patient about their mental/emotional wellbeing as a matter of course, so that opportunities to provide support are not missed. More immediately, though, mental health services need funding to support people who have had a difficult time through lockdown, especially people who have been shielding.

> Much of the collaboration between the voluntary sector and the NHS has worked well.

NRAS has also worked to support our Members' wellbeing through our new NRAS is Here for You service, Right Start (which has run right through lockdown), Facebook Live information sessions and fun video-link events including group singing, quizzes and Tai Chi. Our wonderful Helpline team handled a 600% increase in Helpline contacts in March, and our Policy Manager has kept them up-to-date with daily changes in government guidance in all four nations of the UK.

Communications through lockdown

The pandemic has been a huge challenge for the NHS and the government; it would not be fair to expect every communication to have been perfect. However, we have seen a lot of confusion, especially over shielding advice, and there are lessons we can learn from this crisis.

We are aware that rheumatology teams needed to spend significant time identifying patients who needed to be shielded, especially in the early stages of lockdown. Sending these communications electronically, rather than through the post, could save the NHS £millions in the future.

'The poor relation'

In July's meeting of the Cross-Party Group for Arthritis and Musculoskeletal Conditions, MSP Brian Whittle voiced the determination of many of us that conditions like RA and JIA should not be treated as 'the poor relation' as pent-up demand for NHS care is addressed.

57% of respondents to our May survey reported having rheumatology appointments delayed or cancelled. Some people need to be seen soon to ensure they do not suffer permanent damage.

There is good news here, too. Many people have told us they had appointments via phone instead of face-to-face. On many occasions we have heard that this has worked well, although not all appointments can be 'virtual', and this does not work—nor it is appropriate—for everyone.

Jobs

We know there will be difficult days ahead for some of our Members because of the impact of the lockdown on shops, restaurants, pubs and many other businesses.

As we sent this edition of NewsRheum to the printers, NRAS was launching a survey to make sure the voices of people living with RA and JIA on the subject of employment and COVID-19 are heard. We will share the results of this with the government and make sure employers know what support is available.

Keeping up good habits

We have seen instances of a welcome culture change within health and social care towards embracing change and innovation. For example, people who previously had not used online tools and technology are now much more familiar with this mode of communication.

Much of the collaboration between the voluntary sector and the NHS has worked well. With less face-to-face engagement, resources to support patients' self-management have become more important.

The pandemic has also given added impetus to health care professionals to realise the aspiration of shared decision-making and care plans for people with long-term conditions.

As we move ahead into a 'new normal', there are new positive practices to take from our shared experience of lockdown. NRAS will continue to campaign to ensure that variations in access to best evidence-based care are highlighted and minimised.

Dealing with worries

We also know that many people - especially those who have been shielding - will still feel nervous about leaving the house for appointments. Where your GP or rheumatologist advises, it can be important not to put off being seen if you know that something is not right. People who have gone to their GP or hospital to take bloods have told us they felt safe and were glad they went.

Some readers will also be waiting for a diagnosis, and it is important to aim for early diagnosis to limit the damage that occurs with prolonged inflammation.

By Ailsa Bosworth, MBE

National Patient Champion for NRAS

COVID-19's Impact on NRAS

Who could possibly have envisaged when we were anticipating budgets and work programmes for 2020 during November/ December 2019, that 2020 would bring the devastation of a deadly global pandemic? Well, some did, notably Bill Gates in a TED Talk in 2015, but I think you will understand what I mean.

We all saw China building a new hospital in 7 days on TV back in January, little realising that we would be doing the same thing in London and other major UK cities in fairly short order. This experience has changed so many things for everyone. It's likely that life will never quite be exactly the same as pre-COVID. I've been shielding as I write this for more than 3 months, and I miss my family, my friends and colleagues enormously.

Many patient organisations like NRAS have experienced the double whammy of having to deliver significantly increased support and services, whilst at the same time seeing their charitable income drop through the floor. It's just as well that Clare couldn't see into a crystal ball a year ago and get a glimpse of what she and the Senior Management Team would be faced with less than a year into her role as the new CEO of NRAS. I must say, however, and I can say this more objectively now as I am in a different role as National Patient Champion, and no longer directly responsible for the organisation, that she and the Senior Management Team just rolled up their sleeves and dealt with everything incredibly professionally and calmly. All staff started working from home in March and Clare immediately started delivering Live Facebook discussions, on a weekly basis, to keep you all up to date with relevant information. These have been hugely popular and viewed by many thousands of people. Our social media and communications team have done an impressive job of keeping everyone abreast of information as it emerges. Hats off in fact to the whole NRAS team and particularly the Helpline Team who worked long hours and managed a 600% increase in calls, emails and contacts to the organisation during March and April. People were anxious and confused (understandably) about what level of risk they had and whether or not they should shield/continue to take their medication and needed our support.

We immediately prioritised our front-line services to preserve funds. This meant putting development of some key projects and work-in-progress on hold and this included one of my major projects - developing a new e-learning programme for people with RA and Adult JIA. This new programme is called SMILE-RA (self-management individualised learning environment). We had hoped to launch a taster module at the BSR congress in April, but of course this, along with all other events, got cancelled. In addition, we had to postpone our awareness raising campaigns, WearPurpleforJIA and RA Awareness Day, until later in the year – see website for more details.

In spite of delaying some important pieces of work, we have continued our scheduled programme to launch two brand new websites in 2020, the first being the JIA site in July and the NRAS-RA site following later in the summer/ early autumn. In spite of, and in part because of COVID-19, we launched a new service in May 'Here for You' to help people to connect with our trained volunteers for support through an on-line request, (see website for more info) and are developing others.

I have always been very proud to be a part of this dynamic, responsive and compassionate organisation but never more so than during such incredibly challenging times.

We're not out of the woods yet nor will we be for some considerable time, but we will come out of it and NRAS will be the stronger for it and continue to be here for everyone with RA or JIA, every step of the way.

Josie the Bear raises funds

[illegible]

Rosie's symptoms first started at just 21 months old and she was diagnosed with 12 inflamed joints (and a nasty limp) just after her second birthday. There is nothing worse for a parent than seeing your child in pain so we were upset to know this wouldn't go away but equally we were relieved to know what we were dealing with.

Now, almost 4 years on our brave Rosie must have 2 injections a week as well as regular blood tests (as the meds can affect other things if not careful) and regular eye checks (a lot of children with JIA also have uveitis).

Rosie is now officially in "remission on meds" which means she has no active arthritis. She is such a happy girl and a superstar with it all and we couldn't be prouder. Rosie is now in year 1 at primary school and enjoys her ballet and swimming lessons as well as being part of 3rd Holmes Chapel Rainbows.

Four years ago, we didn't even know that this condition existed, and this is now our fourth fundraising effort for #WearPurpleforJIA (which should have been on Friday 5th June). This year we decided to do something different and our fundraiser was called Where's Josie (our JIA bear)? and we raised £475. My other daughter Lauren (7) helped me to run this event as part of her Brownies charities' badge. For every £1 donated they were given a location of where the bear could be - this could be a business in our village or a local street name. Lauren used a random number generator to pick the winner. We then went to that location with Josie the bear, to get a picture so we could announce the winner on Facebook.

[illegible]

#wearpurpleforJIA at NRAS 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. The day raised a wonderful £45,000 for our JIA services at NRAS and we hope, this year, to raise that and more!

Our 2020 Wear Purple fundraising packs will be available soon as well as our fantastic range of Wear Purple merchandise. You will be able to order your pack online: **jia.org.uk/event/wear-purple-for-jia/**

My Story – Ian Dixon

A return to Golf after 30 Years!

Golf remained my favourite game even though I had to endure the frustrations of being only capable of watching and not playing

My name is Ian Dixon and I am married with 2 daughters and 2 granddaughters. I was diagnosed with RA and Diabetes Mellitus type 1 in November 1976, aged 16. Quite naturally this was a shock being an active teenager having just started my A levels. Four months in hospital followed with two months where I was not allowed out of bed. In the mid-70's bedrest was one of the main treatments for RA including full length resting splints from hip to ankle. I played many sports, and represented my school at football, basketball and table tennis. What concerned me most was that following the onset of RA, being from a family of golf players, I could no longer play golf which I had played since I was 8 years old.

So, I therefore endured an enforced 30 year "medical break" from golf, during which I also had to undertake major surgery for hip and knee replacements.

In 2007 I was placed on the drug methotrexate which seemed to limit the progression of the RA and also limited the inflammation associated with the disease. Whilst I had taken up snooker in the intervening 30 year break, it was golf that remained my favourite game even though I had to endure the frustrations of being only capable of watching the game and not playing it. After 12 months on methotrexate, I felt that my joint pain had reduced sufficiently to possibly explore attempting the game again. From chipping a ball in my back garden, I decided to buy a 7 iron and went to my local playing fields in Hampshire to find surprisingly that I could still actually hit a golf ball again. The shots didn't go far due to my restricted joint movement but generally they went straight. More importantly, I was not wracked with pain and did not have any additional reactions to the evening exercise the following morning.

From there, I started playing at a pitch and putt after work with some work colleagues. Golf lessons with a PGA Golf Professional followed along with membership of my local golf club in Hampshire. Along with re-learning to play this difficult game, I had to overcome the extensive joint damage and loss of power associated with over 30 years of suffering from RA.

When buying a single-seater golf trike to help me get around the golf course, I had a chance conversation with the seller who asked me if I would like to play in a disabled golf tournament the following month at Swindon. From there I learned that there is an active golf scene for golfers with a disability and this is co-ordinated by various UK charities promoting such golf events. Moreover, I learned that the European Disabled Golf Association (EDGA) also held events throughout Europe. With a lot of hard work and practice over that last 10 years I gradually improved my golf and have recently joined Newbury & Crookham Golf Club where I play off a handicap of 12.

[illegible]

Last year I was selected to represent the England Team in the European Disabled Team Championships in Cadiz. I qualified via my then current position on the World Rankings for Golfers with a Disability (WR4GD – Net) and played in the Net Team Competition where England finished runners-up to Czech Republic.

After an enforced 30 year medical break from golf and 6 major total joint replacement operations including 3 revisions, it's not only great to be back playing, but to be competing on an international level is something I could never have dreamed of after being diagnosed with RA!

Could you be an NRAS Ambassador?

This article was originally written for the Spring 2020 edition of NewsRheum, but was held back due to the COVID-19 outbreak. As lockdown restrictions are lifted and we look ahead, now is the perfect time to consider whether a role as an NRAS Ambassador is right for you. As an Ambassador, you would receive NRAS training (currently via Zoom), engage with local health care commissioners and decision-makers, and campaign for the best possible services for people living with RA and JIA in their communities.

NRAS Ambassadors are Members of NRAS who are local campaigners playing an important role raising awareness of RA- and JIA- related issues in their communities.

There are currently three NRAS Ambassador groups, in Manchester, Scotland and Wales. We hope to see these groups grow in 2020 as well as to establish more groups in new areas, in partnership with new Ambassadors. NRAS will provide all new Ambassadors with expert training.

Recruitment is open to motivated people with an understanding of RA or JIA through lived experience, an ability to communicate effectively and commitment to the work of NRAS.

Ambassadors vs Volunteers

NRAS Ambassadors play a different – though equally valued – role to Volunteers.

Ambassadors work closely with our Policy team to highlight issues important to people living with RA to local service providers, commissioners and the government. It can be an exciting role – in 2018 NRAS Ambassadors were invited into No. 10 Downing Street by Rt. Hon Theresa May, Prime Minister at the time.

They have also met leading MSPs in Scotland, held events in the Welsh Assembly and Scottish Parliament, and continue to engage with the Greater Manchester Health and Social Care Partnership. This engagement will continue into 2021 and beyond.

Another ambition for NRAS is to map gaps and shortfalls in services provision across the UK and highlight examples of excellent practice. We want to bring together politicians, people living with RA, NHS commissioners and decision-makers, employers and community service providers. Community services like swimming pools, gyms, yoga groups or bowls clubs can be an important part of self-care and self-management.

RA services after lockdown

When originally written for the Spring '20 edition of NewsRheum, this article looked ahead to life after the Brexit Withdrawal Agreement negotiations. Times have moved fast. We are now, instead, talking with partner organisations and health care professionals about what needs to happen to support RA services after lockdown (see Addressing RA after lockdown: a mini manifesto, page 36).

The government's long-term policy plans still matter, of course; Boris Johnson's 2019 manifesto promised measures to diagnose serious conditions earlier, and to promote prevention where possible. Matt Hancock, the Health Secretary, continues to be keen on new technology and the role it can play in health care.

What does it take to be an Ambassador? It is a challenging role – you are speaking on behalf of others in your community living with RA or JIA, and on behalf of NRAS. With it comes plenty of support, expert training, exciting opportunities and a huge chance to change things for the better. If that sounds like you, get in touch!

> It can be an exciting role – in 2018 NRAS Ambassadors were invited into No. 10 Downing Street by the Prime Minister

To find out more or express an interest in becoming an Ambassador, email campaigns@nras.org.uk.

My JIA Story – Hannah Roberts

It's been almost 12 years since I was diagnosed with Juvenile Idiopathic Arthritis, aged 14. I still have many vivid memories of that time and the 4 years that followed, until I eventually found my 'miracle drug', tocilizumab, which has since put me into medicated remission. I have been very lucky over the past 8 years to experience only a handful of flare-ups. These were during the early stages of my two pregnancies and immediately after giving birth.

> I wish I could go back to my 14-year-old self and tell her that even though it's so hard, painful and life changing, good can and **will** come from this

I certainly didn't feel like a child at 14 – youth clubs with my friends, drinking cider in the park and attending house parties were all activities I involved myself in. Wearing hair extensions and make-up, trying to try to 'fit in' with the crowd. I'd always struggled on and off with friendships – I was super sensitive and often the target of nasty comments. I enjoyed dancing, though, and competed at Blackpool Tower annually. Before I became ill, I won a National Champion title for cheer dancing.

Like the flick of a switch, my life changed forever. I went from being an active teenager to one who was crippled by pain and swelling. I no longer had shouting matches with Mum and Dad, slamming doors and stomping up to my bedroom in a typical teenage fashion. Suddenly, I needed them for everything. Mum stopped working and became my full time carer - lifting me on and off the toilet, feeding me every meal, getting me dressed to spend another day in bed. At an age where I wanted to rebel against my parents, they became my only companions, carers and confidants. They were my safety blankets in what suddenly felt like a very grown-up, scary world.

Friendships dwindled. Obviously I know now that as teens themselves, my peers couldn't have known how to support me through my new reality. But at the time, I felt like I'd been left on the shelf, whilst others continued with their carefree lives. Gathering on street corners with cheesy chips, meeting up at each other's houses to self tan and paint their nails. I envied them. Their lives continued and mine was stuck.

The days were hard but the nights were unbearable. Excruciating pain left me feeling unable to cope. Unable to cope with life. Lying in my bed, day in and day out. Trying to keep up with schoolwork over e-mails. Staring at books with blurred eyes – blurred from tears or from medication. I'd long for that relief from the pain; the same relief would knock me out for hours on end. Waking up in the same spot, wondering what time it was. Mum carrying home-cooked meals to my room on trays. Listening to me, always listening. Telling me she wished she could swap places with me – pure helplessness. Only now that I am a mother myself, can I imagine the pain she must have felt too. The mental struggle was as painful as the physical. I was consumed by depression and anxious to leave the house.

I was referred to CAMHS (child and adolescent mental health services). I remember walking into a poorly lit waiting room, young children running around, their parents telling them to sit down and be quiet - stacks of toys and books available to entertain them. I looked at Mum for reassurance – feeling out of place. Feeling too old. We were called in and a lady with dark hair and a big fringe sat in front of me. She asked me how I was feeling. She proceeded to tell me that all I was experiencing was normal for someone going through puberty. As soon as she said those words, she'd lost me. She didn't understand. I wished that puberty were all I had to contend with.

I refused to go back. With a lot of work and jumping through loopholes, I was able to have a few sessions with an adult clinical psychologist. She taught me how to meditate, gave me techniques and practical coping strategies. I looked forward to talking to her because she wasn't involved – I could be completely honest about how I felt and I always walked out feeling lighter. The sessions came to an end quickly. Looking back, I wish they had continued because some of the mental baggage and trauma from those early days of illness followed me into my adult life – something I have had to work on closely over the past few years.

Starting tocilizumab and regaining my health was an obvious turning point for me, but despite the challenges I faced, I still left school with 10 GCSEs. I went on to study A Levels and eventually go to University. Looking back, some of my greatest achievements to date probably wouldn't have happened if I'd never got JIA, so for that, I'm thankful.

Spending time in the hospital really elicited a passion for caring. The Nurses who looked after me were wonderful and inspired me to do my Nurse training. I graduated with a first class honours degree in 2016, after three years of studying and placements. Although I'm currently shielding due

to COVID-19, I am looking forward to starting my new role as a school staff nurse as soon as it's safe to do so – so I can play a small part in working to improve the health and wellbeing of children and young people. Something very close to my heart, for obvious reasons.

I also met my husband during my darkest days. He became my best friend – the type of friend who lifted the kettle before you even got the chance to ask for help. We spent hours on end doing the fun things I could do, like watching movies and listening to music. With him, I never felt broken. Our friendship blossomed into a relationship and in 2017 we got married. On that day I danced again, taking centre stage, wearing HEELS.

We have since had two beautiful, healthy children. Our son, who is 2 in June and daughter, who will be 1 in July (I know what you're thinking – crazy, right?). During both pregnancies, I stopped tocilizumab from the day the test was positive until I'd breastfed for as long as possible. When my symptoms returned I re-started. It wasn't easy and I do have secondary damage in my left wrist. But was it worth it? Totally. I am extremely grateful for my wonderfully supportive husband, parents and brother who stepped in when I needed them most; cooking, washing, even brushing my hair, just like they did all those years ago.

To anyone out there who's struggling with JIA or to a parent of a child struggling. Everything is going to be ok. I wish I could go back to my 14-year-old self and tell her that even though it's so hard, painful and life changing, good can and will come from this. Also, the mental impact of a chronic illness can be as debilitating as the physical – always seek support.

Wellbeing and Living with RA

The years leading up to my diagnosis, I can only describe as hell on earth. The pain was horrendous, and I felt really frightened about what was wrong with me. It took a couple of years for me to get the diagnosis of rheumatoid arthritis and the day I sat in the consultant's office, I felt like my life was over. I had no idea what it meant when he said, "there is no cure, we can only manage your disease". He genuinely seemed very sad and sorry about the diagnosis. From that moment on I felt as if my life was over. I could barely walk, I couldn't do my job to the capacity that I was able to before that and just taking my daughter to school felt like a really epic journey up Everest.

Finally managing to get a medication concoction that worked for me, I started to feel some relief, but I still struggled. It wasn't until I started learning some self-help techniques that I really started to turn a corner. These self-help techniques were the difference that made the difference for me and now I can say I lead a relatively normal life. I say relatively because in 2018 I had a total hip replacement and being only 44 years old, it hit me hard.

The things that I found most useful were:

- Mediation and mindfulness – my body was clearly under stress anyway and I found that learning very simple meditation and mindfulness techniques activated my parasympathetic nervous system and helped me to relax. I noticed the more I relaxed, the more the pain lessened. Not to mention I started to feel a deeper sense of wellbeing and calm and my anxiety pretty much disappeared.
- Nutrition and diet – I started noticing that certain foods triggered me. Certain nuts, certain cereals. Every time I had them, I would notice that I would get inflammation in different parts of my body and over a period of time I managed to find certain culprits which made me feel worse and other foods which made me feel better. I designed my diet around this, and the inflammation pretty much went completely when I followed this protocol.
- Qi Gong – I have a daily practice of Qi Gong which is very gentle yet very relaxing and has massive health benefits for the body.

By Carolyne Bennett

I am a Life Coach and I work a lot with people on mindset and I found that when these skill sets came in to play and I used them on myself then everything changed as well. I hope this information helps you and that there is something additional that I have mentioned that you can potentially explore that might be the difference that makes the difference for you too.

[illegible]

Events Diary

2nd September	**RheumZoom Scotland**
7 – 13 September	**NRAS Rheumatoid Arthritis Awareness Week (RAAW)**
7 – 13 September	**Remember a Charity Week**
12 October	**World Arthritis Day**
6 November	**Wear Purple for JIA Day**

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Sign up to play the NRAS Lottery today and be in with a chance to be one of our weekly winners. It costs just £1 per week and you have the chance to win up to £25,000!

The NRAS Lottery is organised by Unity, a specialist organisation which runs charity lotteries and, unlike most other lotteries, gives 50p from every £1 direct to the charity.

T&C's are on the website and the lottery is for players over 18 or over. If you already play the NRAS Lottery (thank you!) please consider passing the leaflet onto a friend or family member.

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JIA at NRAS

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