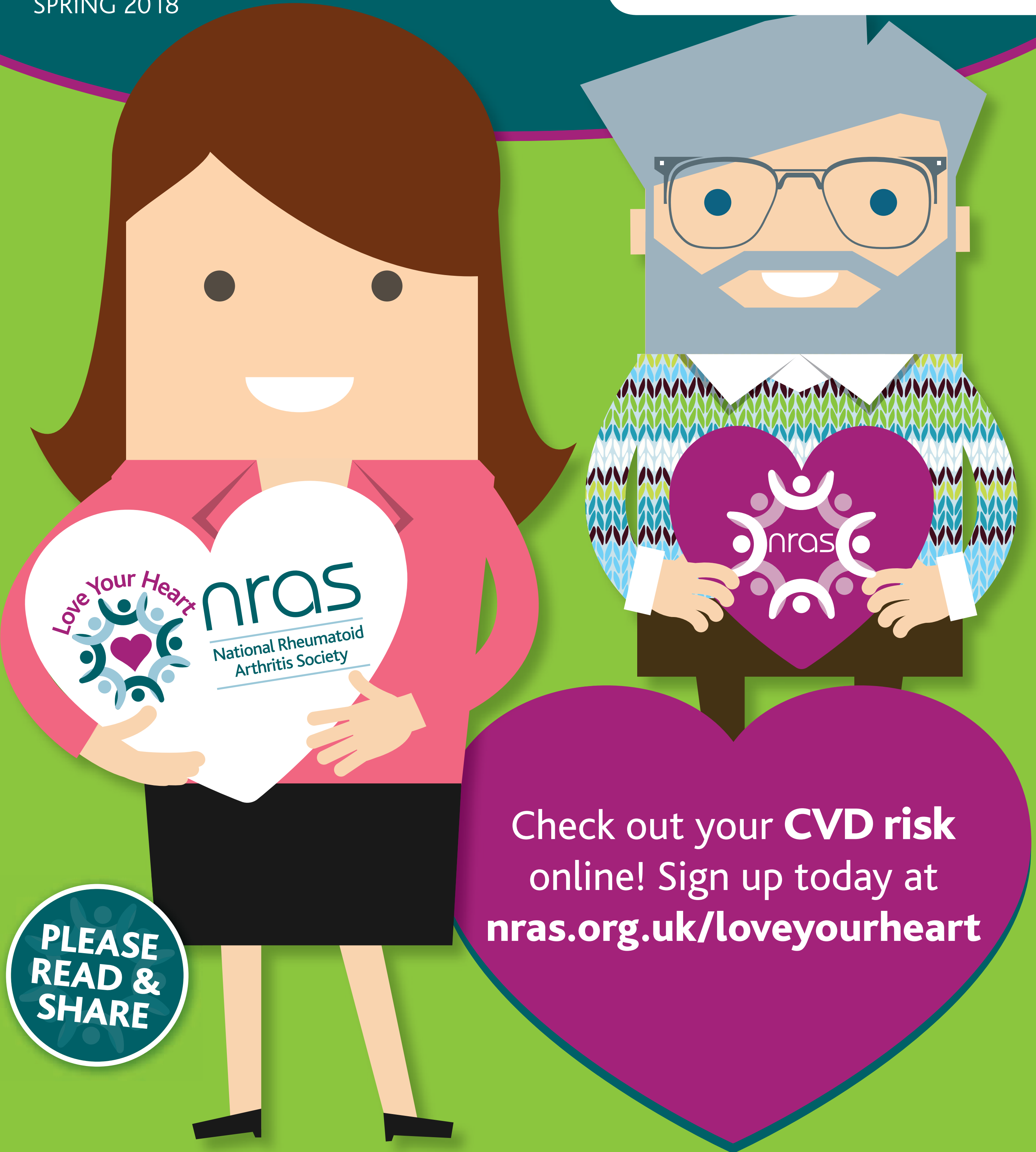
Members' MAGAZINE

SPRING 2018

nras
National Rheumatoid Arthritis Society



Check out your **CVD risk** online! Sign up today at **nras.org.uk/loveyourheart**

PLEASE READ & SHARE

NRAS LOTTERY

Join the NRAS Lottery
www.nras.org.uk/nras-lottery

RA AWARENESS WEEK

18th-24th June
nras.org.uk/raaw

GET IN TOUCH

www.nras.org.uk
01628 823 524

By Ailsa Bosworth, MBE

Chief Executive

Dear Members

Signs of spring are lovely to see and, as I write, I have primroses sprouting all over the garden and the comfrey is starting to flower, so the bees will not be far away. Some sunshine is very welcome after a long, dark and snowy first quarter of the new year. Snow and ice are not welcome companions of people with RA and fear of slipping in such weather is very real! As usual, things could not be busier in the NRAS office and we are preparing for the launch of lots of great new material at the upcoming British Society for Rheumatology annual congress (in Liverpool this year) in the first week of May. We will be publishing three new booklets entitled: ***New2RA***, ***Living Better with RA*** and ***Fatigue Matters***, so watch out for these and do get your order in now.

On February 14th, St. Valentine's Day, we launched **Love Your Heart** a fantastic new, interactive video programme which helps you to understand why people with RA (and other forms of inflammatory arthritis) are at increased risk of cardiovascular disease (CVD). The programme then helps them to assess their own personal risk and go on to set goals to mitigate their risk and improve their lifestyle to reduce their CVD risk. In due course, we hope to analyse and publish anonymized aggregated data from Love Your Heart to show intended and actual behaviour change as well as benefits achieved by those who have completed the programme. To register and complete the programme (it's absolutely free to do), go to **www.nras.org.uk/loveyourheart**

We are currently also gearing up for **RA Awareness Week** and **#WearPurpleforJIA** which are both great opportunities for YOU to GET INVOLVED in raising awareness, get in touch with your MP, fundraise and more for RA and JIA. There's more detail on both events in this issue. Go to pages 8 and 47.

We have also just recently launched a new video for our Apni Jung area of the website for the South Asian communities across the UK and elsewhere. The video is in Hindi with English subtitles, so if you know someone who would benefit from information about RA in Hindi, please signpost them to **www.nras.org.uk/apnijung**

This new resource talks about moving from standard DMARD treatment to a biologic and highlights the cultural issues around this transition identified in a recent research paper by Dr Kanta Kumar.

We've got upcoming Family Days and events for JIA in the NRAS calendar, so please do check out the dates for these on our website **www.jia.org.uk** and book your place now!

If you have filled in our survey on foot health recently – thank you for your input. This was to inform a presentation I'm doing for the Podiatry Special Interest Group at the BSR congress. I am going to be sending out another survey shortly regarding a presentation I'm going to be doing for the European Congress, EULAR, in Amsterdam in June, so please watch out for that and let me know your views on patient rights and safety concerns (in relation to drugs/treatments).

Finally, I'd just like to share a recent email to our helpline team:

"Thank you so much for taking the time to let me talk through my emotions and anxieties- you really made a huge difference to me and I felt so much better after our conversation."

I can't tell you how much we all appreciate getting emails like this. Our team work incredibly hard to provide you with the best service possible and knowing we are making a positive difference puts a smile on everyone's face, so if you get a moment, do let us know if we've helped you. Feedback is incredibly important and helps us to do better!

Have a wonderful summer and stay as well as possible.

Ailsa

If you are receiving this magazine for the first time and are not yet an NRAS Member, sign up today and receive it on a regular basis.

Simply contact **membership@nras.org.uk** to find out more about joining.

Members' MAGAZINE

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;
Clare Jacklin & Michele Le Tissier

The Bolton NRAS Group

10-year anniversary!

NRAS would like to say a massive congratulations to the Bolton NRAS Group, who last October, celebrated their 10-year anniversary. The Group, currently lead by NRAS Volunteers and Members Julie Dorsett and Carol Gray, meet monthly at Bolton One where they work extremely hard to put on an excellent programme of guest speakers for the year and dedicate lots of time to promote NRAS and the Group in their community reaching as many people as possible. Consultant Rheumatologist Dr Vasireddy, was the keynote speaker at this special anniversary meeting and he has supported the Group from its inception. There was also plenty of time for cake and congratulations to all those involved. Thank you to everyone that has supported the Group over the years and continue to make it a success to offer vital support to those living with RA in and around Bolton.

Julie & Carol, Group Coordinators with NRAS Manchester Ambassador Christine Lowe

NRAS Gathering

Scotland 17th April 2018

In the next magazine we'll be able to give you a full report on the "Gathering" which by the time you have received this magazine will have just happened. Professor Iain McInnes, NRAS Scottish patron, was the keynote speaker, Dr James Dale will have presented on how to live better with RA and Dr Mohini Gray will talk about RA, depression and anxiety.
A new addition to the Gathering this year was a 'marketplace' of exhibitions, scientific displays and practical demonstrations, including how ultrasound works.

By Julie Dickins

NRAS East Dorset Volunteer

Everything is going swimmingly well in Dorset….

> We never fail to find pleasure, and fun, in our exercise!

We have all heard about the importance to exercise for those of us living with RA if we are to maintain strong, healthy joints. However, those of us with pain and fatigue may groan at the thought of being physically active. So, when the East Dorset NRAS group was launched in 2012 we wanted to take up the exercise challenge, and as well as setting up a weekly exercise class in the gym we decided to organize a hydrotherapy group.

For many of us with joint pain, being immersed in warm water provides instant relief. Taking a bath can be a struggle, so the thought of a warm pool where we could quite literally take the weight off aching limbs whilst exercising our muscles seemed like a good idea.

In East Dorset there is no longer an NHS hospital with a pool, so we approached our local private Nuffield hospital, which we knew had the warm pool we were looking for. We canvassed our NRAS group attendees and quickly found 12 people who would be interested in hydrotherapy, so went about setting up a meeting with the people at the Nuffield hospital. They were willing to run a half hour session for 8 people once a week with a physiotherapist to lead the exercises and at an affordable cost. So, with an agreed rota system, the hydro group started.

It is hard to describe the feeling of walking down the steps into the warm water, but every one of us gives a sigh of pleasure as the water takes the weight off our joints. Our physiotherapist works us hard with a range of exercises to increase muscle strength, joint flexibility, balance, core strength and cardio vascular health. We often joke that she is preparing us for a synchronized swimming event as she has invented complicated routines for us to follow. The group has become so popular that we now run two sessions a week. As we jog, float or cycle around the pool on our long foam "woggles" we are able to also share our experience of living with RA, we never fail to find pleasure, and fun, in our exercise!

NRAS Pen Pals!

Proof that pen to paper is preferred by people who pause for prose!

Following the call out for NRAS Pen Pals in the winter magazine, we have been delighted to receive so many replies and been able to match up so many people who are now happily making new friendships via good ol' snail mail.

If you'd like to connect with any of these people looking for a pen pal please send your letter c/o Emma Sanders, NRAS, Ground Floor, 4 Switchback Office Park, Gardner Road, Maidenhead, Berkshire SL3 7RJ marking the envelope with the reference name and number and Emma will forward your letter to the relevant person. Don't forget to include your address for them to respond to.

Happy writing!

Vicky 67963

I am 46 years old and I am a mum to two children aged 22 and 18. Married and living in Middlesex. I am a part time practice nurse and I also am the chair of my local community garden volunteer group. I find I feel isolated with my condition and would love to make contact with others in the same situation and I love a good old-fashioned letter arriving in the post. I have a black cat and I love anything crafty and I am obsessed with buttons. Hope to hear from you soon x

Lynda 12465

Hello, witty gregarious female in my 50's, North West area - seeks single male pen pals to correspond with. Age 50 to 65. My hobbies are voluntary work, dining out, music, gardening, TV, theatre/cinema. I also enjoy technology and the internet. I have had RA (JIA) since childhood but maintain an active life and feel disability is no barrier to leading a successful and fulfilling life. Let's hope all your letters to me keep the postman busy.

Valerie 37763

I am nearly 75 years of age. I have rheumatoid arthritis. I receive Rituximab infusion at Solihull Hospital, West Midlands and I am also on methotrexate. Along with other illnesses. I would like a female in my position to write to.

Marie 94995

My name is Marie, just recently diagnosed with RA and presently seeking medical retirement. I live in Edinburgh and am currently rescoping my life due to my diagnosis. I love the great outdoors, but cannot walk any distance, so am looking to take up outdoor photography to enable me to still get out and about with a purpose. I have already undertaken a genealogy course and have started tracing my family history, enjoy reading pretty much anything and am interested in politics and people. I would love to establish penfriends of all ages, genders, social backgrounds and experiences. There is nothing like a letter on the mat to cheer you up, so get writing!

> ***"To write is human, to receive a letter: Devine!"***
>
> Susan Lendroth

> ***"To send a letter is a good way to go somewhere without moving anything but your heart."***
>
> Phyllis Theroux

If you have an advert for a future edition, please also send them to the address above, email **membership@nras.org.uk** or call Emma on **01628 823524.**

रह्युमेटोइड आर्थराइटिस | जैविक दवाइयां

(Rheumatoid Arthritis and Biologics)

We have launched a new video about Rheumatoid Arthritis (RA) and Biologics, in Hindi! This is a part of our initiative 'Apni Jung', which aims to tackle the cultural and language barriers faced by South Asian people with RA in the UK. To watch the video or learn more about RA in Hindi, visit **www.nras.org.uk/apnijung**

By Ailsa Bosworth, MBE

Founder & CEO NRAS

Patients with arthritis and rheumatism in Europe (PARE) brings patients groups together in Copenhagen

On 12th and 13th March I attended a meeting of PARE organisations' Chief Executives in Copenhagen which is funded by EULAR. For those who are not aware of what EULAR is, it stands for European League Against Rheumatism and is the European organisation representing three pillars of work within rheumatology – Scientific (Rheumatologists, Immunologists, etc.), Allied Health Professionals (Specialist Nurses, Physios, Occupational Therapists, Podiatrists and other therapists working in rheumatology) and the Patients' organisations (PARE – People with Arthritis and Rheumatism in Europe).

Unlike the American College of Rheumatology(ACR), across the pond, EULAR is very inclusive of patient organisations and all three pillars work effectively together. The Chief Execs meeting is for the CEOs representing organisations/charities with paid staff, so not all patient organisations across Europe are able to attend. Some patient organisations in Europe are quite small and managed mainly by volunteers. Part of what we do as the larger organisations is find ways to support the smaller patient organisations. We can often share with them specific campaigns which they may be able to usefully copy or adapt for their own country/regional use.

As always, this meeting was really useful. I always come away with new ideas and it is interesting and often beneficial to share experiences with others providing similar services. As a consequence of this meeting, I will be organising a brainstorming session on a number of subjects within NRAS. Of course, all countries have different reimbursement systems and different ways of delivering care but we also have many things in common. The need for earlier diagnosis, reduction in variation of access to best care, access to treatment, biosimilar switching issues, and many more topics know no boundaries which is why it is so important that we come together to speak with a common voice, even if not language!

From snow to sun in a week!

From Copenhagen to Cyprus – what a busy week!

By Ailsa Bosworth, MBE

Invited by the Ministry of Health of the Republic of Cyprus, I attended a two day rheumatology conference in Nicosia on 15th and 16th March. The conference was well attended by rheumatologists, nurses and allied health professionals, Ministry personnel and the patient organisation in Cyprus, Cyplar. The purpose of the conference was to review the state of rheumatology and explore the proposal to develop a national strategy for public awareness of rheumatic and musculoskeletal diseases and the importance of early diagnosis.

I was asked to give two presentations, one looking at how services are delivered in the UK (and elsewhere in Europe) and on our national campaign: Behind the Smile. I received lots of questions about how care is delivered, where there are delays in the UK health system and in particular the role of the rheumatology nurse specialist. My sessions were in English of course as I don't speak any Greek at all! The majority of the conference proceeded in Greek but fortunately I was provided with a translator so I could keep some track of what was being said.

The NRAS/Lilly Behind the Smile videos depicting the story of Jane were very well received and it was clear that the audience were moved by them. As these videos have been translated into other languages (either dubbed or sub-titles applied), I am investigating with our industry partner in this campaign whether it might be possible to translate them into Greek.

The health system in Cyprus is very different to the UK. Their total population is 750,000 and they have both a public and a private system with rheumatologists working in both. The private system costs a lot less than private care in the UK however, and can be accessed by more people therefore than would be the case here. I was impressed by the way in which the Ministry of Health took an active part in the conference over the 2 days. It was opened by their Minister of Health. Imagine Jeremy Hunt opening the BSR conference and senior officials from NHS England and the Department of Health attending the BSR annual congress for the whole three days or even one day!

Behind the Smile *video*

It was very interesting being able to exchange information and views with colleagues from Cyprus and I wish them well in their endeavours to establish a national strategy. It was also immensely flattering and makes me proud to think that NRAS, small as we are, has a reputation that goes beyond our UK shores!

Other Rheum for You NRAS Conferences:

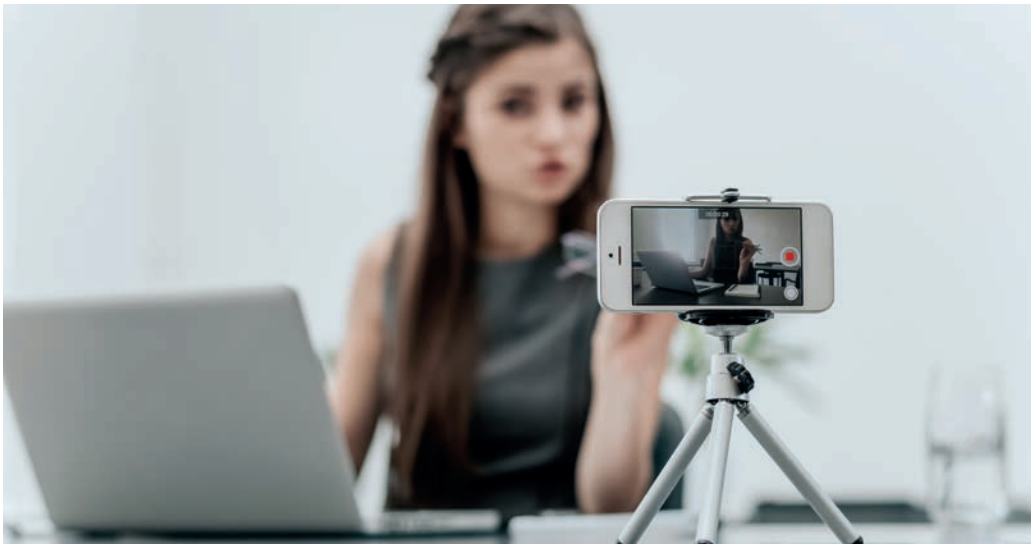
Where are we going next?

The next 2 '**Rheum for You**' conferences are planned to be held in London on Saturday 7th July and then Manchester and Cardiff in September and October, dates to be confirmed shortly. Each conference will include expert keynote speakers covering many different subjects, the chance to hear updates from NRAS and the opportunity to meet and chat to others living with RA. Each event in unique and an excellent opportunity to hear from the leading health professionals and experts, so we very much hope you will be able to join us at one of these events! For more information please email **enquiries@nras.org.uk**

RA Awareness Week

18-24 June 2018

We need your help to support RA Awareness Week!



We are asking all our supporters, whether you have RA yourself, are a family member, friend, carer or healthcare professional, to create a short video and send it in to us

RA Awareness week 2018 takes place from 18th to 24th June 2018. We're looking forward to building on last year's campaign and raise even more awareness of this invisible illness and impact on those that have it.

We are asking all our supporters, whether you have RA yourself, are a family member, friend, carer or healthcare professional, to create a short video and send it in to us. The video needs to be between 30-60 seconds long and can cover a variety of different topics including:

- How RA affects your joints on a day to day basis and how you've overcome different obstacles
- How RA affects more than 'just joints' – such as your eyes, heart, lungs or other areas of your body?
- How RA has affected your work or your education
- Any experiences you have had with your disease feeling invisible e.g. reactions from friends/family or the public about it
- We also want to hear from friends, family, colleagues - how has your RA affected them? Has it made them learn more about the disease? How have they supported you?
- How does having RA affect you emotionally?
- Healthcare professionals – How has RA affected your patients? What support can rheumatology teams give them?

We want your positive and negative stories to share throughout the week although unfortunately we cannot guarantee we will be able to feature them all! You can submit your videos via **www.nras.org.uk/raaw**. If you have any difficulties uploading your videos email **media@nras.org.uk**. Please send them in as soon as possible as deadline for consideration for inclusion in our montage is 15th June. Don't forget you can also share your video through your own channels as well!

As with previous years, RA awareness week packs will be available so you can do your bit by putting up posters and helping us spread the word. Inside the packs will be a card featuring the **#RefRAmeRA** hashtag which you will also be able to share with us. Packs will be sent out nearer the time but you can pre-order yours now by emailing **enquiries@nras.org.uk** or call and speak to Michele on **01628 823524**.

If you are planning on holding an information stand in your local clinic/hospital, supermarket or other public place, make sure you let us know so we can help promote it. Also, don't forget to request all the literature you need well in advance to ensure it arrives on time - email **enquiries@nras.org.uk** with details of your planned event and publication requests.

Verse, violins and voices – NRAS Christmas Concert!

NRAS ended 2017 on a high note with the annual Christmas Carol Concert at St Peter's Church in Maidenhead, just a stone's throw from our offices. It was a wonderful night of stirring music, carols and readings, really starting the festive celebrations in a joyful way. There was not a spare seat in the church and we were delighted to welcome some special guests: The Prime Minster, The Right Honourable Theresa May MP; Eileen and Reverend John Quick, The Deputy Mayor of the Royal Borough of Windsor and Maidenhead and Consort; and Her Majesty's Deputy Lord Lieutenant of Berkshire, Professor Susanna Rose JP DL.

We would like to thank all the schools and groups that gave their time to making it a truly magical evening and in particular to Mr Roger Witney who took on the role of musical director. We are always truly grateful for the support of local businesses such as Mars, Marks & Spencer, Sainsbury's, Tesco and The Handmade Cake company, who help us with donations towards the refreshments and a special mention this year to The Shanly Foundation, which also supported the event. A fabulous total of £1,724.57 was raised.

Could you become an

NRAS Telephone Support Volunteer?

Starting any new medication can be daunting and a many people may experience anxiety and concerns about what the new therapy may mean for them. This is where talking to someone else who has been on the medication for some time can really help to allay fears and give some confidence in following the clinician's advice to try something different.

With the increasing use of biosimilar medicines as well as the new JAK inhibitors becoming more prevalent, the NRAS Helpline are getting more requests from people wanting to speak to others who have experience of these new medications.

If you have been on a biosimilar (such as Benepali, Remsima, Inflectra or Truxima) or a JAK inhibitor (such as tofacitinib, baracitinib) for at least 6 months, your RA is well controlled and you think you might like to offer support to others on these topics by volunteering to be a telephone volunteer, please contact us by email; **volunteers@nras.org.uk**
or by phone: **01628 823 524**

Full support and training will be offered to suitable candidates.

Just 20 minutes of exercise can reduce inflammation!

Physical exercise brings numerous long-term health benefits such as reducing the risk of cardiovascular disease, controlling weight, improving metabolism and strengthening the heart, bones and muscles. Regular physical activity also lowers blood pressure, reduces type 2 diabetes and some cancers states the US Department of Health & Human Services.

New research adds anti-inflammatory effects to this list with as little as 20 minutes exercise per day. Researchers from the University of California-San Diego School of Medicine – led by Suzi Hong Ph.D., from the Department of Psychiatry and the Department of Family Medicine and Public Health – hypothesized that exercise would improve the body's anti-inflammatory response by activating the sympathetic nervous system.

Physical exercise activates this system which helps to increase heart rate, blood pressure and breathing therefore helping the body to keep up. Whilst exercising, hormones e.g. epinephrine and norepinephrine are released into the bloodstream activating adrenergic immune cell receptors.

Researchers tested the theory that one 20-minute session per day would be sufficient to activate the sympathoadrenergic response and suppress the production of monocytic cytokines.

Monocytes are white blood/immune cells that help fight off bacteria and infections. Cytokines are a protein helping other cells to become "effector" cells which can kill off cancerous or infected cells.

One of these cytokines is TNFα which has properties that aids the body's immunological response by helping bring inflammatory cells to the site of an injury.

Although inflammation is needed for the body's immune response, too much inflammation can lead health issues. Chronic inflammation may also contribute to diabetes, obesity, celiac disease, inflammatory arthritis, fibromyalgia, or bowel diseases such as Crohn's or ulcerative colitis.

Researchers asked 47 participants to walk on a treadmill for 20 minutes every day with the intensity rate adjusted to suit individual's fitness levels. Blood samples were taken both before and immediately after the exercise sessions and the researchers hypothesis was proven.

"Our study found one session of about 20 minutes of moderate treadmill exercise resulted in a 5 per cent decrease in the number of stimulated immune cells producing TNF," says Dr Suzi Hong.

Although the anti-inflammatory benefits of physical activity are already known to researchers, Hong explains, this study explains the process in more detail.

Suzi Hong also makes a point in the research that moderate exercise for those with reduced strength or mobility can still make a significant difference,

"Our study shows a workout session does not actually have to be intense to have anti-inflammatory effects. 20 to 30 minutes of moderate exercise, such as walking, appears to be sufficient. Feeling like a workout needs to be at a peak exertion level for a long duration can intimidate those who suffer from chronic inflammatory diseases."

So, don't think you have to be a top athlete to make a difference to your health. Small steps lead to big differences!

What is GDPR and what will it mean for you?

The General Data Protection Regulation (GDPR) (Regulation (EU) 2016/679) is a regulation by which the European Parliament, the Council of the European Union and the European Commission intend to strengthen and unify data protection for all individuals within the European Union (EU).

The GDPR is clear that an indication of consent must be unambiguous and involve a clear affirmative action (an opt-in). It requires all organisations to keep clear records to demwonstrate that consent has been given and this includes NRAS.

The GDPR gives a specific right to withdraw consent. NRAS needs to tell people about their right to withdraw consent and offer you easy ways to withdraw at any time.

Shortly, you will be receiving a communication from NRAS by post or by email, depending on your current preferences which will ask you to opt-in.

Why is opting-in so important?

If you don't opt-in, after 25th May, we will no longer be able to contact you about the things you want to hear about. Your involvement with NRAS enables us to continue to achieve lasting positive outcomes for those living with RA and JIA. Don't forget to send your GDPR opt-in form back to NRAS as soon as you can so we can continue to stay in touch with you and you don't miss out on what could be vitally important to you, your health and the future of rheumatology care.

Don't get left out!

You need to opt-in! ☑

The law is changing, everyone **MUST** opt in. We need you to tell us **WHAT** information you want and **HOW** you want to receive it.

Remember:

Look out for the NRAS consent form

nras National Rheumatoid Arthritis Society

Don't miss out on everything that NRAS has to offer!

Living with Rheumatoid Arthritis? Inflammatory Arthritis?

Check out your
CVD risk!
www.nras.org.uk/
loveyourheart

Love Your Heart

A unique online interactive programme to help you understand and manage the increased risk of Cardio Vascular Disease (CVD) that living with inflammatory arthritis brings.

> *"Before I did this programme, I thought that I was doing pretty well in terms of diet and exercise but it showed me that there was a lot I wasn't aware of, that my knowledge of lifestyle factors wasn't adequate and I needed to do more to help myself. I found it a valuable and life-changing experience to do this programme."*
>
> Participant living with RA

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National Rheumatoid
Arthritis Society

Changing Minds, Changing Services, Changing Lives

For further info, contact us at **loveyourheart@nras.org.uk** ♥

Living with Rheumatoid Arthritis?
Inflammatory Arthritis?
Love Your Heart
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National Rheumatoid Arthritis Society
Check out your **CVD risk** online! Sign up at
nras.org.uk/loveyourheart

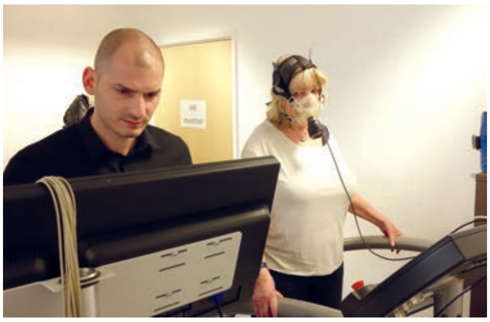
NHS
The Dudley Group
NHS Foundation Trust

Love Your Heart

Getting to the heart of the matter!

By Ailsa Bosworth

Well over two years ago, I visited the Dudley NHS Foundation Trust (Russells Hall Hospital). I was visiting their RA unit to undergo a test of my cardiovascular fitness in their special unit which has conducted very interesting research into the area of cardiovascular disease (CVD) in RA.



I met with Professor George Kitas and Professor George Metsios and was put onto the treadmill with an oxygen mask on to measure oxygen intake and CO_2 output. They also measured my fat to muscle ratio and did an ultrasound scan of my carotid artery. I wanted to find out more about how people like me with long-standing disease could improve their ability to exercise and reduce their CVD risk, and they were keen to show me. As part of this process I met Dr Holly John who had developed, as part of her PhD, a group programme to educate people with RA about their increased risk of heart disease and address lifestyle issues affecting heart disease within their own control. I was very impressed with the programme and the positive results achieved. I wanted NRAS to find a way to make such a programme available to the wider RA population in the UK and I was delighted that Dr John was entirely happy to allow us to adapt her programme to bringing it to a wider audience.

We partnered with film production company Streaming Well to create an on-line video programme and had to seek funding for this major and costly project.

Having successfully obtained funding for what we decided to call 'Love your Heart' over 2 years ago we then started work on the framework for this ambitious project. This has been the largest project we have ever undertaken and after years of hard work and valuable contributions by a number of people with RA, health professionals and experts in subjects such as smoking cessation and diet/nutrition, we are absolutely delighted to have launched Love Your Heart on St. Valentine's Day, 14th February 2018.

Dr John said *"The increased risk of CVD for people with RA has the same level of severity as those who suffer with type 2 diabetes. It's astonishing how many people with RA don't know that their condition could be detrimental to their heart. Once aware, it's very easy to manage risk factors that are within their control with adapting healthier lifestyle, so Love Your Heart will be able to significantly raise awareness of this and help to address this major co-morbidity which can shorten the lives of those with RA."*

The online programme is available for people to register, free of charge, at **www.nras.org.uk/loveyourheart**. It is an engaging, educational platform, where people who participate in the programme will be able to:

- understand the reasons why RA increases CVD risk
- calculate a QRISK®2 score (a GP recognised prediction algorithm for CVD)
- learn how to reduce the risk of CVD
- log progress through a series of personal behavioural adjustments and goals

We know, only too well, that in spite of the numbers of people with RA in the UK (>400,000) it does not have the public awareness of diseases such as Parkinson's (127,000) and Multiple Sclerosis (100,000). It is still a relatively misunderstood and invisible disease. Getting to a diagnosis can therefore often be challenging, as not only do people not recognise the symptoms

> I found it a valuable and life-changing experience to take part in this programme.

(Love Your Heart – continued from page 11)

as a medical emergency, often many are unaware of the increased risk of CVD so I'm glad that we've had the opportunity to work with Dr John and hope that the Love your Heart programme will help all of us living with RA to lead longer and healthier lives by addressing those risk factors that are within our own control. Currently CVD accounts for just over a quarter of deaths in Britain and costs the economy billions in healthcare. We hope that the NRAS Love Your Heart programme will have a real impact on helping to reduce the risk of CVD in people with RA.

NRAS is the first charity in our field to offer such a ground-breaking, interactive video. It is unique in that it not only provides patient education, but it also provides a goal setting structure through which people are supported to change their behaviour. The data from this programme will also significantly help rheumatologists and GPs and will become a referral platform when people are diagnosed. This illustrates what can be achieved when a patient-led charity like NRAS works alongside healthcare professionals and we are hugely excited by its potential.

NRAS is looking to find people who are happy to share their RA story with the media...

We are interested to hear your RA story to share with our PR team Mash and help spread awareness for this (mostly) invisible condition during RA Awareness Week in June.

- What hurdles have you overcome with your RA?
- How did your family, friends and colleagues react when you told them you had this condition – did they even know what it was?
- Do you have some interesting anecdotes of life with RA?
- What has been the reaction from members of the public to your invisible condition?

If you're happy to be interviewed and photographed for a magazine or newspaper and help us spread the message, please get in touch with us soon by emailing michelelt@nras.org.uk

RA Matters Online

Experts beaming in to your home….

NRAS is excited to announce a new project for 2018 where we will be hosting a small number of 'webinars' with healthcare professional speakers that are experts in their field!

The ethos behind this project is to be able to bring you exclusive access to the most up to date information from keynote speakers who will be presenting on many different subjects relating to RA. NRAS is extremely fortunate to have the support of many respected health professionals from across the UK who we have already expressed interest in being part of the #RA Matters online webinars.

Many of you are really keen to hear about the latest research, how exercise can help your RA, the latest developments in RA treatment and therapy and much more, these webinars will give you access to all this and more no matter where you live. So if it is impossible for you to attend an NRAS group meeting or an information event or it's just not your thing then this gives you access to experts from the comfort of your own home.

What exactly is a webinar, anyway?

A webinar is a live web-based video conference that uses the internet to connect the individual hosting the webinar (NRAS) to a wider, larger audience–the viewers and listeners of the webinar from all over the world. Hosts can show themselves speaking, switch to their computer screens for slideshows or demonstrations, and even invite guests from other locations to co-present the webinar.

The NRAS **RA Matters** online webinars will feature presentations by experts followed by the opportunity to ask questions in real time that the presenter will respond to live.

So, what do I need in order to take part in a webinar?

You can access a webinar through your desktop computer, laptop, tablet or smart phone, so long as you have access to the internet and Google Chrome (internet browser) or by downloading the app (a link would be sent to you on registering for a webinar). Once you register, to attend a webinar, detailed instructions will be emailed to you with step by step instructions.

When will they be happening?

We are currently finalising all the dates of the webinars for 2018 and we will be announcing the topics and expert speakers very soon. Keep a look out via the Member's e-news, the NRAS Facebook, Twitter and HealthUnlocked pages as well the NRAS website. (Please ensure you have opted in for receiving emails from NRAS so you don't miss out on announcements of the dates and times of the #RA Matters online webinars).

At NRAS we are always trying to find new and innovative ways to bring you the most up to date information and support to enable you to live better with RA. We feel this is going to be a really great way to do this and we hope you'll think so too! The webinars will all be hosted early evening enabling us to reach as large an audience as possible who want to watch and participate live, however if you miss the bus home from work don't worry you won't miss out as all the sessions will be recorded allowing us to share these with you to watch back at a later date.

What matters to you, matters to us! **RA Matters Online** coming to a screen near you soon.

www.newspaper.com

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www.nras.org.uk/webinar

News from the world

1

By Zoe Ide,
Gaye Hadfield and
Debbie Maskell

Diagnostic tests for RA now and in the future

As many patients know Rheumatoid Arthritis (RA) can be difficult to diagnose as its signs and symptoms mimic so many different diseases. It also can be frustratingly elusive – often hiding itself away as soon as you have that vital appointment:

Over the years there have been many developments in diagnosing RA and the future looks brighter still. We are seeing improvements in diagnostic testing that will have far reaching implications including the ability to predict the course of the disease (prognosis) and the identification of which treatment will have the best result early on in the disease, removing the unacceptable trial and error endured currently by most patients as they 'hope' a particular drug works for them.

This is summarised below:

It was here a moment ago Doctor!!

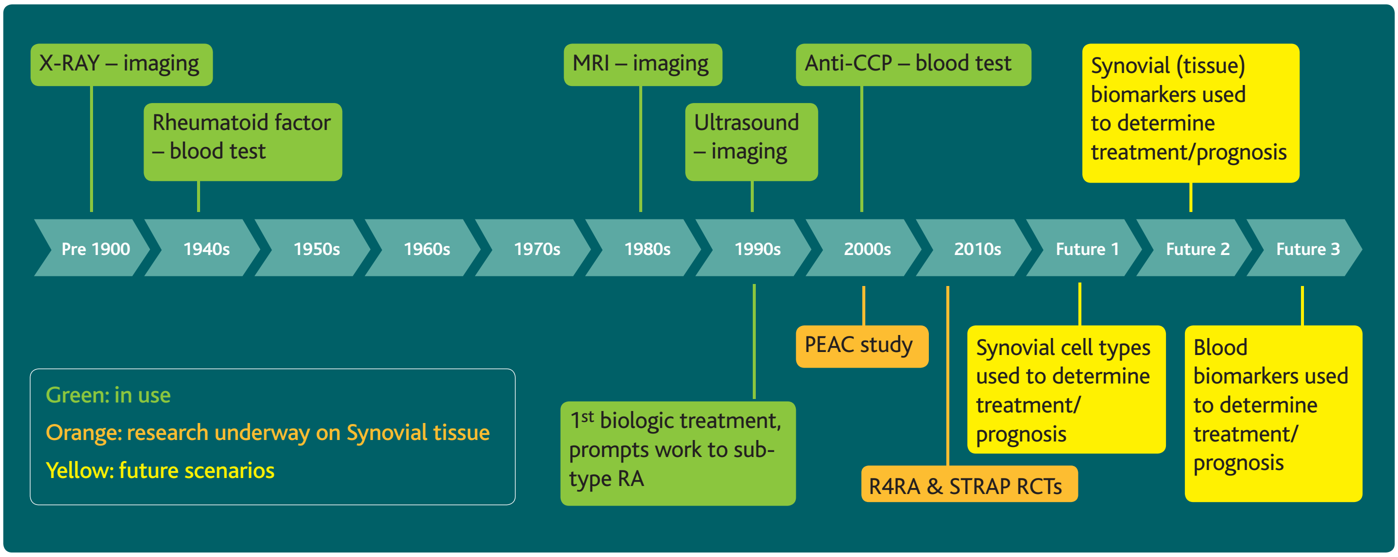


Figure 1 – Diagnostic tests, current and future

Current testing

Patients attending a rheumatology clinic with suspected RA currently undergo a thorough physical examination. They are asked questions about their symptoms and family history, blood samples are taken to measure a number of markers and they are offered tests that provide images of joints through x-rays, ultrasound and MRI. Each test can help support or eliminate a diagnosis so that eventually, with the help of skilled clinicians, many of us do reach a definitive diagnosis. Following a diagnosis, these tests continue to be used to monitor the progression of the disease, helping a doctor to recognise when treatment alteration or change is required.

Throughout this process there are uncertainties for the patient: What is my prognosis? Will I end up with significant disability if I don't take immunosuppressant therapy? And probably the biggest question of all which drug(s) are going to work best for me?

Biological Therapies

Since the 1980s there has been the introduction of a number of biologic therapies for RA. These are monoclonal antibodies that target very specific parts of the immune system (the NRAS ***Medicines in Rheumatoid Arthritis*** booklet is a great source of information on these important treatments). Researchers hope to be able to identify what part of the immune system isn't working well for an RA patient and match the treatment to the patient. This is known as personalised or stratified medicine and has the potential to help clinicians and patients make more effective decisions about treatment. In this article we would like to tell you about the use of tissue biopsies as an important and exciting new development in this field of research.

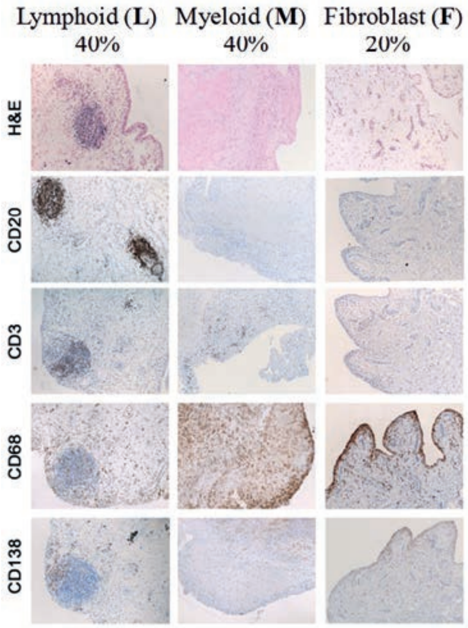
What is a biopsy?

A biopsy is the taking of a tissue sample so it can be examined. In RA a small piece of inflamed tissue from the lining of a joint (synovium) is retrieved using a needle under a local anaesthetic with ultrasound guidance

The synovial tissue can then be stained and examined under a microscope to determine the cell type, this is known as the pathotype.

Different pathotypes > Stratified medicines

Three main pathotypes (predominant cell types in the tissue) Lymphoid, Myeloid and pauciimmune-fibroid have been identified each with different cell composition. These are being investigated to enable stratification of the patients (a way of grouping) so that individuals receive the treatment most likely to work for them.



Three types of pathotypes

Professor Costantino Pitzalis from Queen Mary University of London is leading several trials in this area including:

1. ***The Pathobiology of Early Arthritis Cohort*** (PEAC), collecting clinical, imaging and biological data on patients from the time they are diagnosed, and start treatment on DMARDs. **www.peac-mrc.mds.qmul.ac.uk**
2. ***A Randomised, open labelled study in anti-TNFa inadequate responders to investigate the mechanisms for Response - Resistance to rituximab versus tocilizumab in RA*** (R4RA) this study has completed recruitment and the results will be available next year. **www.r4ra-nihr.whri.qmul.ac.uk**
3. ***Stratification of Biologic Therapies for RA by Pathobiology*** (STRAP) is a randomised clinical trial recruiting patients for whom DMARDs are or have become ineffective and are moving onto a biologic medicine for the first time. **www.matura-mrc.whri.qmul.ac.uk**

We know the lymphoid pathotype contains a greater proportion of B-cells than the other pathotypes and because the biologic treatment rituximab targets and reduces B-cells we predict that rituximab will work better in patients with this pathotype. This is being tested in STRAP and is running at seventeen hospitals across the UK see. You can find out if your hospital is one of those 17 at **www.matura-mrc.whri.qmul.ac.uk/strap_recruiting_centers.php**

Research in this exciting field is suggesting it may soon be possible for all RA patients to have a biopsy, that will inform clinicians as to which drugs are going to work best for the patient first time. As well as looking at the cells in tissues, researchers are also looking at the molecular/genetic picture so that further in the future it might be possible to replace the biopsy with a simple blood test.

The vision for the future is that a simple test will make getting it right first time a reality. The right drug for the right person at the right time.

If you'd like to know more about this exciting research email **g.hadfield@qmul.ac.uk**

By Ann Bates

www.annbates.co.uk

Any One of Us

I became a Member of the National Rheumatoid Arthritis Society to offer my support to the organisation and to help me to understand how members of my family and my friends were feeling as they coped with the day to day problems associated with the invisible illness known as RA.

As I followed the 2017 campaign to raise awareness of RA via social media I thought that Behind the Smile had great visual impact. From the hand-held smiles which told of the effort required to put on a brave face often for the sake of others, to the short films telling of the daily struggles that people with RA face, I began to understand how difficult life must be living with an illness that goes unnoticed because it is invisible.

I am a ceramic artist and have been working with clay for over 25 years making hand built vessels and tiles. By chance, in autumn last year I received a call-out from an artist in Derby to take part in an exhibition, also entitled Behind the Smile, to raise awareness of invisible illnesses. I saw this as an excellent opportunity to help raise awareness of RA and one that I was keen to pursue.

It is important to me that my work has meaning and especially for this exhibition I wanted to make something thought provoking and different. Eventually, the idea came to me of forming the image of a face from teardrop shaped pieces of clay. I hoped that it might suggest a fragility and vulnerability that can often be concealed behind a confident smile.

It is important to me that my work has meaning

I soon discovered that making this piece was going to be a real challenge! I watched many YouTube videos to learn how to place the features and the planes of a face as well as the shadowing needed to emphasis certain areas. There was also the issue of gender and ethnicity that I wanted to avoid, this piece of work had to transcend boundaries. At times it seemed overwhelming especially when I was confronted with about 200 teardrop shaped pieces of clay waiting to be coloured and transformed into an identifiable image of a face. However, on reflection a small thing compared to the feelings and problems that those living with RA face each day.

Eventually when all the individual clay teardrops were coloured with glaze, and looking like pieces of a puzzle, I fired them in my kiln. When cool, I attached the teardrops in sequence to a display board and the image of a face was revealed.

Initially, the work is intended to be viewed from a distance as the features appear more defined. On closer inspection the teardrop shapes become more visible revealing the way that the image is made and reinforcing the fact that although someone may look OK there may be underlying problems that are not immediately obvious.

To see more of Ann's work visit **www.annbates.co.uk**

Androgynous, and of no particular race, Any One of Us appeals for recognition of invisible illnesses that can often lie behind the smile.

Community Fundraisers start off the year with challenges galore!

Only a few months into 2018 and we've already seen some great people complete amazing challenges and others signing up to year-long personal challenges!

February found Carl Geoghegan on the summit of Mount Kilimanjaro! It was a challenge he had toyed with for many years then finally took the plunge or should I say scaled new heights when he signed up in November 2017 to raise funds for NRAS, for which we are extremely grateful. Carl said 'I am hoping to raise money for the **National Rheumatoid Arthritis Society**, which is a charity close to my heart as I suffer from RA myself.' Carl funded the trip himself and raised a staggering £1094.75. Congratulations Carl on achieving your dream!

Carl Geoghegan

Hannah Jewers completed the Cambridge Half Marathon on Sunday 4th March and finished it in 2hours 7 minutes and 41 seconds for her first ever half-marathon – an amazing achievement. Hannah wrote on her Just Giving page, 'I have chosen NRAS as I was diagnosed with RA 10 years ago. I am lucky that it is controlled by drugs and I can lead an active life without too much trouble. For others it is not the case.' Hannah raised a fabulous £393.75.

KPS Team

The cold, snowy snap of weather played havoc with some of the other events that were due to take place around the UK. The Bath half-marathon was cancelled, which meant our runners, who had been training so hard, were unable to run, but they have all booked themselves onto future events such as the Yeovil Half and the Bristol Half. One small brave group from the KPS (Kingswood Prep School, Bath) Team still took to the streets and braved the bad weather completing the 13.1 miles. They've raised a fantastic £8058.75 so far for JIA services at NRAS. We wish all our runners good luck for their future events.

A cheque for £242 was presented to Bronwen Cranfield, NRAS Community Fundraiser when she was invited to speak to the Extend Exercise group that meet in Staines Community Centre. The money had been raised by the group, which meets regularly for gentle exercise and other social activities.

Hannah Jewers

Bronwen Cranfield and the Extend Exercise Group

By Johanne Bertaux-Strenna

My experience of living with RA

My name is Johanne, I am 35 years old, and work as a freelance Costume Designer and Maker. I was diagnosed with RA ten years ago, when I was just 25. There have been ups and downs, and lots of necessary adjustments have been made in terms of lifestyle and diet - but I can happily say that I am able to lead an active and fulfilling life now.

I think the key to living with RA is finding the right balance: it's all about using your "spoons" wisely (some of you, I am sure, will be familiar with the term "spoonie"!) and not be afraid to be selfish at times, even though it may feel like you are letting people down, or putting yourself first. Challenging perceptions is also a big one: RA is an invisible illness, so if you happen to be not too shabby looking and young like I am, eyebrows will often rise quizzically if you choose to turn down an invitation, don't drink or party as much as your friends do, or need to take the lift rather than the stairs because your right knee is playing up (or left knee, or right ankle, or whichever joint has decided to give you grief on that given day!).

I do think, however, that it is crucial to educate people who don't know about RA or chronic illness, as ignorance just leads to fear and misperception - until these are challenged.

The toughest time of my life with RA came about earlier in 2017. About one year ago, I stopped taking methotrexate and decided I would try to go the natural route. I was fine for the first couple of months and was so happy to finally be able to "feel" my body again, and not be in the constant mind fog and cold I seemed to suffer from on methotrexate. A few months later, I suffered symptoms even worse than when I was first diagnosed, and as a result I had to stop working altogether! To add insult to injury, my dad passed away, which added immense emotional distress and made me feel more lethargic and depressed than normal.

At home most of the time, on benefits as my only source of income, and suffering so much from extreme stiffness and pain that would wake me up at night that not even the strongest doses of co-codamol and ibuprofen could calm down, I finally decided to go back to traditional medicine.

This time on methotrexate injections, in combination with hydroxychloroquine and natural remedies such as echinacea and multivitamin tablets, I am active again, tougher and a lot happier. I have almost entirely regained the grip in my hands, morning stiffness has practically disappeared, and flare-ups are much fewer and far between and a lot easier to manage.

I think the biggest change has been realizing that it's ok to ask for help, especially when it comes to manageable symptoms like pain, inflammation and depression. Exercise, although it might seem counter-intuitive and can be hard to get into when you are in pain but really helps to make you feel more energized as well as keeps inflammation in check and joints lubricated.

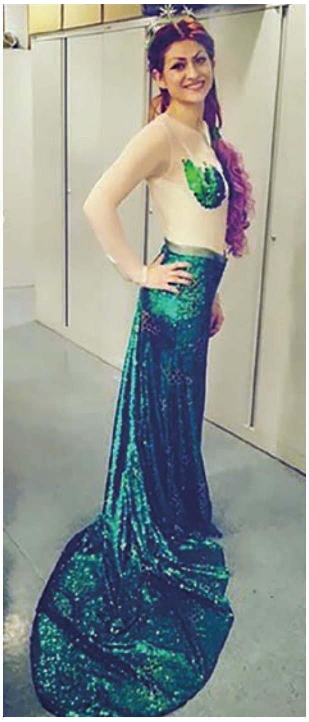
Keeping a regular meditation practice has also worked wonders, as it helped me to create mental images and positive thoughts that are now second nature. I visualize my pain as a long-haired Daenerys-type warrior queen that I call Pandora, and when it gets intense, I challenge her to a fight - and I always win, of course.

I think the biggest change has been realizing that it's ok to ask for help

London International Gospel Choir

Finally, last but not least, joining a gospel choir a few months ago (London International Gospel Choir) was absolutely instrumental in helping me to heal physically and mentally.

One thing I can say for sure is that RA has moulded me into an incredibly resilient warrior, with a very high threshold for pain, and a very low tolerance for "b..ll..it" (excuse my French!). It is hard enough for a healthy person to successfully navigate life in a crowded, noisy, polluted and hectic sprawling metropolis like London, but when you manage it with chronic (and sometimes incredibly debilitating and mind-numbing) pain, side effects from medication, multiple food intolerances, a weakened immune system topped off with chronic fatigue which affects your whole body, it makes me feel pretty bad-ass!



If you're interested in Johanne's costume work take a look at her website: **johannebertaux.wixsite.com/jbscostume**

You can find out more about the choir Johanne talks about at: **internationalgospelchoir.uk**

nras
National Rheumatoid Arthritis Society

DON'T DELAY CONNECT TODAY

DON'T DELAY, DONATE TODAY!

Support the Rheumatosphere Team in raising awareness of Inflammatory Arthritis while raising funds for NRAS

Professor Iain McInnes' team from the Glasgow Science Centre take on the Hebridean Cycle Way **185 miles** – **10 islands** – **4 days!**

As part of **EULAR's "Don't Delay, Connect Today"** campaign

14th-17th May 2018

To donate, visit Rheumatosphere's JustGiving page:
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Help them reach their target of £4000! Every penny counts!

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When saying I do...
...do NRAS a favour too!

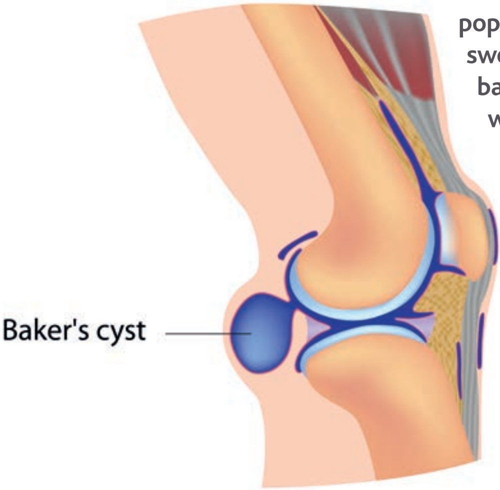
Thinking of something original and different to give your wedding guests that means a bit more than sugared almonds can be tricky. On your special day you can also do something special for others by considering giving NRAS lapel badges as Wedding Favours.

For a donation of £1 per guest NRAS will provide you with an attractive place card and an NRAS badge for you to give to your guests. If RA has meant something to you and your family then it will mean something to your guests too. It is also a great way of raising awareness of RA long after the honeymoon is over!

To place an order for wedding favours please email us on **fundraising@nras.org.uk** or call us on **01628 823 524**.

Dear Helpline

I have developed a swelling behind my knee and have been told it is a Baker's cyst. Can you tell me more about it and what treatment I need?



A Baker's cyst, also called a popliteal cyst, is a fluid-filled swelling that develops at the back of the knee. It is caused when the tissue behind the knee joint becomes swollen and inflamed.

There are many things that can cause a Baker's cyst including damage to the knee from a sports injury or blow but it can also be caused by a health condition. Rheumatoid arthritis is one of the conditions that can cause a Baker's cyst and they are more common in women than men. This may be because more women are affected by rheumatoid arthritis than men. People of any age can develop theses cysts, including children but the usually they develop in people over 40.

What should you do if you have one? You won't necessarily need treatment if it isn't causing you any symptoms. Over the counter painkillers and anti-inflammatories can be taken to reduce any swelling and pain. The age-old remedy of a bag of frozen peas wrapped in a tea towel placed on the swelling can also help.

If the cyst doesn't go away on its own or is causing problems, then you may need to see your GP. In some cases, it may be necessary to drain the cyst.

Dear Helpline

I have rheumatoid arthritis and I am currently taking disease modifying drugs. I was supposed to visit my daughter and her family recently, but my grandson developed chickenpox. I know that because of the drugs I take my immunity is compromised and so I didn't go as I was worried about getting shingles. My friend said that you can't catch shingles from chickenpox. Is she right?

This is a question that we frequently get asked on the helpline. Your friend is right, you can't catch shingles from coming into contact with someone who has chickenpox or from someone with shingles either for that matter.

Many people have chickenpox in childhood, but after the illness has gone the varicella-zoster virus remains inactive (dormant) in the nervous system. The immune system keeps the virus in check, but it can be reactivated later in life and cause shingles. It is not known exactly what causes the virus to be reactivated but age and physical or emotional stress are possible triggers.

However, you can catch chickenpox from someone with shingles if you haven't had chickenpox before. The blisters of shingles contain live virus. If a person who has never had chickenpox makes direct contact with an open blister or something with the fluid on it, they can contract the virus and develop chickenpox.

You can read more about shingles and chickenpox on the NHS website:
www.nhs.uk/conditions/shingles
www.nhs.uk/conditions/chickenpox

Important advance for women of childbearing age with moderate to severe RA

Label change for UCB's Cimzia (certolizumab pegol)

The European Medicines Agency (EMA) has approved for the first time the label change for an anti-TNF, Cimzia, stating that it can potentially be used for women with RA, psoriatic arthritis, and ankylosing spondylitis during both pregnancy and breastfeeding. Clinical studies showed that there was minimal transfer of Cimzia through the placenta and breastmilk from the mother to the infant.

It is very important that women of childbearing age have their condition well controlled before and during pregnancy for both the mother and baby's health and to reduce any adverse pregnancy outcomes.

Active disease in pregnancy carries the increased risk of miscarriage, preterm delivery and smaller than average babies at birth.

During pregnancy, disease activity may spontaneously go into remission but some 50% of women will still need some form of treatment. Women will obviously have concerns about the drugs used during pregnancy and the effect of active disease on the unborn child. There may also be a conflict after birth in the need to control the disease for the health of the mother, but also the nutritional needs of the child and the desire to breastfeed.

Dr Martin Lee, consultant rheumatologist at Newcastle upon Tyne Hospitals NHS Foundation Trust said, *"Women in the UK suffering from moderate to severe active rheumatoid arthritis, active psoriatic arthritis and ankylosing spondylitis will now have an option that enables them to manage their condition effectively during pregnancy and in the longer-term. Currently some pregnant women in the UK stop taking their anti-TNF treatment during pregnancy. It is important for mothers to manage their condition in order to support the good health of both the mother and baby. The availability of a treatment option that can be taken during pregnancy enables women to protect their health, as well as their babies and is an important milestone in the treatment of immunological conditions."*

Vitamin D may reduce the chances of developing rheumatoid arthritis

A new study, carried out by the University of Birmingham, shows that those consuming plenty of vitamin D in their diet could be lowering their risk of developing rheumatoid arthritis.

Vitamin D is considered an essential part of healthy living and the research has revealed more about its relationship to inflammatory diseases such as rheumatoid arthritis.

Researchers analysed samples of synovial fluid, from joints, and blood from rheumatoid arthritis patients. The results showed that maintaining good vitamin D levels can be effective in preventing diseases such as rheumatoid arthritis, but is less beneficial once the disease has already become established, as the inflamed joint immune cells were much less sensitive to vitamin D.

Dr Louisa Jeffery, an author of the study said: *"Our research indicates that maintaining sufficient vitamin D may help to prevent onset of inflammatory diseases like rheumatoid arthritis."*

"However, for patients who already have rheumatoid arthritis, simply providing vitamin D might not be enough. Instead, much higher doses of vitamin D may be needed, or possibly a new treatment that bypasses or corrects the vitamin D insensitivity of immune cells within the joint."

Based on these findings, the team are looking to carry out follow-up studies to determine why rheumatoid arthritis leads to vitamin D insensitivity and how this can be overcome, as well as to establish whether this effect is seen in other inflammatory conditions.

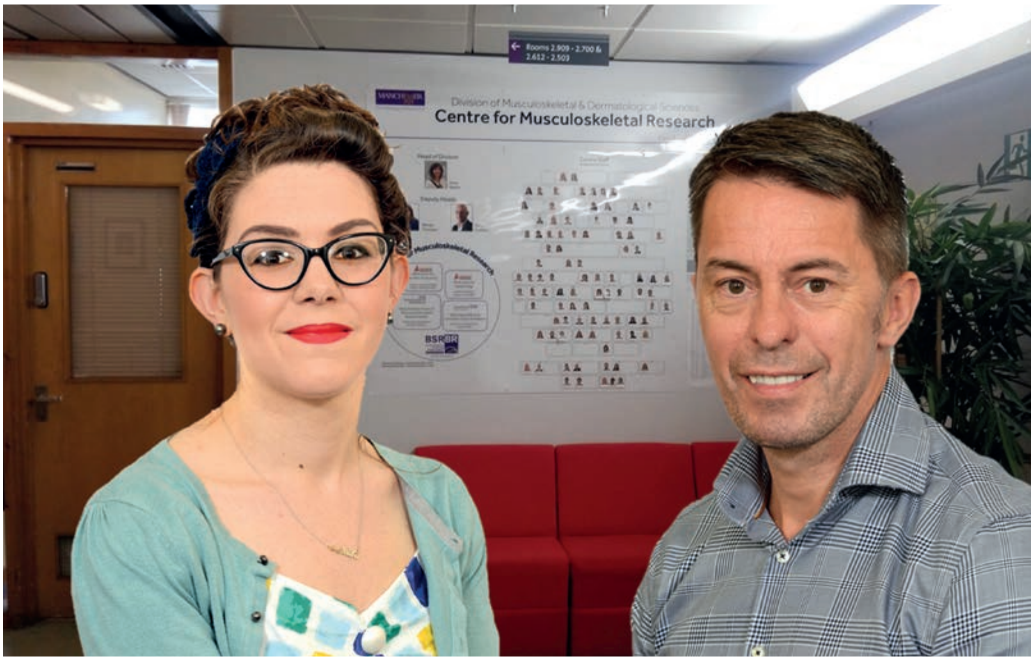
Vitamin D is considered an essential part of healthy living

The QUASAR study

Quality of life, sleep and rheumatoid arthritis: The QUASAR study

By Katie Druce

Post-doctoral Research Associate and Dr John McBeth, Reader in Epidemiology, University of Manchester



What's exciting is that we've been asking these questions for a long time, but it's only now we have the technology available to be able to answer them.

Health related quality of life (HRQoL) is defined as the impact of one's health on physical, emotional and social well-being. People with rheumatoid arthritis (RA), often report reduced HRQoL even when their disease is under control. The problem is that we don't fully understand what causes reduced HRQoL and we struggle to know how to improve it.

People with RA often say that sleep disturbances affect HRQoL, but understanding what people mean by sleep disturbances is tricky! For some people what this means is that they can't get to sleep, while for others the problem is that they don't sleep for long enough, or they may wake up in the morning feeling unrefreshed despite having slept through the night. Sleep is also linked to a number of other symptoms which are interconnected, such as pain, fatigue and mood. This means that some people may experience sleep disruption as a result of night-time pain, while for others sleep disruption makes their pain more severe.

As Epidemiologists, we've struggled to accurately measure the relationship between HRQoL, sleep and other symptoms. That is because traditionally, we recruit participants into studies and ask them to report information once every six months, or so. Historically, it has also been difficult to objectively measure sleep outside of artificial laboratory settings and we have tended to only rely on subjective (patient reported) sleep. As a result, we know very little about how sleep disruptions change over time and how objective markers of sleep may affect HRQoL.

Aware of these challenges, Dr John McBeth and colleagues at the University of Manchester's Arthritis Research UK Centre for Epidemiology, decided to investigate the use of smartphone applications (apps) and wearables (such as activity trackers) as a new way of collecting data.

Speaking about the study, John, who is the study's Principal Investigator, said "What's exciting is that we've been asking these questions for a long time, but it's only now we have the technology available to be able to answer them. In the past, studies have been limited to asking people how they think they slept, but by asking people to wear a piece of kit, similar to a smartwatch, 24 hours a day for 30 days, we will be able to track the biological rhythms of a person's sleep patterns. For example, it will tell us when they went to sleep and when they woke up as well as if and when they woke during the night and how restful their sleep was. It will also monitor activity levels throughout the day. We will also ask people to use a specially developed smartphone app to record their own perceptions of how well they believe they slept each night, information about the symptoms they experience each day, and information about their HRQoL".

The purpose of QUASAR is to help us work out how we can best treat people with RA and improve their HRQoL. Our ultimate goal is to support patients to come up with personalised strategies to address their own specific needs.

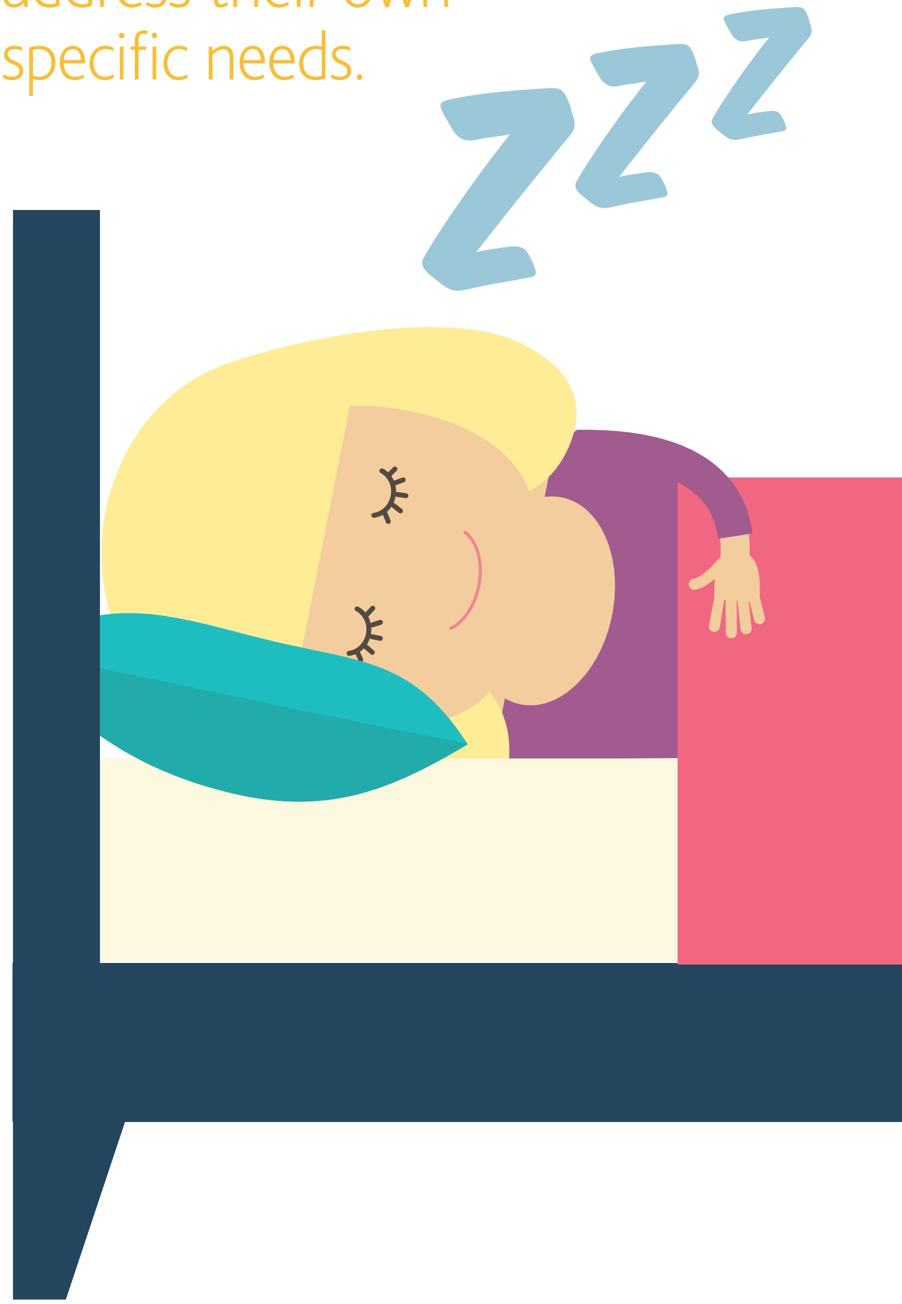
To help us achieve this, we ask people who participate in QUASAR to do a few different things. First, participants complete a baseline questionnaire, which asks about general health, sleep and HRQoL. Next, participants wear a sleep/activity monitor, 24 hours a day for 30 days. Finally, people are asked to use an app, which can be downloaded onto a smartphone or tablet, to record all the other information we are interested in. The app is used to complete a morning sleep diary, report daily symptoms and complete some follow-up questionnaires on days 10, 20 and 30 of the study.

As the study co-ordinator and person in charge of the day-to-day running of QUASAR, I have been very grateful to NRAS for helping us to recruit participants. To date, we have recruited 152 people from London, the North West, the North East and the Midlands. What's particularly exciting is that the experience from previous studies told us that only 50% of people we recruited would give us enough data over the month, but in reality more than 80% of our participants have given us the data we need. Although our recruitment is going well, we're definitely still on the lookout for more participants! In the coming months you may hear about the study through the NRAS emails, which will provide you with some study information and a link to complete an online screening questionnaire. Once we've received the screening questionnaire, I give all eligible people a phone call to have a wee chat about the study and answer any questions.

If you'd rather not wait for the email to land in your inbox or perhaps may have missed it first time around, you are most welcome to contact me directly using our study email address **sleepinra@manchester.ac.uk** and I will send you the study information. I very much look forward to talking to you!

Find out more about this and other research studies at **www.nras.org.uk/clinical-trials**

> The purpose of QUASAR is to help us work out how we can best treat people with RA and improve their quality of life. Our ultimate goal is to support patients to come up with personalised strategies to address their own specific needs.



Hydrogel invented to combat rheumatoid arthritis

Scientists at the Institute for Basic Science (IBS) have invented a hydrogel to potentially treat rheumatoid arthritis (RA). The jelly-like substance could be used to deliver drugs directly into joints and to absorb excess fluids. The research was reported in the journal Advanced Materials.

Nitric oxide (NO) is a gas produced by immune cells at inflamed joints. It stays in circulation for less than 10 seconds before binding to other molecules. Kim Won Jong group leader at the Centre for Self-Assembly and Complexity, at the IBS explains that ***"Nitric oxide is like a double-edged sword. It regulates inflammation and protects our body by killing external pathogens. However, when in excess, it is toxic and may cause RA, as well as other autoimmune diseases, cardiovascular diseases and cancer."***

The scientists at the IBS looked at using NO in a novel way to actually help treat RA. They manufactured a gel using acrylamide and crosslinking it to form a hydrogel that can contain a large amount of water. The hydrogel acts like a net that can trap drug molecules in it. Nitric Oxide breaks up the net, freeing the drug and absorbing more fluids allowing the drug to be delivered to the affected joint directly and more effectively.

This study is in its early stages at the present time and scientists at the IBS are looking into creating a nano-sized hydrogel in a mouse model so that it can be absorbed into the joint. It will be a while before it will be ready for clinical trials in humans.

Could you be our next £1,000 winner?

Here's what previous winners had to say…

"We spent the cheque many times over in our heads but have decided to put it towards a 14-night cruise from Southampton to The Baltics as we would love to see Russia. I would urge everybody to join the NRAS lottery as I pay by Direct Debit so no hassle and the money goes towards [helping] people who suffer from this awful condition."

"I started playing the NRAS lottery after my Mum died in 2011. We had a collection for NRAS (and British Lung Foundation) at her funeral and after that I wanted to continue helping NRAS in a small way financially. I am taking my husband, sister and her partner out for lunch this Sunday, but haven't decided how to spend the rest. I'll probably put it towards the cost of our upcoming holiday at Lake Garda!"

"WOW this could not have come at a better time as my partner and I are going through IVF so what a wonderful help this money will be. I shall keep playing the Unity Lottery. Love and support to all my fellow RA sufferers."

You too can sign up to play the NRAS Lottery and be in with a chance to be one of our weekly winners. It costs just £1 per week and you have a 1 in 63 chance of winning a prize of up to £25,000! You are allocated a six-digit number, which will remain yours for as long as you play the lottery. Winners have to match 3, 4, 5 or all 6 digits in the correct sequence to win and you can enter as many times as you like. The draw takes place every Saturday and prize cheques are sent out directly to you so there's no need to go through a claim process. What could be simpler?

Join online to play at **www.nras.org.uk/lottery** or call **01628 823524** for a postal leaflet which gives you all the details you'll need.

By playing the NRAS lottery, you will be supporting us in Changing Minds, Changing Services and Changing Lives for those living with RA and JIA.

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

Can dietary fibre help against arthritis?

Researchers at Freiderich-Alexander-Universität, Erlangen-Nurnberg (FAU) have discovered that a fibre-rich diet can have a significantly beneficial effect on chronic inflammatory diseases and can also lead to stronger bones.

Everyone's intestines carry bacteria and they aid our digestion by breaking down fibre into smaller components that can be absorbed by the body. They also protect against harmful organisms that have entered the intestine and so protect against illness. However, there are a multitude of different bacteria in the intestine and depending on the mix, the intestinal flora can actually cause illness.

It is the break-down products from the bacteria that affect the immune system the researchers from FAU have shown and not the bacteria themselves. Subsequently this has a knock-on effect in auto-immune diseases such as rheumatoid arthritis. How the intestinal bacteria themselves communicate with the immune system is unclear.

A by-product of the digestive process of fibre is the release of short-chain fatty acids and these are important as they can stimulate intestinal movement, provide energy, and can also have an anti-inflammatory effect.

The research team focussed on the short-chain fatty acids propionate and butyrate which can be found in the joint fluid. These may be important in affecting the performance of joints.

Under the leadership of Dr Mario Zaiss from the department of Rheumatology and Immunology at Universitatsklinikum Erlangen, the team was able to show that more short-chain fatty acids could be made, especially propionate, by using a healthy diet, rich in fibre, to change the bacteria in the intestine. A reduction in the number of bone-degrading cells was seen when there was a higher concentration of short-chain fatty acids in bone marrow leading to a substantial slowing down of bone loss.

Dr Zaiss says "*We were able to show that a bacteria-friendly diet has an anti-inflammatory effect as well as a positive effect on bone density. Our findings offer a promising approach for developing innovative therapies for inflammatory joint diseases as well as for treating osteoporosis, which is often suffered by women after the menopause. We are not able to give any specific recommendations for diet at the moment but eating muesli every morning as well as enough fruit and vegetables throughout the day helps to maintain a rich variety of bacterial species.*"

> *"We were able to show that a bacteria-friendly diet has an anti-inflammatory effect as well as a positive effect on bone density.*

FindMeCure

How to access future treatments for Rheumatoid Arthritis now

By Daniela Shikova

FindMeCure Foundation

I once heard someone say *"I'm exhausted from trying to be stronger than I feel"*. He was a patient suffering from Rheumatoid Arthritis for years and battling its symptoms at home, at work, on the street, while having fun with his friends. He is one of that 1% of the world population, one of the millions of people worldwide fighting an invisible illness and struggling with normal daily activities that we usually take for granted.

Why wait another 10 years and not benefit from it now?

Why are people still struggling?

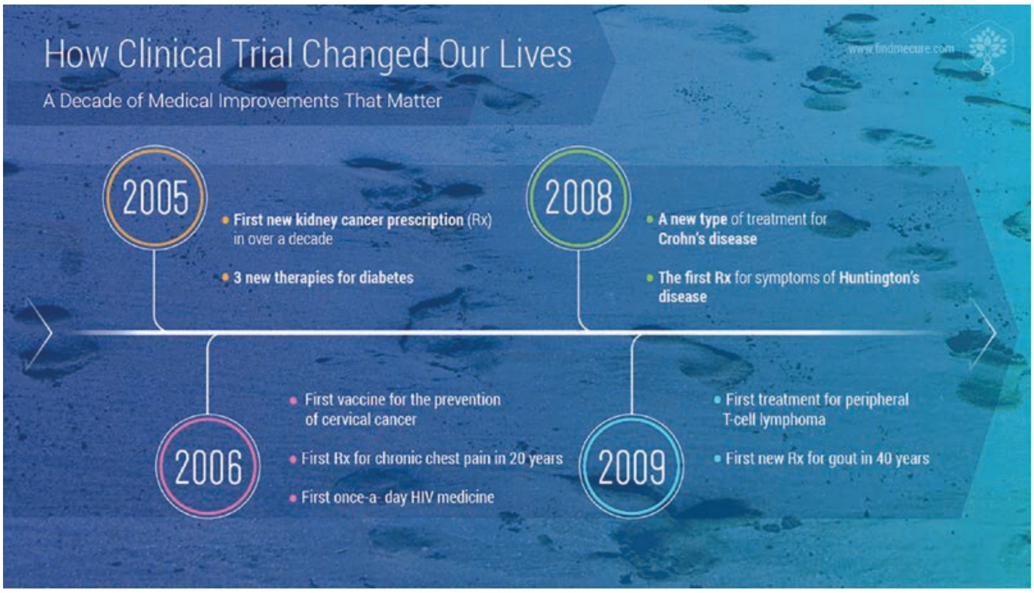
So why, with all that is currently available like various anti-inflammatory drugs, disease modifying anti-rheumatic drugs, steroids, biologics, surgery, diets, additional therapies such as acupuncture, hydrotherapy and exercise are people still struggling?

It turns out in many cases that current therapies while life changing for many people there is still an unmet need for thousands with uncontrolled disease ultimately of course people really want a cure! For many reasons, there may come a time when someone with RA will need to think about what happens if or when their treatment fails to control their symptoms.

There is though always innovative therapies being developed and explored but finding out about them isn't perhaps as easy as it could be.

90% of people worldwide are not aware about how to participate in or what the benefits are of being part of a clinical trial.

Clinical trials (also called clinical studies) are an integral part of the drug development process – without them, modern therapies would never be accessible to those who need them. It is a regulated way for patients to have innovative treatment years before it is available in the pharmacies or hospitals. Being tested on animals, healthy volunteers and then patients with a certain condition, a compound is potentially turned into a promising medicine that could change or even save lives. After researchers test the product in the laboratory and in animal



studies, the successful treatments move on to clinical research, where they are tested in people who volunteer to be study participants motivated by various factors:

- Not satisfied the current available treatments
- Encouraged to take part by their doctor
- Want to contribute to the advancement of medicine
- They don't have any other option
- They want to benefit from an innovative therapy

You can see below how clinical trials have changed our lives through the years and review the key medical innovations:

> Over 90% of the people rank their experience of taking part in clinical trials highly and would recommend it to a friend yet only 15% of the population are actually aware of the clinical trials potentially available to them.

Find Me Cure

FindMeCure is a platform that gives access to all ongoing clinical trials around the world and guides patients through the application process. The unique algorithm allows assessing trials on their safety and credibility and suggests trials relevant to patients' needs and personal criteria.

To cope with this huge lack of awareness among patients and caregivers, the platform has expanded its goals and together with FindMeCure Foundation are revolutionizing the way people find, understand, make a decision and apply to be considered to participate in a clinical trial. The Foundation has been actively working to empower patients looking for a more innovative therapy, thus potentially giving access to future medications to individuals much sooner.

This is why we are really grateful to our partners at the National Rheumatoid Arthritis Society, the International Alliance of Patients Organizations, the American Chronic Pain Association and many other patient organizations and platforms worldwide for joining this mission and helping us to spread the word about a healthier world is possible through education and innovation.

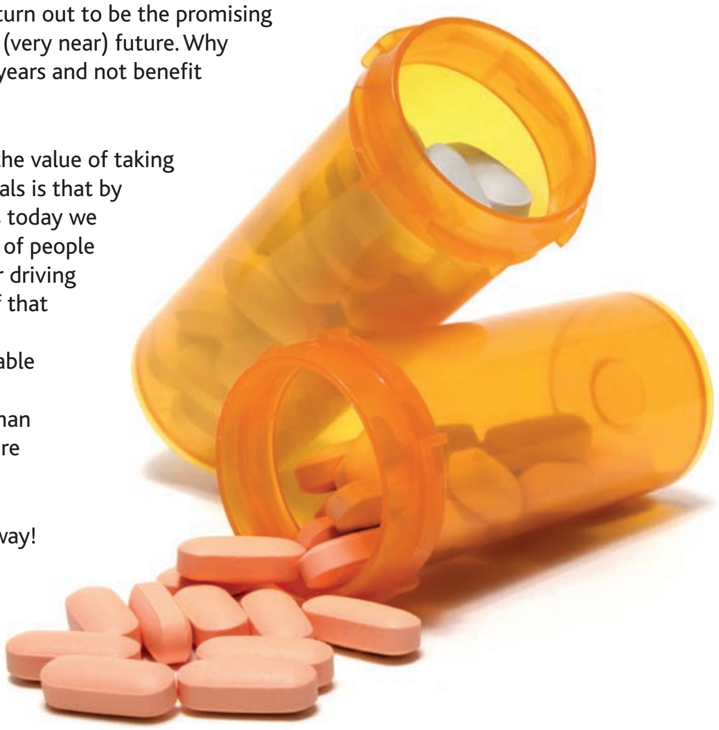
I am pleased to announce that you can already access all ongoing clinical trials for Rheumatoid Arthritis worldwide on the NRAS website through a special search widget: **www.nras.org.uk/clinical-trials**

There are currently **387 trials worldwide studying all kinds of treatments** and one of these trials may turn out to be the promising treatment of the (very near) future. Why wait another 10 years and not benefit from it now?

We believe that the value of taking part in clinical trials is that by helping ourselves today we can help millions of people in the future. Our driving force is the belief that there is no such thing as an incurable disease but only conditions that man hasn't found a cure for yet...

...but it's on the way!

> By helping ourselves today we can help millions of people in the future



By Hyejee (Nicole) Kim, Luwaiza Mirza, Lucy Challenger

Year 2 medical students

(Mark Braniff and Heidi Lempp,
Module Leads,
Kings College, London)

Representation of mental and physical pain in art and medicine

With patients who live with rheumatoid arthritis

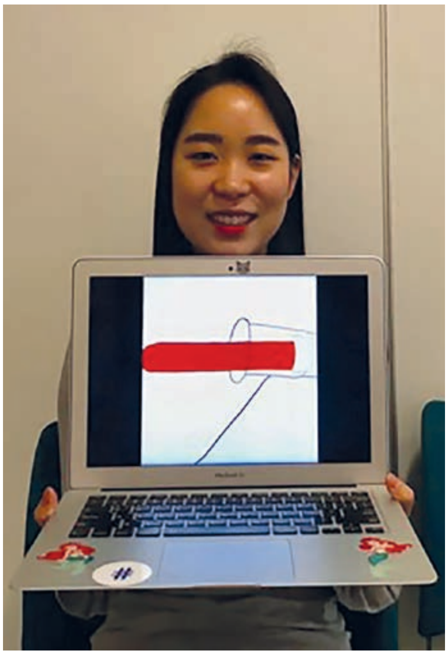
All three of us were able to create a piece of art which accurately reflects their pain experiences.

During a Special Study Module in the new medical undergraduate curriculum for medical students in Year 2 at King's College London, three students explored the representation of mental and physical pain in art and medicine, with specific focus on pain experienced by patients who live with Rheumatoid Arthritis (RA).

We each did independent research in the ways pain is expressed in various forms of art, including paintings, poems, music, and sculptures, and attended exhibitions at local galleries to gain an understanding of the relationship between pain and art.

We had a meeting with patients from the Department of Rheumatology at King's College London who described their individual pain journeys, allowing us to obtain an insight into the social and personal impact of this long-term condition on their lives.

As our final assessment we each met with one patient each to collaborate with them to create our final artwork. Over time we gradually got to know them and their unique RA pain experiences. All three of us were able to create a piece of art which accurately reflects their pain experiences.



Hyejee (Nicole) Kim. 'An animated video representing the patient's rheumatoid arthritis journey'

Lucy Challenger. 'A visual representation of the loss that comes with long term pain'

Luwaiza Mirza. 'The art work will be the voice of the patient'

Mick Worral from the Whale Tankers with Cathy Twilton and Pam Butler from the Solihull NRAS group.

Denise Ellis from Conference Contacts with Ailsa.

Charity of the Year

Charity of the Year partnerships have raised fantastic sums for NRAS in the past. They are hugely beneficial for the charity, raising vital funds, which enable NRAS to provide essential services. They also help NRAS reach many more people, raising awareness of rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA).

If you are a golf club captain or about to become one, a Rotary or Lions' President, or work for an organisation that selects a Charity of the Year, nominating NRAS to be considered could have lasting benefits for your charity, those we support and the wider community. Charity of the Year can have other benefits too, helping energise staff, or rally support from your community group, social club or golf club.

Thank you to our 2017 Charity of the Year partners!

Conference Contacts	AA Insurance (Newcastle)
Whale Tankers	Red Lion (Little Missenden)
Carillion Communications	

If you would like to find out more about Charity of the Year fundraising programme, please contact the fundraising team on **01628 823524** or email **fundraising@nras.org.uk**

We could be great together!

A partnership with us is a great way to motivate and unite your employees while helping us raise vital funds and awareness for Rheumatoid Arthritis and Juvenile Idiopathic Arthritis (RA and JIA). We provide:

- Press and PR support
- A calendar of events
- Support resources
- Places for national sporting events, charity treks and other fun activities
- Corporate volunteering opportunities

www.nras.org.uk/charity-of-the-year

* use MY data

> ***"The type of treatment that I had depended so much on the data of patients who went before me"***
>
> Patient Advocate, use MY data

* use MY data

Case Study – Patient Advocate Stories

John Reeve
Patient advocate, use MY data

My son Tim had leukemia. Just before he died he was asked if he would give some additional blood samples and without hesitating he said yes.

I know that Tim was passionate about trying to help other young people in particular, not have to go through his experience. That he wanted to do everything he could do to help them.

Really, I have taken on Tim's passion. I believe that all of the wonderful things that cancer patients are able to have now is the result of people in the past giving their data, giving samples and making them available for research purposes. I think now we have a duty to do that for those people that come afterwards.

Please, please, please; we have to make sure that the data is protected and dealt with properly and confidentially, but please, please, please give your data and make sure that it's used well to help other people.

We are building an online library, where the patient voice is heard direct, talking about the rewards of using their data

http://www.usemydata.org/stories5.shtml
getinvolved@usemydata.org.uk

"The only source of data is the patient."

Use MY data is an independent movement of patients, relatives and carers. Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

What we do

- We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.
- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- We provide learning resources for patient advocates on patient data issues, including:
    - hosting workshops for patients and the public, focussing on topics related to patient data
    - a library of resources of data security, consent
    - narratives from individuals about how collecting, storing and using data can help patients.
- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.
- We advise and support organisations who want to collect, store and use patient data for patient benefit, on topics such as consent, audit of clinical practice, security and privacy.

Details of some of our previous workshops

Our workshop topics are suggested and prioritised by our members. Just a few examples of the workshops we have previously run:

- **Primary Care's pivotal role regarding patients and their data –** we examined what is being done to help GPs have a conversation with patients about the uses and sharing of patient data
- **Commercial uses of patient data –** we brought together a range of commercial companies, patients, bodies that govern data and data privacy organisations, to understand how and why commercial companies use NHS data
- **Patient data and tissue samples; benefits, barriers and concerns –** we heard from pathologists, patients, researchers and governing bodies, and examined the benefits of and barriers to donating tissue samples
- **Who uses your data?** We explored who uses patient data, why they use it and the benefits and risks of its use.

Patient data saves lives – let's acknowledge it

This work uses data provided by patients and collected by the NHS as part of their care and support

- use MY data members have developed a citation that recognises the benefits of using patient data and acknowledges the patient contribution
- We want the citation to be included on all publications using patient data.
- Understanding Patient Data has adopted the citation, encouraging its use on all work

underpinned by patient data, including publications, presentations, event materials and press releases.

Who we are

- Members are patient advocates; patients, carers or relatives who wish to build confidence in the use of patient data for research and analysis.
- Associate Members work for patient organisations, charities, research institutions, public sector and commercial organisations and support the work of use MY data.
They are united by an interest in sharing healthcare data to improve patient outcomes under appropriate levels of consent, security and privacy.

Get Involved

Join us – there is strength in numbers! To join use MY data, or get more information, please get in touch:

getinvolved@useMYdata.org.uk

www.useMYdata.org.uk

@useMYdata

> ***"Through data use, treatments, outcomes and patient benefits can and are radically improved."***
>
> Patient Advocate, use MY data

Winter Flu

A Challenge for the Friends of HRU!

By Allison Elder

NRAS Scottish Ambassador

I became an Ambassador in April 2017, little realising that, less than a year later, I would be called upon by the Friends of Highland Rheumatology Unit (HRU) to support their campaign to retain the 10 in-patient beds apparently under threat at the unit.

The HRU offers invaluable multi-professional assessment, treatment and education to patients with autoimmune inflammatory diseases throughout the Highlands and Islands. In January this year NHS Highland requisitioned 5 beds under the guise of "winter flu pressures" but with no reassurances that these changes would be temporary. Friends of HRU rose to the challenge, formulating a campaign which has been well supported by rheumatology health professionals, a local MSP, councillors and, most importantly – patients.

The Scottish Government's **Better Health, Better Care: Action Plan**, December 2017, under the heading of 'improving quality', promotes 'spreading best practice in care for people with long-term conditions'. The HRU ticks this box on a daily basis – why jeopardise this wonderful example of best practice?

Hopefully, by the time we go to print, this will no longer be an issue and everyone involved with HRU will be Friends again!

NICE National Institute for Health and Care Excellence

By Victoria Thomas

Head of Public Involvement at NICE (National Institute for Health and Care Excellence)

NICE to see you, to see you….

I'm slightly worried that the title of this piece might give away my age a little, but then I'm sure all those Strictly Come Dancing fans out there will also recognise one of Brucie's catchphrases!

It's a real pleasure to be able to communicate with NRAS's thousands of Members about the work of NICE, how our guidance can help support people with rheumatoid arthritis and how people with RA and their carers can work with us to make sure our guidance focuses on the things that really matter.

What is NICE's job?

Our job at NICE is to produce guidance and advice for health and social care on the best care people should be offered, according to the best available evidence.

> Our aim is to improve the quality of care that people receive whether they're visiting a GP, are under the care of a specialist service, or live in a care home.

Most of the work we do is specifically aimed at people delivering and using health and social care services in England. Our recommendations can be about a wide range of topics including medicines, surgical procedures, medical devices, promoting wellbeing and preventing ill health, and providing care for people with a range of illnesses and conditions.

Anybody can use the information from NICE to check if they are getting a good service and the best care possible.

In some cases we're also asked to look at value for money (we call this 'cost-effectiveness'). So we consider if a new treatment offers patients enough 'bang for our buck' - is it worth the money it costs compared to the treatments already available? Would we be better spending the money somewhere else? These are really difficult decisions to make and we have very detailed processes to help us make these decisions.

Involving patients, carers and members of the public

NICE is committed to involving people who use services, carers and the public in the development of its guidance and other products. By involving the people who will be most directly affected by the guidance, NICE ensures we are person-centred and relevant as possible for the people who matter most.

Our work is underpinned by our charter and a number of key principles. Core to these principles is the commitment to making sure there is meaningful patient and public involvement in developing our guidance, advice and standards. I've been at NICE for over 16 years now and it's my great privilege to lead the dedicated team at NICE, the Public Involvement Programme, that supports this key element of our work.

Working directly with people

All NICE committees include at least two 'lay members', who can be patients, carers, service users, their advocates or the general public. The expertise, insight and input of these lay members is essential to the development of all NICE guidance and advice, and helps us to make sure that our work reflects the needs and priorities of those who will be affected by them.

There are lots of different ways people can be involved in our work. NRAS is one of our long-standing and highly valued stakeholder organisations who can help shape the outline of our guidance and its final recommendations. As individual patients and carers we're always looking for new people to join our committees. Some of these look at individual areas of care and other committees are more generalist, so you may consider a wide range of topics.

At any one time we have around 250 to 300 patients or carers working with us on our committees, and lots more who come and tell our committee members about their experiences of their illness and the treatment they've had for it. If you're interested in joining one of these committees, we advertise our vacancies on the website, **www.nice.org.uk/Get-Involved/our-committees**. We also hold our most of our committee meetings and Board meetings in public. Please register if you'd like to come along!

Supporting people with rheumatoid arthritis

Over the years we've produced a lot of guidance and advice on RA

- A clinical guideline looking at the whole of RA care. This guideline is currently being updated with the up to date version publishing in the summer of 2018.
- A quality standard on improving care for people with RA.
- A briefing on monitoring people's response to biologic treatments.

We've also produced a wide range of what we call 'technology appraisals' guidance which lets the NHS know which drugs they should make available to people with particular conditions. The drugs we've recommended for people with RA can be found also on the website at **www.nice.org.uk/guidance**. This is the bit of our work that attracts the most publicity and controversy. If you've heard of NICE it's likely that it's this area you've heard of!

All of our guidance helps you find out what treatments you might be entitled to, what good healthcare looks like, and can help you have a conversation with your doctor about what treatments might best for you.

Sharing decisions

We're keen that our guidance is used as a starting point for you and your healthcare team to come to decisions together about what's likely to deliver you the most benefit. It's important that these decisions also take account of what matters to you (your values) and what you would like to get out of your treatment (your preferences). We call this approach 'shared decision making' and it's something NICE is increasingly involved with.

Improving what we do

We've recently looked at how we're working with patients and the public and identified some areas that we need to improve. I've written a blog about it on our website if you want to know more.

I hope that finding out what NICE does, and the way we work with patients, has been useful for you. I'm really looking forward to hopefully working with some of you in the future.

> I'm really looking forward to hopefully working with some of you in the future.

NEW WAYS TO DONATE

amazonsmile
You shop. Amazon gives.

Supporting NRAS is now only one click away...

NRAS is now one of the charities you can select to support through Amazon Smile! By selecting NRAS when prompted at checkout, Amazon will donate 0.5% of your purchase total to NRAS at no extra cost to you.

NRAS are one of only a handful of registered charities that you can select through Amazon Smile. Just follow this link **https://smile.amazon.co.uk/** and when prompted to pick a charitable organisation, type in **National Rheumatoid Arthritis Society**, select it and shop as you normally would on Amazon.

fundraise with facebook

Support NRAS by creating a Facebook Fundraiser

Are you celebrating a milestone in your life like a significant birthday or special anniversary? Lots of people have already created Facebook Fundraisers to mark special occasions and raise much needed funds for NRAS. The benefits are far reaching as it enables us to continue supporting thousands of people living with RA. It is quick and easy to set up a Facebook Fundraiser and best of all every penny raised goes to the charity. A Win Win! You don't end up with yet more bath salts or that strange ornament from Aunt Lucy that nobody quite knows what it is, and your charity gets to do more for those in need.

Setting up a Facebook Fundraiser is quick and easy and all you need to do is go to your Facebook page, click on the drop-down menu at the top and furthest right and select 'Create Fundraiser' to get started.

If you need any help setting up your Facebook Fundraiser please contact the NRAS fundraising team on **01628 823524** or by email at **fundraising@nras.org.uk**.

Chloe Scarlett at EULAR

> I thank NRAS for the opportunity and look forward to being involved in similar events in the future.

On the 14th of February 2018 I arrived in Brussels are the NRAS Young PARE delegate at the 21st EULAR Annual Conference. The European League Against Rheumatism (EULAR) is an organisation which represents people with arthritis/rheumatism (PARE), health professionals (HPR) and scientific societies of rheumatology of all the European nations. As the NRAS young PARE delegate I was there to represent people under the age of 35 with arthritis, although as a patient with JIA – diagnosed at 2, I was also very interested in information regarding much younger patients. For the 21st conference the slogan was 'Don't Delay, Connect Today'. The slogan is also the base for the campaign this year to encourage people to seek medical advice as soon as they notice a difference in their bodies, to support early diagnosis and treatment of MSD (Musculoskeletal Diseases).

On Thursday the Young PARE delegates met for the first time, the focus of the workshop was 'Learn, Lead, Inspire!' We had the opportunity to share experiences of our own diagnosis' and how this process differs in different countries within Europe. As a group, we then had to identify an idea which could be used across Europe to support young patients with MSD within education. One idea shared by a delegate from Brussels was Bednet, a system whereby a student who is unable to access school due to illness can take part in lessons via a live stream through a computer supplied to them. It was very interesting learning about all the successes and challenges, it made me realise how far we have come, but how much further we must go.

On Friday Morning delegates were given the option to visit the Parliament of the European Union, it was an informative visit learning about how laws are passed and how it is structured. On Friday afternoon and for most of Saturday I had the opportunity to attend three workshops. The first was about how to ensure young people with RMDs (Rheumatoid and Musculoskeletal Diseases) have access to education, the second focused on how to promote early diagnosis of RMDs in children and the final workshop was about the legislations and laws which are currently being endorsed by EULAR to support patients with MSD in Europe.

On Saturday afternoon there was a Best Practice Fair, in which over 30 delegates presented projects from their organisations. All conference delegates were then asked to vote for the best presentation and project. I had taken the JIA Explained and JIA in Schools pack produced by JIA at NRAS, there was a lot of interest in the project and many delegates from countries all over the world expressed a need for something similar in their home country. When it came to the presentation of the winner I was over the moon that my presentation and the JIA at NRAS project had been chosen as the winner! I was presented with a certificate and three boxes of Belgian chocolates! I then joined the other two winners on a panel to answer questions from the delegates about the project. There were many requests for translations of the leaflets, I explained that much of the value of the project came from asking the questions and from the research. I encouraged those asking for translations to ask the questions in their own countries of their own patients to ensure the appropriate information is included in their leaflets.

It was an honour to represent NRAS at the 21st EULAR conference of PARE. I met some amazing people from all over the world, passionate about representing patients with RMDs and about making the world a better place for them. I thank the NRAS for the opportunity and look forward to being involved in similar events in the future.

Campaign to improve access to paediatric rheumatology services in Wales

NRAS is continuing its campaign in Wales to improve current paediatric rheumatology services in the country. Following the debate that we secured in the Welsh Assembly last year, where our motion for improved services was passed by Assembly Members, we have been working hard behind the scenes with commissioners to help shape the future of the service.

On Monday 26th February, along with Arthritis Care Wales and the British Society for Rheumatology, we met with Andrew RT Davies AM, Leader of the Welsh Conservatives, and Rhianon Passmore AM, a Labour Member. Both politicians were very supportive of the campaign, recognising the need to improve services for children with juvenile idiopathic arthritis in Wales. A number of Assembly Members have also asked questions to the Cabinet Secretary for Health and Social Services to follow-up on this campaign.

The Welsh Health Specialised Services Committee (WHSSC) are in the process of reviewing the current provision of paediatric services and are due to make a decision on a proposed service at the end of the first quarter of the year. Following the decision, we will work with WHSSC and the Welsh Government to either implement an improved service or to continue to campaign for a full multidisciplinary paediatric team service in Wales. You can follow further updates here: **www.nras.org.uk/campaign**

If you would like to join the campaign, we would love to hear from you. Please see this link: **www.nras.org.uk/campaign-with-us or email Matt at campaigns@nras.org.uk**.

Shaping the RA service in Scotland

The Patient Voice

As you will remember there have been two recent initiatives aiming to assess and improve standards of treatment and care for people with RA across Scotland - firstly, the audit of newly diagnosed patients which will be repeated this spring, and, secondly, the survey of people with established disease. There is excellent news about this - at first slow to 'get off the ground' in clinics, once the time allocation was extended, momentum picked up. Now a really good result has been achieved with sufficient completed questionnaires from a spread of centres to give an excellent basis for analysis. We'll keep you posted on results and on plans arising from them...a big thank you to all who took part!

Plans for piloting the **Swedish Quality Registry** in Scotland (initially Lanarkshire and Paisley and, hopefully, to be rolled out further after that) are progressing well and the launch will have been on 22 March. If you attend clinic in either of the pilot areas look out for information on how to participate. This has huge potential for improving the quality of rheumatology services and improving real patient involvement.

NRAS launches UK-wide campaigns network

For many years, NRAS has had Ambassador networks operating in Scotland and Wales, and more recently in Manchester, where health and social care is devolved. NRAS Ambassadors have helped to raise awareness of RA and JIA locally, developed close links with local hospitals and rheumatology units, undertaken large scale projects and campaigned on issues including health, social care, welfare etc.

Following the success of the Ambassador networks, NRAS is launching a new nationwide campaigns network to ensure that people in all parts of the UK are enabled and empowered to campaign on issues important to them and to NRAS. This may involve meeting your Member of Parliament to discuss disability benefits, using social media to raise awareness of RA and JIA, or setting up a petition for your local hospital regarding access to services for example.

Anyone can do it! You can find an easy to use step-by-step guide to campaigning using this link: www.nras.org.uk/campaign-with-us. There is also a downloadable Campaign Guide on the website. We can also send you one in the post if you prefer.

If you would like to discuss how you can campaign with NRAS, we would be delighted to help you, and we will be there every step of the way to support you. You can contact Matt at **campaigns@nras.org.uk** or on **01628 823524**

BSR launch second HQIP audit in May 2018

By Ailsa Bosworth, MBE

Founder & CEO NRAS

In 2013 the British Society for Rheumatology (BSR) won the tender from the Health Quality Improvement Partnership (HQIP, who are the government agency who carry out national health audits) to carry out a mandated national audit on early inflammatory arthritis/rheumatoid arthritis. We were really pleased about this from a patient perspective as we felt that this was the single thing most likely to drive up standards of care for people with RA and that has indeed been the case, although there is still much to do to address inequality of access to best care.

Patient and public involvement

The BSR have ensured excellent patient involvement in the audit. People with RA have been very much involved in the planning of the audit including two of the lay representatives on the working group at BSR being NRAS Trustees Zoe Ide and Jennie Jones. Zoe was directly involved in the previous phase of the national audit and has served until recently, as Chair of the Patient and Public Involvement panel which will provide patient input into the development of the audit.

I am on the Senior Governance Group which has been established to provide strategic oversight and governance for the project, including final approval of all project documents and outputs.

6,354 patients with a diagnosis of RA were recruited in the first phase of this audit which ran from 2013 to 2016. In the first phase data was collected over just a period of 3 months, however in the second audit, data will be collected over a 12 month period and include annual review as detailed below. Waiting times from GP referral to consultant first appointment and other indicators will be measured against NICE Quality Standard QS33 for Rheumatoid Arthritis.

Phase 2 of the audit is due to start in May this year.

Dr Jo Ledingham, Clinical Audit Director says,

> *"HQIP support and funding for phase 2 of this audit underlines the importance to the health economy, but also to society more widely, of the early identification and treatment of inflammatory arthritis. Many rheumatology units have struggled to achieve the quality statements set by NICE and this audit should be a tool that can be used to assist units in improving the care they can provide to these patients."*

In this second phase of the audit, the following criteria will apply in regard to data collection:

Eligibility of patients and dataset to be collected

- Patients aged 16+ presenting for first time with RA, Psoriatic Arthritis (PsA), Axial Spondyloarthritis (AxSpA)
- Focus of audit will still be on the 7 quality statements of QS33 (NICE Rheumatoid Arthritis Quality Standards)
- Data collection for patient with Axial Spondyloarthritis – referral time and waiting time to first appointment only
- More extensive data collection for patients with RA at three time points: baseline, 3 and 12 months,: time to commencing treatment, DAS, treatment targets, biologics use & holistic annual review
- Patient Reported Outcome Measures are being collected for patients with RA ; MSKHQ (used to evaluate the health status (and to monitor changes) of patients with a range of musculoskeletal (MSK) disorders), HAQ (this is a tool which measures functional mobility), multi-morbidity (this looks at other conditions the individual may have alongside their RA), work, depression and anxiety.
- Data on staffing levels, service models, support services etc. for each rheumatology department

We would strongly encourage all patients with RA who are asked to fill in the above questionnaires to do so and complete all of them to the best of their ability at each of the time points above. The importance of collecting this data from patients cannot be over-estimated in our view. It is through the collection of such valuable data from rheumatology teams and their patients that rheumatology units will be able to bench-mark the standard of their care and services against each other and against the national average. The information gathered is likely to be a powerful lever to bring about positive change in terms of timely appointments and universal high quality care.

We are really pleased that the audit has been extended to 12 months in phase 2 as this allows information the be collected on the annual review process, which all patients should receive, and what is measured within this review.

For further information about the audit, you can visit **www.rheumatology.org** or contact NRAS.

Patient involvement

In medicines research and development

By John Patton

NRAS Member, Volunteer and Scottish Ambassador

Along with over 50 patients from 28 European Union countries I'm half way through an eighteen month course to become a Fellow of the European Patients' Academy. We are learning to influence the design and development of medicines needed to treat, and occasionally cure, the growing number of identified human diseases around the world. This is the third course, and possibly the last, as EUPATI (the EU Patients Academy on Therapeutic Innovation) is run under the EU Patients Forum, and sponsored jointly by the EU and a range of industry partners.

Up to now the patient view has not sufficiently been taken into account by academia, pharmaceutical companies, regulators or government. While successful medicines have been developed for some diseases – biologics for RA sufferers, for instance - the process has been criticised for being too slow, too profit driven, and for treating patients as subjects rather than engaging us as participants. Becoming an expert on the process of drug development will give me as a patient the knowledge and confidence to take an active and respected part in some of the previously closed off parts of this research and development process which has been so positive for RA sufferers over the past 20 years. But it is now feared the research may run out of steam before a cure – mentioned as a real aim by researchers – is achieved.

As an NRAS Ambassador in Scotland I am already involved in promoting the interests of people with RA, but as one of only two Fellows of the Patients Academy in Scotland I hope to have more influence on the next generations of treatments which we all need to keep us going. You can see and use written materials from EUPATI at **www.eupati.eu**

Prescription Charges Coalition

NRAS co-chairs the Prescription Charges Coalition, which is campaigning for a review of the exemption criteria for prescription charges. In June, it will be the 50th year anniversary of the medical exemption list, which grants people with some conditions free prescriptions and excludes others, such as people with rheumatoid arthritis and juvenile idiopathic arthritis. Managing a long-term condition is a costly business for many, but for those not entitled to free prescriptions it can mean tough choices between heating the house or paying for a prescription to be dispensed.

We are calling on the Government to urgently reform the prescription charge exemption criteria in England and make prescriptions free for people living with all long-term conditions.

Please visit **www.prescriptionchargescoalition.org.uk/** to sign the petition.

What a difference a call makes!

By Eileen (Allanah) Hutchinson

Hi, I'm Allanah. I had a busy life with three kids, working full time, lots of social events and hill climbing....until one Sunday in March 2011, I woke up in pain. All my joints were swollen, I couldn't move. Luckily my doctor got me admitted to hospital and within a day they told me I had rheumatoid arthritis and started me on a strong steroid drip.

So you would think I would be upset. No, I was just shell-shocked as many of my family had RA and I had the RA blood test which said I didn't have it.... I know now those tests can be unreliable!

My contact with NRAS, luckily for me, happened very quickly. As I was off work and couldn't walk at that stage due to pain, I went on what my family call 'tinternet'!

I wanted information about RA and I found the NRAS website full of information about early treatments and what to expect and it made me feel more informed.

But I was lonely. I had never not been at work with the constant talking, meetings, socialising. As a nurse I missed the feedback from my patients giving me validation that I had made the correct career choice. I missed human contact and someone to talk to.

My kids at this stage were out at college, then doing their after-college activities. My husband was working 7am to 7pm running his own company. I wasn't angry about this but as a year turned into retirement due to sickness I became very alone, sad and needed answers to questions.

I looked again at the NRAS website and found their helpline number. I must have thought about ringing it for a week before I was brave enough to ring.

I needn't have worried! The lady at the other end of the phone was so understanding. She let me talk .... and I mean talk lol!

I think I spoke for half an hour before I drew breath! Everything came out. All my fears about my illness, all my worries about treatment, my worries about my career and money and my worries about not feeling like I could manage to be a mum.

These things tore at my heart but the lady on the helpline was there for me and helped me realise that I was still the same person and that I was still valuable to my family.

Over a few years I would regularly ring the helpline with worries about treatments or just on days when I needed to sound off to someone, and the staff were always wonderful and helped me come to terms with my illness and what was rapidly becoming, unfortunately in my case, disability.

They helped me figure out for myself how to manage my illness and cope. Sometimes I rang more than once a day, particularly when I was being retired on ill health. They always said ring when you need and as often as you need and were my main source of support.

I think because I had this support I didn't get severe depression which I think I was heading towards at that time. I realised that, ok I have RA and I can deal with this!

A few years later I felt I wanted to "pay back" for all the help I received, and I trained as a telephone support Volunteer. I listened to others who had just been diagnosed with RA. I could empathise, and I hoped my experiences helped others who had asked to speak to someone with RA.

I feel the helpline was invaluable and literally saved my life on my darker days.

Now.... I've found " the one"! The treatment that works for me. My husband took early retirement and we now have quality time together. The kids are at university and thriving. Things are good and I'll never forget the helpline for getting me back to my normality! And would like to thank NRAS and the helpline for making my life better.

I would say don't hesitate to call the helpline. It's amazing and you will get the help and support you need!

The NRAS helpline can be reached on **0800 298 7650** or by emailing **helpline@nras.org.uk**

NRAS is here for you every step of the journey with RA

Charlotte Kettle Age 7

By Chris Kettle

Charlotte's Dad

Harvey's Gang tours of the hospital labs demystify the scary unknown!

Charlotte's journey began in late 2016 when we noticed she had developed a limp. Initially we thought it was her shoes so went to the shoe shop and got her properly fitted. This didn't help. We took her to the GP and we were told that it "definitely wasn't arthritis" and to keep an eye on it. She had bloods taken and her (ESR) inflammation markers were slightly high. We took her to a physiotherapist who looked at her range of movement and suggested she had some kind of hip pathology and recommended an X-ray. Back to the GP we went, armed with the physio's letter and refused to budge until we had the x-ray.

This, as is we now know is not surprising, came back normal. We went on holiday to Disneyland and Charlotte couldn't manage to walk more than a few minutes without stopping. She wanted to go to bed rather than go to watch the evening light show. This was heart-breaking to see. At this point we decided to really dig our heals in with the GP. Another blood test showed another slightly high ESR so we pushed again for a referral to see a paediatric rheumatologist.

Our persistence paid off and Charlotte was diagnosed with poly-articular JIA on 9th June 2017, the same day as the Blaydon Races. Credit to the team at the Royal Victoria Infirmary, Charlotte was in the following week and had 3 lots of daily prednisolone infusions. She was bouncing after this and was trying to show us her Pilates moves on the sofa! Methotrexate was started a week or so later and administered via the spring-loaded pen.

This still causes anxiety on the days she has the pen, but the improvement is amazing. Being on various Facebook groups you tend to hear the negatives, but her legs improved from being rigid in June to being more agile in October. Her wrists had not responded as well, and she needed to have joint injections recently.

Harvey's Gang

She really doesn't like needles anymore and this is one of the reasons that we asked the children's play therapist for their help and they suggested **Harvey's Gang**, an initiative run at the Royal Victoria Infirmary in Newcastle.

Harvey's Gang is now in at least 9 hospital Trusts and is spreading across the UK and beyond. Children and families see where the blood samples end up in the lab.

Children are 'Trainee Biomedical Scientists' for the day, just like Harvey. They can see and meet the machines and the scientists that test their blood. They can ask questions, look at their own blood cells through a microscope and the children and families can get further information from the experts.

Bushcraft Days

In 2016 we were contacted by the paediatric rheumatology team at the Nuffield Hospital in Oxford as they were concerned about some teenagers with JIA who were becoming disengaged with their condition, resulting in them missing appointments and not taking medication. We worked with the team in Oxford to run our first Bushcraft Day for young people aged eleven to sixteen, giving the specialist nurses, physiotherapists and psychologists from Oxford the opportunity to chat and re-engage with the young people whilst joining in the fun.

Bushcraft Days involve young people taking part in four outdoor activities such as shelter building, wild food workshops, wilderness trails and fire workshops. The other participants have the same condition and similar issues, and those running the activities understand the problems and the fact that participants may need to take medications during the day or have to limit participation due to pain. We plan to run our next Bushcraft Day in Oxford on Thursday August 16th at Camp Wilderness, Cornbury Park. Spaces are limited so call to book your place on **07834 609249** or email **jia@nras.org.uk**

"Thank you for an amazing day at Camp Wilderness. I'm still trying to wash off the mud. I thoroughly enjoyed the day with the range of games and activities we had on offer. I enjoyed learning the different ways you can start a fire the most as this will be helpful for scouting and other such activities. Meeting other people was great too! I spoke with a number of people on the day who have JIA and it's amazing how we all live our lives in confidence. In fact, I'm trying to keep in contact with one person I met as we got on rather well. I would certainly recommend the day to all JIA patients as it's an opportunity to meet people who all share something in common and you feel like you fit in. Just one thing: could we do it again? Thank you again for an amazing day."

Tom, aged 15, Oxford

Thank you again for an amazing day

Living with a child with juvenile idiopathic arthritis

By Jeanne Donohoe

> Her outlook and plans for the future amaze me and make me so proud.

Rowena was diagnosed with JIA at two years old so we have not really got much experience of her not having arthritis. The early years were a constant round of blood tests and hospital appointments, including the Eye clinic where she had routine checks for uveitis. She had occasional steroid injections in her left knee and some physio appointments to try to keep her strong physically. She had pain in many joints including her jaw.

Rowena developed Scoliosis in her teens and as a result she became weaker during this period and her arthritis became more of a problem. She needed stronger pain medications.

The long-term aim was to stop further damage to her joints, and so Rowena started sulfasalazine combined with methotrexate injections. Side effects and subsequent consultations suggest that this combination is not working. We await results of special blood tests to see if she can take the next drug 'up' and whether the consultant will agree to the cost!!!

Rowena has been planning to go to university for several years; she wants to study Psychology and is doing very well at college with her A levels. She has had to take an extra year to do them because of her drug treatment and its effects but if all that gets sorted out by the summer of this year she will then have her last year to improve her stamina and prepare for leaving home. Whilst I would love to keep her close to me and fear her leaving I also understand how co-dependent our lives have become and I really want her to fly the nest and find some independence.

Most of her early schools were helpful and understanding while she was young but less so as she moved onto secondary. The school eventually had to be told by her consultant nurse that she MUST do half days until her stamina improved and as a result Rowena achieved great grades in her GCSE's.

In Hampshire we came under the lovely care of Southampton paediatric arthritis clinic, met other families, and went onto the Facebook support group, local and national. We have also been on a weekend away with other families and young people with JIA, so much information and all so new and amazingly enlightening.

My lovely daughter and her bright future keeps me positive. She gives me so much love and she brings joy to my life. Her outlook and plans for the future amaze me and make me so proud.

Living with JIA

By Rowena Panton

Arthritis has not impacted every part of my life, at least it didn't at first. The major thing it did affect was my education. It's a pretty big deal when you can't write as much as the teachers want you to, so they have to mark you down for it because you have arthritis in your fingers and wrists.

When I was in primary school I sat on chairs at the edge of the hall for assemblies with the teachers while all the other kids sat on the cold hard floor for longer than I would be able to. In secondary school I was able to have a word processor in class which really helped but the teachers were all frustrated with it. I had an iPad provided by the school which didn't have word on it, so I had to go through an ordeal to convert it to a word document and then print it out and do this multiple times for all my lessons. My teachers wanted the work at the end of the lesson but I had to give it to them the next day or later which caused them frustration, which I can understand. They later gave me a different tablet with an attachable keyboard which could print easier but had little memory so I had to bring my own memory stick and the teachers were always suspicious that I would go on the internet so they'd watch over my back. I understood but it's frustrating.

In college everything surrounding my medical conditions is so much better handled. It's so different to my previous experiences. I can bring in my MacBook to college which was generously part funded by CCAA and their donation. It is lightweight and fast working letting me print off my work easily or email it to my teachers straight away. In college the mood and atmosphere about disabilities are completely different. In fact, anyone can bring a laptop to college and use it. The student has to take responsibility for it. The college supplies Chromebooks to those who need them and can't get their own. College is simply a more tech friendly place. I felt singled out in secondary school but in college when other students find out you have extra time or a computer they say 'lucky you!' There's simply a more positive outlook.

#WearPurpleforJIA 2018

Friday, 8th June 2018

Save the date as it is approaching at speed and, as we go to press, we already have over 50 families registered to take part in **#wearpurpleforJIA 2018**. This year we want this event to be bigger and better than ever, building on the success of previous years. Lots of the families already involved are organising 'purple dress down or up days' or 'purple bake sales' at their school or nursery, helping to raise awareness about JIA in children and young people. NRAS would love for you to get involved and sign up to be part of. You can be as creative as you like with what you do to help raise awareness and funds. You could hold a sponsored purple walk, a "deep purple" music night or take on a personal purple challenge – have fun and help us to reach the perfect purple target of £25,000 which will help support even families living with JIA.

To find out more or to register to take part in **#wearpurpleforJIA 2018** please visit the #wearpurpleforJIA Facebook page, become a friend of the page and share photos of your event or challenge.

You can also register via the NRAS JIA website **www.jia.org.uk** where you can sign up for a purplucious fundraising pack, or call us on **01628 823524** to have a chat about your event ideas.

18th-24th June

SAVE THE DATE

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National Rheumatoid Arthritis Society

JIA at NRAS

Helpline: **0800 298 7650**
General: **01628 823 524**
e: **helpline@nras.org.uk**
w: **www.nras.org.uk**

Ground Floor
4 Switchback Office Park
Gardner Road
Maidenhead Berkshire
SL6 7RJ

/nationalrheumatoidarthritissociety
/jiaatnras

@NRAS_UK
@JIA_NRAS

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