

# Members'

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# MAGAZINE

SUMMER 2019



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**By Ailsa Bosworth, MBE**

National Patient Champion

# Dear Members

Well, here it is, after over 18 years, my last 'Dear Members'! I stood down as CEO at the AGM on June 26th and am now taking on a new role as NRAS National Patient Champion which, from September will be a part time role, giving me a bit more time to devote to family and other activities. My daughter is expecting her second daughter in mid-August and so some grand parenting duties will be required!

Founding NRAS and working as its CEO for this length of time, has changed my life immeasurably for the better. It has been an incredible journey and I have been profoundly moved and impressed by so many of you I have met over this time. It's actually quite difficult to sum up in a few sentences what NRAS means to me. NRAS has been, and will continue to be, a huge part of my life and that of my immediate family who have put up with usually coming second in terms of priority for so long!! It's been a privilege, humbling, I've learnt so much and the NRAS team have made me so proud on so many occasions by their hard work and passionate approach to improving life for people with RA and JIA.

The team sprang a surprise 'do' on me on Friday 21st June and I was somewhat overwhelmed with everyone's kindness and good wishes – video messages – presents and flowers – they can be a devious lot (!) and how they managed to get all the organisation done without me spotting anything was going on, I don't know!

There is no way that I could retire completely, I'm just not ready for that yet, however, working less hours and focussing on work where my lived experience as a patient and the knowledge and experience gained as CEO of NRAS can benefit NRAS and those we serve is what I shall be focussing on going forward from September. This will include research activities, working with EULAR, contributing to national standards and guidelines as well as continuing to support NICE Health Technology Appraisals as new therapies come into the NHS. I will also be continuing to work on a number of technology projects I've been leading on which will ultimately lead to our being able to substantially increase the supported self-management resources we currently offer and help us to reach, support and help more people. Lot's more to do yet!

I am also truly delighted that my friend and colleague of more than 12 years, Clare Jacklin, will be taking over the reins. Clare successfully went through a very rigorous recruitment process laid down by our Board of Trustees and I couldn't be more pleased to be handing my 'baby' to her as I know she will take good care of it! You all know Clare well and the continuity this appointment brings will reassure everyone that it will be business as usual at NRAS going forward with no sudden changes in direction or focus. We have a three-year strategic plan which came into force in January this year and Clare and the team will be keeping a strong focus on executing that although I know that Clare will bring her own personality and vision to bear in leading the charity through the next years.

So, it's not 'goodbye', I shall be wearing a different hat and I look forward to continuing to work with you, our members and volunteers, and all the rheumatology health professionals, our industry partners and other stakeholders as we move forward under Clare's leadership.

It's been hard work, enjoyable (most of the time!), and an extraordinary privilege being the CEO of your patient organisation since 2001.

With warmest wishes

# Members' MAGAZINE

## Contents

- 2 Dear Members
- 3 Free Information Event for Your Employer | Members' E-Newsletters
- 4 Seated Yoga
- 7 Spring Fundraising for NRAS
- 8 Question Time with Clare Jacklin
- 10 A Day in the Life of An Occupational Therapist
- 12 An Unmet Need: Differences in the ways that men cope with RA | Disease Remission and CV Risk
- 13 Pathways to Better Care in Manchester | RA in Wales
- 14 What is Joint Protection?
- 16 Ask the Helpline
- 18 Cannabis for Pain: Hype or Hope?
- 19 My Story: Alice Dyson-Jones
- 20 Raising Awareness of RA Amongst Politicians
- 21 18 Years with Ailsa Bosworth CEO
- 25 Elephant in the Room
- 26 Rheum for You
- 27 Other ways to give
- 28 RA Awareness Week 2019
- 31 Gum Disease & RA | Low Vaccination Uptake Among RA Patients | Osteoporosis in RA
- 32 NRAS Challenge Events
- 34 NRAS Groups
- 35 Edinburgh and Lothians NRAS Group Launch | Right Start Service
- 36 Racing Driver Josh Stanton partners with NRAS | Richard Boucher takes on Great East Swim
- 37 Pass On Something Wonderful
- 38 "Taplowites" Reunion
- 40 EULAR – The European League Against Rheumatism
- 41 Healthy Summertime Recipes for Families | JIA Family Day in Leicester
- 42 Wear Purple for JIA
- 44 Events Diary

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

Editor of this issue;  
Tracy Bracher

# Free information event for you and your employer

On 18th September, NRAS will be hosting an event in London called 'Time to Work.' This will be an opportunity for people with RA and JIA to bring their employer to an informative event about how RA and JIA impacts people's working lives.

The event will offer help and advice for employers, such as providing information about RA and JIA, guidance on the types of government schemes available to support employers, and give an understanding of how employers can better support their employees with long-term conditions. It will also provide advice for people with RA and JIA on work and employment and the type of support they can expect from their line managers.

Amongst the speakers will be high profile professionals from the business world, the charity sector and healthcare.

This will build on NRAS's 2017 *Work Matters* report, where one of the recommendations included the need for people to have 'access to good quality, accurate information about their rights in the workplace and are able to sign-post their employer to reliable sources of support and help.'

**Work Matters**  
A UK wide survey of adults with Rheumatoid Arthritis and Juvenile Idiopathic Arthritis on the impact of their disease on work

**Time to Work**  
18th September 2019  
2pm-4pm  
The King's Fund, London  
Bringing together people with RA, their line managers and their employers to discuss long-term conditions in the work place.  
For more information and to register to attend, please visit:  
[www.nras.org.uk/timetowork](http://www.nras.org.uk/timetowork)

If you would like to attend or for further information, please email [campaigns@nras.org.uk](mailto:campaigns@nras.org.uk)

## Members' E-Newsletters

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





By Sue Moon

# Seated Yoga

Yoga has, quite simply, enriched my life... on every level!

I was 35 years old when my busy, active life changed dramatically with the onset of seropositive rheumatoid arthritis. Within a short time I was walking with two sticks, often needing a wheelchair, and spending time in hospital. I was unable to work, drive or look after my young family without help. The RA was, and sometimes still is, aggressive and unstable.

As a British Wheel of Yoga Diploma holder I had been practising, studying and teaching yoga over many years. A couple of years before I became ill I was inspired by the Viniyoga of Yoga approach, and became the student of a very

special teacher. Just after the diagnosis of RA I embarked on, and successfully completed, a further five years training to qualify as a Viniyoga Practitioner and continue my studies and training.

Viniyoga is not a style, but a name used to describe an approach to yoga. It aims to make the practice of yoga relevant to every person in every situation – young or old, fit or unwell, active or sedentary. Poses or postures and practices are adapted to suit individual needs and circumstances.

Techniques include posture, breathing, reflection, sound work and meditation. These sit well alongside traditional rheumatology therapies and medicine.

Yoga is not about tying yourself in knots, standing on your head or following some ancient rituals. Yoga is a tool for positive change, helping develop physical, emotional and mental well-being.

You don't need any special or expensive equipment to practise yoga, just a willingness to take a short time away from your everyday life, on a regular basis, to practise. It's helpful if you wear warm, not too tight clothes, and find a quiet space where you will not be disturbed or distracted.

The practice suggested here should be accessible for most people and take approximately 15-20 mins. Sitting on a firm chair or stool, your feet need to be flat on the floor - if they don't reach, use something like a large book or very firm cushion under them. The important thing is to "sit tall" with your back straight and shoulders relaxed and down. You can place your hands, with palms down, on your thighs and your elbows bent in a restful position.





In this approach to yoga, attention to the breath is very important, so move into and out of each position using a slow inhale or exhalation. It sounds complicated but you will find, with practice, the slow rhythmic movements become very natural. Repeating slowly and mindfully several times and linking the breath with the movement, allows us to work safely, easing stiff muscles and joints. The simple poses can strengthen muscle tissue, ease pain, improve mobility and well-being. Always, of course, work within your boundaries - and as you know these can change constantly with RA!

I am in awe at the powerful support yoga has been in my life and the students I have worked with over the years. I hope this article may inspire you to try yoga, although the outline given here doesn't do justice to the potential benefits yoga offers. For those of us who live with a debilitating disease, it can change our relationship with, and our attitude to, the difficulties we may experience... to embrace change in our lives in order that we can move forward and live well with RA.

## Starting Positions For A Simple Chair Yoga Practice

### Position 1

Sit tall, shoulders relaxed, hands resting palms on your thighs towards knees.



### Position 2

Sit tall, shoulders relaxed, hands resting palms on abdomen. Elbows in and relaxed.



### Preparation

Seat yourself in a light, airy room. Wear some loose clothes / trousers. Take a few moments before you begin to settle yourself, maybe close your eyes and notice your breath in and out.

### Breath Awareness

Allow breath to be comfortable, longer than your unconscious everyday breathing. We will talk about inhale/exhale; this is to breathe slowly in and out with a slight pause after each inbreath and outbreath, ideally through your nose.

Explore your breathing, inhale and exhale softly and slowly.

# Your Moves

### Movement 1

Start in position 1. On inhale, raise arm as far as is comfortable. Lower arms as you exhale. Alternate arms.

Repeat 4 times



### Movement 2

Start in position 1. On inhale, raise both arms only as far as comfortable. Lower arms on exhale.

Repeat 4-8 times



Yoga is a tool for positive change, helping develop physical, emotional and mental well-being.

The Viniyoga approach to yoga aims to make the practice of yoga relevant to every person, young or old, fit or unwell, active or sedentary

Movement 3

Start in position 1. On exhale, take right hand to rest on the right shoulder slowly turning head to the right at the same time. As you inhale, bring arm, elbow and face forward. Exhale to lower arm down.

*Repeat alternate arms 4 times*



Movement 4

Start in position 1. You need only to lift your leg a few inches to stretch back of leg. Inhale, straighten leg stretching heel away, exhale point toes down, then inhale stretch heel away again. Lower leg on exhale.

*Repeat alternate legs*



Movement 5

Start in position 2. On inhale, take arms out to the side, a movement which gently opens and stretches inside arm and elbow. Exhale return arms. (Try to sit tall throughout not arching back).

*Repeat 4-8 times*



Movement 6

Start in position 1. On inhale, turn palms upwards. On exhale, turn palms downward.

*Repeat 8 times*



Movement 7

Start in position 2. Palms over eyes, inhale and exhale.

*Repeat 4-8 times*



Movement 8

Start in position 2. Sit, allow shoulders to be soft and relaxed. Elbows in and relaxed. Close eyes and focus on your breath in and out. Try to make the exhale a little longer.

*Repeat 8 times*



If you would like to find out more about this approach to yoga, or find a teacher who can offer individual lessons or a class near you, go to the "Association for Yoga Studies" website [www.ays.org.uk](http://www.ays.org.uk)

Sit quietly for a few moments until you feel ready to gently stretch and open your eyes.



# Spring Fundraising for NRAS



## Frogmore House & Garden NRAS Open Day – 30th May 2019

It was just by chance our Event Fundraiser Raman Fenech wrote a letter to Buckingham Palace In January 2019 asking to be added to the list of beneficiaries for the charity open days. Little did we know that we would be selected for this year which was fantastic news and we were very excited and honoured to have this rare opportunity to raise awareness and funds for NRAS.

Frogmore is the Royal Family's secret bolthole, tucked away in Windsor Castle's Home Park. The Frogmore

Estate and Gardens comprise 33 acres of private gardens within the Home Park adjoining Windsor Castle, in the Royal County of Berkshire. It is the location of Frogmore House, a royal retreat, and Frogmore Cottage.

Total amount raised

**£13,029**



## BridBeat singers

at a concert in aid  
of NRAS on 18th  
May raised over

**£400**

# Question Time with Clare Jacklin

Tracy Bracher sits down with Clare to talk about her new role as CEO of NRAS



What made you apply to come and work for NRAS 12 years ago?

I'd worked at two charities previously and was keen to get back into working in the third sector. To be honest I, like many others of the general public without links to inflammatory arthritis, knew nothing about RA. So those first few months were a challenge and a steep learning curve.

What was your first job at NRAS?

My first role in NRAS was as Volunteer Network Manager as it was then. It entailed recruiting, training and supporting volunteers to offer peer support via the telephone support service as well as local groups. We only had 5 local groups back in 2007!

How many people were there at the time you joined?

The small NRAS office back then had just 11 people working for the society. Little did we realise then how fast the organisation would be required to grow to keep up with demand for our services. We now number 25 (11 of whom are part-time)

Name three highlights of your career to date (your proudest moments)?

It goes without saying that the proudest moment must be being selected to take over from Ailsa as CEO. I never in a million years would have thought as I came through the NRAS door 12 years ago that I would be taking on such an amazing honour. My other highlights have been the success of the Behind the Smile awareness campaign videos that we produced with the support of one of our pharmaceutical partners and another that stands out is the work we did on the impact of Emotions, Relationships and Sexuality resulting in a very unique resource booklet which I tend to call the "50 Shades of RA" book!

What facts about RA still shock you today?

The unfairness and inequity of access to appropriate care across the country. There is still far too much evidence of 'postcode' lottery for health care. Why should someone's health be diminished and them be penalised just because of where they happen to live. While there are many fantastic rheumatology units around



the country exemplifying best practice of care there are still far too many hardworking health professionals who are hampered and hindered in the care for their patients by draconian bureaucracy, lack of investment and focus on meeting targets and budgets instead of meeting the needs of the people they serve.

### What words of wisdom did Ailsa impart on you when she handed over the baton?

Well the handover is ongoing as I'm so glad that Ailsa is still very much a key member of the NRAS team but over the years the many words of wisdom and guidance that I have been fortunate to receive from Ailsa can probably be summed up in one short sentence. Do the best you can to the best of your ability remembering that you can't please all the people all of the time, but as long as what you do comes from the desire to do the right thing that's all that can be asked of you.

### What would you like to say to our members in one sentence?

My vision for NRAS is to make it a true 'society' where all our Members feel proud and part of NRAS working together to change minds, change services and change lives.

### If you met someone in an elevator what would you tell them about NRAS?

I work for an amazing patient organisation that is the only one in the UK with a specific focus on rheumatoid arthritis and juvenile idiopathic arthritis. Two very misunderstood auto-immune conditions that can have devastating impacts on individuals' and their families' lives if not treated promptly and effectively. NRAS is all about ensuring that we support all those living with these conditions to know more about their conditions enabling them to better self-manage, and we campaign for improved equitable services across the UK. One of our favourite sayings in NRAS is you don't know what you don't know... that's why NRAS exists to support individuals, their families and their health teams every step of the way. You can help us to make a real difference; here's my card! Oh, is this your floor?

### What are your hopes for people with RA or JIA?

My fervent wish is that one day maybe we wouldn't need an organisation like NRAS because there would be a cure for these conditions so no one would need information, support and advocacy. However, in the meantime my hope for all those living with long term conditions like RA is that we all play our part in improving public awareness and tolerance of those with invisible

disabilities which in turn will lead to improved understanding of the importance of holistic care for all. Treat the person not the condition.

### If you were on a speed date and you had two minutes to tell your date about yourself what would you say?

Gosh! This is a challenge. Well firstly I shouldn't be on a date as I am happily married to my long suffering, first husband, (I just say that to keep him on his toes!) Martin for the last 27 years. I have two grown up children, Hannah who is just finishing her master's in psychology research methods and Paul who has just obtained a Merit on his post-graduate course in Sports Therapy. So, first thing to know about me I am a proud mum! We also have a lovely dog called Lotty, who is a bit like her owner these days, old and a bit wonky but still up for a nice walk.

My mantra is a day without laughter is a day not lived to the full. There is so much around us to laugh at, or with, including ourselves I try to find something to be joyful about every day. If I had to sum myself up in a few words it would be these, I work hard and play hard. Coming from Irish working-class stock I was raised in Salford, then the west of Ireland, but somehow didn't end up with webbed feet despite the number of soakings I got as a child! I have in recent years discovered I have two half siblings which came as a bit of surprise to my sister and I but a welcomed one. Having just taken on the most important job of my life (next to the one of being a mum) I am probably going to be a wee bit busy for some time to come but I am relishing the challenge of leading a fantastic organisation into its next chapter.

Finally, with me you get what you see, I don't do hidden agendas, I'm not that good an actress! In the magical words from that great song the Greatest Showman – "This is Me"

.....  
 "A day without laughter is a day not lived to the full."





## By Catherine McCoy

Hand Therapy and  
Rheumatology Occupational  
Therapy Service Lead  
Occupational Therapist and  
Advanced Clinical Practitioner,  
Salford Royal NHS  
Foundation Trust

A Day in the Life of...

# An Occupational Therapist

Occupational Therapists provide specialist assessment, treatment and practical support to help individuals in maintaining or regaining ability, confidence and independence in activities that are important to them. I work as an Advanced Clinical Practitioner (ACP) in the rheumatology and the orthopaedic hand service at Salford Royal Hospital. ACPs are experienced and highly skilled clinicians from a range of healthcare backgrounds, such as Occupational Therapy (OT), Physiotherapy, Podiatry, Paramedics and Nurses. They have advanced qualifications and have developed knowledge and skills that enable them to extend their clinical practice beyond the traditional scope of their background profession.

OT is known for having a particularly holistic approach to patient assessment and care; meaning that we consider the overall physical, mental and emotional wellbeing of an individual, rather than focusing more specifically on the symptoms of a disease. This means that, despite often working within specialist clinical areas, OT is a very varied role and every day is different, something that I really enjoy and value in my job. I hope that describing 'a day in the life of an Occupational Therapist' will help to demonstrate this, and support in understanding the wide scope of what OT can offer.

### 8.00am-9.00am

#### Multidisciplinary Radiology Meeting

Once a month we have a team meeting where the therapists get together with the Doctors and Radiologists (doctors who are specially trained to interpret the images from x-rays and scans) to discuss any patients who have complex needs. This meeting provides the opportunity to bring together the expertise of different members of the team to help make decisions on the best care that we can offer our patients.

### 9.00am-12.30pm

#### Early Inflammatory Arthritis Clinic

This clinic runs once a week and provides 'one-stop' access to OT, education about medications and diagnostic ultrasound imaging for patients being investigated or treated for inflammatory arthritis. This brings together members of the multidisciplinary team to provide a more efficient service; preventing delays in diagnosis, reducing the need to attend multiple appointments and aiming to provide patients with early drug counselling to start treatments as soon as

possible. Within this clinic I introduce patients to the role of the health professionals within the team (including when and how to access these services), advise regarding maintaining independence in activities of daily living (home, work and leisure activities) and educate regarding joint protection, appropriate exercises and managing fatigue. I also assess for and provide specialist gloves and splints that can support the hands and wrists and help in managing symptoms such as pain, stiffness and swelling. Once patients have started treatment, I support the team in evaluating whether the treatments are effective in reducing disease activity and also identifying when medications may need to be reviewed. It takes a number of weeks before it is known if a drug treatment is going to be helpful for a patient. During this period steroid injections are sometimes helpful to reduce pain and/or swelling of the joints and this is also something that I am able to provide within my ACP role.

### 1.00-1.30pm

#### Referral Triage

After lunch I look through the referrals to the Rheumatology OT and Hand Therapy service and make decisions about how quickly patients need to be seen and what would be the best clinic for them to be seen in.

### 1.30-3.30pm

#### Rheumatology therapy clinic

In the afternoon I have a rheumatology therapy clinic where I see patients who have been referred to OT with a range of rheumatological conditions.

The first patient today is a young lady who has good control of her inflammatory symptoms on treatment but who is struggling with weakness of



her grip and fatigue. She works full time and has young children. She feels that her busy lifestyle doesn't allow her to stop and rest and often feels exhausted and frustrated that she doesn't have the energy to enjoy life the way she did before her diagnosis. We discuss how she is managing with home, work and leisure activities to identify the tasks that are particularly difficult. We discuss practical ways in which some of tasks could be modified to help reduce the strain on her joints and I suggest some assistive devices that may help at home and work. We discuss what activities are most important to her and prioritise these in forming a treatment plan that includes strengthening exercises for her hands and attending a relaxation session. I also provide an activity diary for her to bring to the next session so that we can explore how pacing and planning might help in managing her fatigue.



My next patient is an older lady who has had rheumatoid arthritis for many years and has hand deformities that are limiting her in everyday tasks. It has been fantastic to see how medications have developed to the point that now, we rarely see the very disabling hand deformities that used to be caused by inflammatory arthritis. Unfortunately, for patients with long standing disease, these drugs were not available when they were diagnosed. While this lady no longer has inflammation or pain in her hands, over time the disease process has caused damage to the joints and soft tissues. Deformities to the hand joints are making it difficult for her to do some everyday tasks. She has been referred for assessment to help support her in deciding if she would benefit from hand surgery, and if so what procedure would be most helpful in improving her hand function.

We discuss the symptoms this lady experiences in her hands, what activities she finds difficult and why (for example whether it is because the hand is weak, if the position of the joints limits the type of grip required for the activity, if there is any numbness in the fingers affecting the ability to pick up and manipulate items in the hand etc.). We discuss some gadgets that may be helpful and I also fit some small splints to correct the position of some finger joints to help with hand function. We discuss surgical procedures that may be helpful, what the potential benefits and limitations of each would be, and what

the post-surgery rehabilitation would involve. Following the assessment I complete a report for the hand surgeons and arrange for her to be seen jointly in clinic with myself and the hand surgeon.

*"You wouldn't think that a little splint like this would make such a difference. With my finger in that position I can grip so much better. It feels better too- it's better supported."*



*"Discussing how I use my hands has made me realise all the things that I can do. They might not look great but I suppose I have kind of got used to how they are and over the years have found my own way to do things."*



.....  
 "You wouldn't think that a little splint like this would make such a difference. With my finger in that position I can grip so much better. It feels better too – it's better supported"



# An unmet need

## Differences in the ways that men cope with their RA

Rheumatoid arthritis affects around two to three times more women than men. As a result, studies are likely to have a similar gender ratio, which can be unhelpful if the findings would be different for men than they would be for women. One particular area that has been investigated by researchers is the area of self-management courses.

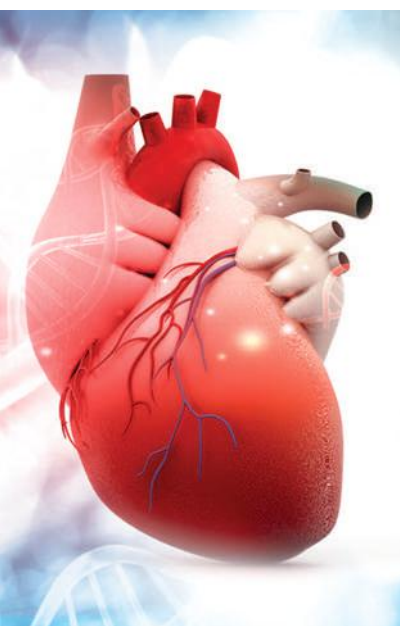
Self-management programs look at a number of areas that patients have some control over, including the impact that diet, exercise and other lifestyle changes has on their condition, as well as looking at pain management skills, the importance of a good support network and communication with healthcare professionals. However, in overall assessments of self-management, possible differences between genders can be overlooked.

In previous studies, when compared with women, men have been shown to experience greater stress if their disease caused them to have to stop working. It has also been reported that men experienced a greater effect on social activities since diagnosis, whilst women overall feel greater

emotional stress than men with regards to their RA. Some studies have looked at the preferred methods of self-management and found that physical activity interventions had a greater effect for men on health-related quality of life than interventions that included education, peer support and monitoring by healthcare professionals.

In a more recent study, researchers focused on the effects of RA diagnosis on the male patient's perception of their masculinity, gathering data from 6 all male focus groups, attended by 22 men with RA and followed up with one-on-one interviews with 5 of the men.

The study concluded that men dealt with their masculinity post diagnosis by retaining, rejecting or renegotiating it. Of the 5 men interviewed after the focus group, two pushed through pain to continue masculine activities, two replaced masculine roles they could no longer do with other roles, while one rejected masculinity completely. Common themes across the interviews included the feeling that being in work was important with regard to masculinity, as was trying to fit in with friends socially.



# Disease remission

## associated with an 80% decrease in CV risk

A recent study, which was presented at this year's Annual European Congress of Rheumatology (EULAR 2019) has shown an 80% decrease in levels of cardiovascular (CV) risk for rheumatoid arthritis patients in remission.

The study looked at around 800 patients and assessed them over a 3-year period. CV risk was defined as heart attack, stroke or congestive heart failure. 'Pre-clinical' early signs of CV disease (defined as lesions on arteries detected by ultrasound) were also reduced, by 75%.

The study also looked at 'traditional' CV risk factors, such as high blood pressure and type 2 diabetes, and found that these factors were less common in patients who were in remission.

This reduction in CV risk shows the importance of effective disease control, and gives a positive message that remission, which is becoming increasingly common with advances in medication, can reduce some of the health risks associated with the disease. Remission was reached and maintained by around 40% of patients in this study.



# Pathways to better care in Manchester



NRAS is continuing its work in Manchester to integrate the services that NRAS provides into the rheumatology pathway for people diagnosed with RA. Recent meetings have brought together patients, clinicians and NHS management.

The devolution deal for health and social care in Greater Manchester presents a unique opportunity for NRAS to embed its services within care pathways, ensuring that newly diagnosed patients receive the help and support from the charity as and when they need it. This is also a good chance for NRAS to promote its new Right Start service, demonstrating how this complements services provided by rheumatology teams in line with NICE guidelines.



NRAS is lucky to be working with dedicated and experienced consultants, nurses, physios and other health professionals on this project, as well as our

volunteer Ambassador team. If you would like to be kept up-to-date and to get involved, let us know! Let us know by emailing [campaigns@nras.org.uk](mailto:campaigns@nras.org.uk)

## RA in Wales

### Event in the National Assembly for Wales

On 17th July, NRAS held an information drop-in event for Assembly Members in Wales to raise awareness of rheumatoid arthritis, following last month's successful RA Awareness Week.

Last month, NRAS commissioned a YouGov survey which showed that only 19% of people in Wales were aware of what rheumatoid arthritis is, compared to 24% in Great Britain more widely and 27% in Scotland. When asked what RA was, the results of the survey showed that 39% of people identified a description of osteoarthritis in Wales, compared to 30% in Great Britain and 27% in Scotland.

Findings from NRAS's mental health report showed that people in Wales with RA are less satisfied with their life, believed the things in their life were less worthwhile and were less happy. Most concerning, 1 in 3 people with RA in Wales who had requested or been offered

psychological or emotional support had never received it.

NRAS staff were delighted to join Welsh Ambassadors Rich and Carl, along with other NRAS Members in Wales to inform Assembly Members about some of the key policy issues, and most importantly, to raise much-needed awareness of this disease.





By Michaela Davies

Hand Therapist

# What is Joint protection?



Joint protection involves using techniques and assistive technology (aids and equipment) to minimise the stress and force placed on joints, to reduce pain and prevent or protect against further joint damage or deformity. This is a long-term approach to daily tasks and activities and can also be described as “task modification”.

## What are the benefits?

Joint protection can help reduce flare ups and long-term joint and soft tissue damage, and can help you to feel in control through self-management. When given a framework in which to support yourself, it can assist in building robust coping strategies that help you through challenging times.

### Protection using positioning.

- Use two hands to support in carrying and choose two handle options.
- Use bigger joints: spread the load over as many joints as you can. Can you use your upper arm to support/carry/push/pull?
- Use the flat or heel of hand: consider pump dispensers for a variety of products not just hand soap i.e. shampoo and conditioner or your favourite sauce!
- Posture: consider what position your body and arm is in to lessen strain and obtain additional force through the upper arm.

## Protecting using gadgets

Which are:

- Use non-slip materials to help steady, grip, twist, open or place items onto.
- Go hands free! Prop up objects to avoid being in one position too long.
- Thicker handles – Pad out or replace handles. There are plenty of styles and sizes of sleeves that fit over handles of all sorts of household items to add bulk, which are available on the internet. Get creative and utilise non-slip materials to your advantage. Add a toggle or charm personal to you on zips like handbags or jackets to grab onto more easily.
- Reduce weight – use a smaller option, a lighter model, or split the load: quick ideas include opting for a smaller towel, kettle, plate or hairdryer and when the time comes, to replace appliances like a Hoover – consider a lighter smaller option.
- Create stability – use straps, edges, and work surfaces, non-slip feet /mat so less strain is placed on the supporting hand.
- Use leverage – to open jars and tins etc. there are numerous gadgets available to help.
- Change containers – if you can't open a container maybe consider decanting the product into a different one you can more easily manipulate (not with chemicals though! Find an alternative option – sprays, wipes etc.).



The internet has opened up access to many assistive devices that claim to help with daily tasks. Take care when selecting these items, keeping in mind the basic strategies explained herein: Try finding gadgets using the term "Arthritis" as a keyword before the tool you are looking for i.e. "Arthritis" pen, can opener, knife, chopping board etc.

### Protecting by avoidance

Whilst we need to maintain hand grip strength and active range of movement -there are some positions that can cause pain. So it's best to avoid where possible:

- Pinch or twist actions
- Prolonged grips in one position
- Vigorous repetitive actions
- Heavy lifting /weights
- Narrow and /or slippery handles.

### Pacing



Patients tell me all the time striking a balance between rest, activity and exercise is a difficult skill to master, especially when they are enjoying something. Pacing is very individual but find your baseline, and where possible, stop before reaching exhaustion or entering into your pain zone. You might break the task into chunks, do something else, or rest and then return to it on the same day or another day. You might need to plan ahead more, but it is worth it!



### Problem Solving

So next time you come across a problematic / painful activity ask yourself:

**Can I do it differently?**

**Can I adapt it?**

**Is there a gadget that can help?**

**Can I prioritise – does it need to be done today, or at all?**

**Can someone else do it?**

**Delegate** – do the bits you can do and then request help. This isn't about giving up, or failing; it's about being assertive, realistic, pragmatic, and in control of looking after your health so you get to enjoy and complete the activities you want. Ultimately, you are the best person to recognise potential opportunities and adapt them to you.

When given a framework in which to support yourself, it can often assist in building robust coping strategies





**Helpline**  
**0800 298 7650**

# Dear Helpline

I would like to speak to someone about my RA. How can I contact your helpline and what support can they offer?

Our helpline team aim to help anyone who contacts us and if we can't, then we can signpost you to someone who can. When it comes to any issues that can affect someone with RA, or anyone else affected by the condition, we are there to provide you with information and support. We can be a listening ear, but we are also very knowledgeable about RA and JIA. If someone asked us what a 'typical' day on the helpline was like, I think we would struggle to answer that, but hopefully we can give you an idea of what we can do to help.

## When can I call the helpline?

Our helpline is available Mon-Fri, 9.30-4.30 on **0800 298 7650**. We also respond to emails during those hours, which can be sent to [helpline@nras.org.uk](mailto:helpline@nras.org.uk).



*The NRAS Helpline team*

## Are you medically trained?

We're not, and even if we were, we could never give what we would term 'medical advice' (e.g. telling you whether to stop your medication or change dose etc), as only you and your own healthcare team can

make those sorts of decisions (together) about your health. However, this does not mean to say we don't have a good knowledge of RA and the medications used for it, and we can talk you through this information, and potentially look at some of the options which may be available to you.

For example, you may have been given a choice of medications and given information on each drug. We could talk you through some of the differences between medications. We would not tell you which one to choose, but would aim to help aid you in making this an informed decision and perhaps having a clearer picture of what you might want to ask your rheumatology team.

## How many calls do you take in a day?

This can vary greatly. Typically each member of the helpline team might take between 5-10 calls in a day, and the average call time is around 15-20 minutes long. However, it is not uncommon to have calls that are up to around an hour in length. We don't want anyone to feel they have to be cut short in speaking to us, as sometimes people may have a lot of questions or a complex issue they need to discuss in detail. We are mindful, however, of the fact that too long a call can start to become less productive, as there's only so much information you can take in at once.

## What topics do you cover?

As I mentioned, we cover a very broad range of topics, so as well as discussing medication, we might also talk about the effect RA is having on someone's relationships and work, what benefits they might be entitled to, what research there has been either recently or more generally in RA etc. If we feel a query is outside of our expertise, we will also signpost you to some other great organisations that might be able to help you. We also have an extensive resource of publications and articles on a variety of topics, which we will often send out after a call. These can also be viewed, downloaded or ordered on our website.

## Who calls the helpline?

Most of the people who call our helpline are people who have, or suspect they may have RA, but we are here to support anyone affected, in any way, by the condition, so this can also include partners, friends, family and work colleagues.

It's a great privilege to work on the helpline. We speak to some amazing people, and it feels good to be able to help and support people over the phone, whether that's just by offering a listening ear, answering questions, improving understanding of this complex condition or helping someone to develop a plan to help them move forward.



# Dear Helpline

## Why do I feel so tired?

Extreme tiredness, known as fatigue, is unfortunately a common symptom of RA and many people say it's the one they struggle with the most, as there's no equivalent to a pain killer for fatigue.

When you have RA, a lot of processes are occurring in your body, including pain, inflammation and general disease activity, and all of this uses up energy and can make you feel very tired. This can be just one of the many reasons that people with RA experience extreme tiredness. Pain can make getting a good night's sleep very difficult, and low mood/depression, which is more common for people with long-term conditions to experience, can also contribute to fatigue.

So, since the reasons for fatigue in RA are complex, as you might imagine, the ways of managing it are also. Dealing with fatigue can seem overwhelming, and you may feel that making small changes won't make enough difference, but anything you do to gradually improve your fatigue will improve your quality of life. The following are some of the common strategies people use to help manage their fatigue, but everyone's fatigue is different, so it's important to find what works for you.

### Pacing out your activities

On days when you have more energy, it can be tempting to try to get more done, but you may find that if you do that, in the days that follow, you can feel even more tired. Pacing activities is undeniably hard to do though, as it is not always easy to fight our instinct to get a little more done while we can. Some people find keeping track of their activities helps. For example, if you have a set of activities to complete by the end of the week, you could try using a traffic light system to define the more difficult activities that take up a lot of energy (red), the quick jobs that require little energy (green) and the in-between (amber). Try not to have more than one red activity in a day.

### Sleep well

It's the most obvious reason for feeling tired, yet sometimes gets overlooked. Do you sleep all night, or does pain wake you up? If it does, perhaps having plenty of pillows to prop up sore joints could help, or taking painkillers just before you go to bed. If you consistently wake

at the same time, maybe that's become habit. If that happens, try not to reach for your phone or TV remote or make a late night caffeinated drink. If you can't get back to sleep, maybe get up and sit in the dark for a while and go back to bed. Stimulating your brain can make it much harder to sleep and more likely that your body clock will continue to wake you at that time.

### Diet and exercise

Eating a healthy diet and getting regular exercise can greatly help with fatigue. When you feel exhausted, sometimes exercise feels like the last thing you want to do, but if you build up the level you can do very slowly, you may be surprised at the level of improvement you see to your fatigue. Walking is a good activity to do, and easy to build up, as you can use landmarks (such as a tree, lamp post etc) to see how much further you are walking. Eating healthily is also important, and you should also aim to drink plenty of fluids throughout the day (preferably water), as dehydration is a common cause of tiredness.

### Medication

Whilst there may not be a specific pill for fatigue, it is still an RA symptom like any other, so make sure that you discuss this with your rheumatology team. It could be a sign that your disease is active and that a change of medication might be needed. Fatigue can also have other medical causes, such as anaemia, to which people with RA are more susceptible, so it could also be worth speaking to your GP about your fatigue.

If you're struggling with fatigue and want to read more about ways to manage it, have a look at our fatigue booklet, which covers this and more in depth. It can be ordered or downloaded at: [www.nrqs.org.uk/publications](http://www.nrqs.org.uk/publications)

The reasons for fatigue in RA are complex, as you might imagine, the ways of managing it are also.





## By Clare Jacklin

National Rheumatoid Arthritis Society CEO

# Cannabis for pain

## Hype or Hope?

While at the European League Against Rheumatism congress in Madrid in June last year, our Head of RA Services and I attended a lecture on the topic of cannabis and cannabis-based derivatives such as CBD cannabidiol

The use of cannabis based products to treat pain in RA is a topic that comes up regularly in discussions on Facebook and our online community HealthUnlocked so I thought it would be useful to share a summary of the lecture here.

The question is can medical cannabis be recommended as a new analgesic option in musculoskeletal conditions? The answer is not simple or clear-cut according to Professor Serge Perrot, Professor of Clinical Pharmacology at Paris Descartes University and a rheumatologist and Head of the Pain Centre at Cochin-Hotel Dieu Hospital, Paris. "All the meta-analyses (examination of data from a number of independent studies of the same subject, in order to determine overall trends) and literature reviews have demonstrated that, for example in fibromyalgia, in back pain, in neuropathic pain, "it was not very different from placebo." That said there are "specific clinical cases" where cannabis-based treatments may be useful on an individual basis, which "speaks in favour of authorising the products", said Prof. Perrot. He went on to say that emerging data suggests that cannabis-derived medicines may prove to be more effective for conditions such as anxiety, sleep disorders, and loss of appetite, rather than specifically for pain.

Dr Steve Alexander, Associate Professor in molecular pharmacology at the University of Nottingham Medical School, said that some of the effects – or side effects – of these medicines may be relevant to rheumatology patients. For example, the drowsiness that has been associated with some cannabis preparations could be beneficial, since improved sleep does affect

people's subjective scores of pain.

Dr Alexander in an interview with the Congress News said "We know there's a broader story, and that it's not just pain itself – it's all the ancillary things that go alongside it, such as anxiety, depression, comorbidities, and so on. I think therefore, that the message is one of tentative hope"

According to Dr Alexander there was in the order of 85 registered clinical trials for cannabinoids in a variety of conditions being conducted and if only a modest proportion of these trials prove to be successful, he suggests "that's quite a major advance".

While the lectures from both Prof. Perrot and Dr Alexander were quite complex and scientific my big take home message was that there is still a huge amount of research required and it is not as simple as some messaging on social media would have you think. I feel that far more clarification is required when talking about cannabis as there are many different varieties of cannabis plants and products out there. There is a massive difference between medicinal cannabis and what some chap in the pub may offer you in a little plastic bag! In a recent Time magazine article, I also read that only 31% of CBD products that were tested actually had the amount of CBD in them that they claimed on their labels!

In conclusion, NRAS will keep a watchful eye on developments in this controversial topic but as it stands today our position is that there is still no proven scientific evidence of benefit for those living with inflammatory arthritis. I would highly recommend that extreme caution should be taken when purchasing any CBD products or indeed any other 'complementary' products, online or via high street retailers without due-diligence and research into the producers of the product and always tell your rheumatology team what you are taking alongside your usual RA medication/s.

Footnote: In the US the FDA (Food and Drug Administration) has taken action against some CBD manufacturers making specific condition-related health claims, however many companies are still unabashedly marketing products as curatives. In short this is big business and it will take some time to bring in proper regulation to ensure safety.





## My Story

# Alice Dyson-Jones

"You probably need to slow down a bit, you had a sinus operation last month and your back and shoulders are the stiffest I've ever seen them. You need to give your immune system a chance to do what it's meant to do, and you should see your rheumatologist, your meds may need adjusting... good news though, your tennis elbow is much better, I'm signing you off."

My physiotherapist had just delivered good news, but it still feels like a killer blow, my joints are sore and I'm stiff all over, I feel like I'm 100 years old today. I need my meds to work for me, I don't want to hear they may not be doing the job as well as I expect.

"What about yoga, would that help?" I ask, she smiles. "What about sports massage?" she sighs.

"You're the highest level athlete I see at this clinic, your body needs to catch up with you, congratulations once again." I leave the clinic to go to work pondering a new plan.

I was diagnosed with Rheumatoid Arthritis on 1st December 2011 at 9am. It was -2 and I was wearing a pair of flip flops, the only shoes my poor feet could bear...rain, shine or even snow. I'd shuffled around for the past three months, unable to do my trousers up, fasten my bra, or pick up my 6 month-old daughter. It felt like someone had injected crushed glass into my blood and stolen my life.

The consultant explained... I'd had some blood tests... my rheumatoid factor was over 1000, over 15 is considered elevated. I had also tested seropositive. It was undisputedly Rheumatoid Arthritis.

"What about hockey I said...I play hockey." She looked at me, slightly surprised that this was my first pressing question.

"Do you play for England?"

"I wish." I replied.

"We need to concentrate on getting you better first. We'll get you started on a drug combination therapy as soon as possible."

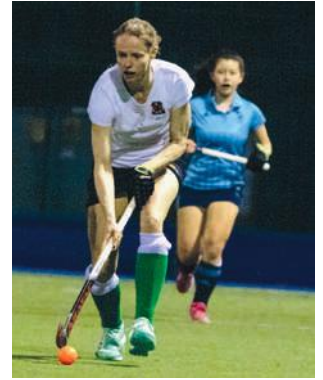
"Will I be able to play again?" she smiled and gave me a steroid injection in my left buttock.

As I left the clinic, I made a mental note, I had just fast tracked this consultant to 'very important person in my life' status. She had a treatment plan for me, and I'm a girl who loves a plan.

In 8 years a lot has happened. I've been pumped full of more medicine than I care to think about, I've nearly died from neutropenic sepsis, I've had over 40 antibiotic prescriptions and now I'm sitting at my desk, downloading the app 'TEAMO' which is 'The all-in-one online management platform & mobile app for sports teams & clubs.' The ENGLAND MASTERS Hockey logo appears in view...I catch my breath...it looks like I did make it into the England Masters Hockey team after all. I smile and want to cry at the same time. I must remember to drop my consultant an email, I know she'll be thrilled.

The life I have now has changed beyond recognition. I've worked hard to educate myself about the disease, to try to make the ghost that hides under my skin my friend. I have looked for the gifts in the darkest of days, and I know that I am more determined than ever to pursue the dreams that really matter to me. In September I have been invited to Jersey to play for an Intergenerational England Squad, the Lionesses.

I may have Rheumatoid Arthritis, but it is not what defines me.



By Alice Dyson-Jones

"She had a treatment plan for me, and I'm a girl who loves a plan."



# Raising awareness of RA amongst politicians

Over 300 people emailed their MPs, MSPs and AMs to inform them about RA and the impact it has on people's personal, family and working lives



During this year's RA Awareness Week, NRAS took an increased focus on raising awareness amongst people who can make a real difference to the lives of people with RA and JIA: our politicians.

Over 300 people emailed their MPs, MSPs and AMs to inform them about RA and the impact it has on people's personal, family and working lives. Many people shared their responses from their politicians with us, and it's great to see that we are raising awareness amongst politicians; some of whom did not know what RA is!

A motion was put in the House of Commons praising the work done by the charity in raising awareness of RA and calling on the UK Government to do more to improve the access to effective medicines and mental health support; 25 MPs signed the motion. Another motion was put in the Scottish Parliament recognising the importance of early diagnosis and the need to raise awareness; this was signed by 21 MSPs.

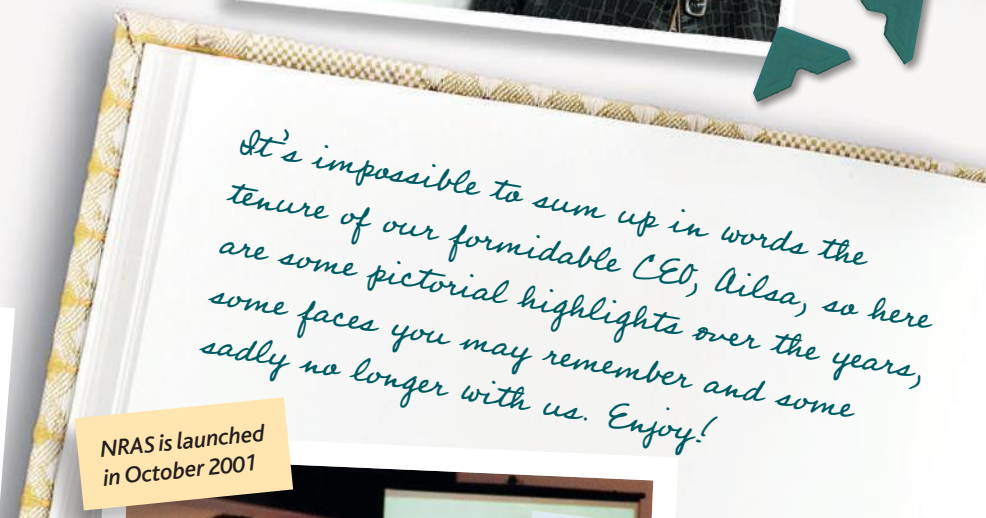
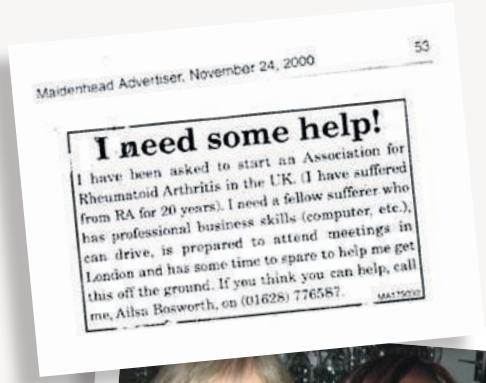
Many other politicians shared their support on social media or on their personal websites. Nine MPs raised important issues to Government Ministers, meaning that our campaigns are being heard right at the heart of Government.

If you would like to get more involved in our campaigning work, let us know! Email us at [campaigns@nras.org.uk](mailto:campaigns@nras.org.uk)





# Celebration & highlights of the last 18 years with Ailsa Bosworth CEO



NRAS is launched in October 2001



Ailsa & Gloria with 'Charitable Organisation of the Year' award



I would just like to pass on my thanks to her for all she has done. She very kindly came and spoke at our NRAS group some years ago which I remember very clearly. I have also been lucky enough to meet her at other functions too.



I am sorry to hear that Ailsa is stepping down but quite understand as she has worked so hard for people with RA, setting up NRAS over the years whilst coping with her own problems.



Nicky Kennedy, Sue Oliver, Maggie Carr, Liz McIvor and Vicky Chamberlain



Rt Hon Theresa May MP and the NRAS team



Ailsa and the original Ronettes at an NRAS Christmas concert







She has achieved so much over the years and helped so many people and leaves behind a wonderful legacy in NRAS. Long may it continue.



10 Downing Street reception for charities in Berkshire – Nov 2018



10th Birthday with Trustees from left: Wendy Garwood, Sue Ball, Andrew Kennedy, Mark Liddell and Di Skingle



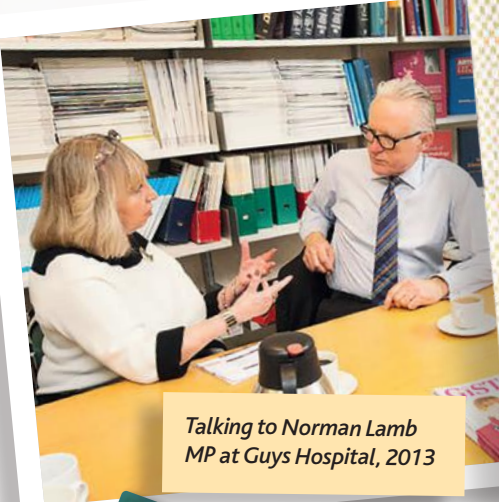
Welsh Assembly 2012



Ailsa and Jeremy Vine on BBC Radio 2 – July 2014



NRAS 10th Birthday, 2011



Talking to Norman Lamb MP at Guys Hospital, 2013



Ailsa & Prof David G I Scott at Great North Run in Ailsa's wheelchair





Prof David G I Scott with Ailsa and Linda Riordan, former MP for Halifax

I was delighted to learn of Ailsa's MBE, I am writing to say how deserving she was, I so admire her in every way – despite her many years of coping with RA.



Ailsa receiving her MBE – April 2016



BBC local radio interview during RA Awareness Week



She has achieved so much since the early years of NRAS and so many patients (including myself) have benefitted in numerous ways. She is an inspiration to us all and still continues to work on our behalf day to day combined with all your staff, our lives our made more bearable.

er completing elchair



NRAS guests with Philip May, inside the No 10 Downing Street reception – Nov 2018



Diwali dinner and dance with Mayor of Slough and Kanta Kumar – November 2018



The NRAS Ronettes; Ailsa, Lorraine and Emma at the NRAS Christmas Concert 2018

May I add my grateful thanks to her for giving me the opportunity to help run our local group with all the support needed to support a lot of people over the years. I am sure she will continue to do great things as a National Patient Champion. She is an incredible lady and works so hard. Long may she continue.



Ailsa at her 'not retiring' do!



Celebrating #WearPurpleforJIA 2019



Could I also pass on my congratulations and best wishes to Clare in her new position as CEO of NRAS. I am sure she will do a great job.



Some of our wonderful Scottish Ambassadors past and present with NRAS Scottish Patron, Prof. Iain McInnes CBE



Ailsa was presented with a commemorative book, showing how it all began with an ad in the Maidenhead Advertiser



NRAS staff with Theresa May





# Elephant in the room

Scottish Parliament Reception at Holyrood



By Sheila MacLeod

Chair of the  
Scottish Ambassadors



Matt Bezzant and Iain McNicol from NRAS pictured with Liz McKay-Saville (L) and Sheila MacLeod (R)

The Scottish Parliament Cross-Party Group on Arthritis and Musculoskeletal Conditions – of which NRAS is an enthusiastic member – hosted this event on the evening of 15th May in the Garden Lobby at Holyrood. Matt Bezzant and Iain McNicol attended from Maidenhead joining a number of Scottish ambassadors, volunteers, supporters and friends. The CPG's other constituent organisations were well represented also, along with their guests. The resulting company made for an interesting evening with many good and worthwhile conversations to be had.

You may be wondering about the catchy title of the event? I have to say the reason for calling it 'Elephant in the Room' was never quite clear, even to those present! But if it implied a group of serious health conditions affecting very large numbers of people yet insufficiently recognised and acknowledged, this occasion did much to confront these issues head on. The speakers were splendid, compelling and hard hitting. Professor Iain McInnes, Director of the Institute of Infection, Immunity and Inflammation at Glasgow University, an international authority on the pathogenesis and treatment of inflammatory arthritis who heads a hugely influential research programme – and is also NRAS patron in Scotland – spoke with his usual charm and shining conviction on the revolution in therapies which has taken place in recent years and exciting prospects for the future. Under the heading 'How bad does it get?' Professor Colin Howie of the Department of Orthopaedic

Surgery in Edinburgh University, consultant orthopaedic and trauma surgeon and past president of the British Orthopaedic Association, tackled, with impressive directness, the issue of rapidly growing waiting times for orthopaedic surgery. He demonstrated just how bad things have become in terms of human suffering through the frank and articulate accounts given by a number of his patients. This made an eloquent case for action and intervention. Response from the Minister for Public Health and Sport, Joe Fitzpatrick MSP, sought to be reassuring, but the overwhelming impression was that steps surely needed to be taken to provide better and swifter access to what we know to be cost-effective and life-changing surgeries.

The CPG, under its convenor Brian Whittle MSP meets again on 11 September and the agenda then will include a presentation from NRAS based on Scottish data drawn from the Emotional Health and Well-being Matters report published in November 2018. We welcome this chance to highlight an important issue for people living with RA, and indeed many of the other conditions covered by the CPG, to focus on its Scottish dimension and to flag up implications for influencing Scottish health policy.



# Rheum For You



If you haven't had a chance to attend one of our Rheum for You mini conferences, we would encourage you to look out for details of upcoming events to see when we might be coming to a location near you! We book health professional keynote speakers who present the latest information from the world of rheumatology and, where possible, bring you updates from the regional Volunteer Ambassadors, plus the opportunity to meet some of the NRAS team. Coming to an NRAS Rheum for You event is also a great way to meet others living with RA and their relatives and make new friends. Cost constraints only allow us to hold three events a year, with one annually in central London, plus two other locations. Over the last few years we have held events in Nottingham, South Gloucestershire, Swindon, Durham, Cardiff and Manchester.

The Manchester Rheum for You mini conference in March was very well attended with a waiting list for spaces and attendees came from as far as The Lake District! Clare Jacklin, NRAS CEO gave an update on all the latest news from NRAS, followed by **Dr Katie Druce, Research Associate**, who presented details of the Sleep in RA study they have been conducting at the Arthritis Research UK Centre for Epidemiology in Manchester. The second keynote talk of the day was presented by **Dr Meghna Jani, NIHR Academic Clinical Lecturer, University of Manchester and Honorary Consultant Rheumatologist** at Salford Royal Foundation Trust, who discussed the benefits and harms of medicines used in rheumatoid arthritis.

We had two interesting talks from  
**NRAS Manchester**

**Ambassadors Chris and Ralph** on their journeys to becoming Ambassadors and the work that they have been involved in so far, and we were also treated to a Tai Chi taster session from **Anne Crichton, Senior Trainer from the Tai Chi for Health Institute**, followed by a talk about the benefits of Tai chi and how it has been adapted to be safe for those with limited mobility. **Two Occupational Therapists, Catherine and Lucy from Salford Royal Hospital**, gave up their Saturday to set up a table full of gadgets and talk to attendees in the breaks and let them try items out for themselves.

On Saturday 22nd June, the annual **Rheum for You** mini conference took place in London – this was the fourth year we have held this event in London due to its continued success! Places were all fully booked for an afternoon of expert speakers. We were thrilled to be joined once again by keynote speaker, **Dr Frances Humby, Senior Lecturer and Honorary Consultant Rheumatologist, Centre for Experimental Medicine and Rheumatology, Queen Mary University of London and Barts Health NHS Trust** (who presented at the very first Rheum for You in London back in 2016). Dr Humby presented a fascinating overview of: 'Understanding autoimmunity and rheumatoid arthritis: disease triggers to effective therapies'.

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www.nras.org.uk

**Changing Minds  
Changing Services  
Changing Lives**  
for people living with  
Rheumatoid Arthritis and  
Juvenile Idiopathic Arthritis

We're here for you when you need us

Contact NRAS  
**0845 458 3969**



The presentation raised many interesting questions and points of discussion with everyone who attended.



The second session of the day was all about getting involved in research and saw two representatives from the National Institute for Health Research, **Caroline Hing (Consultant Orthopaedic Surgeon, St George's Hospital London)** and **Dr Cristina Tacu (Consultant Rheumatologist, Brighton & Sussex University Hospital)** joined by **Sandra McKinnon, Patient Research Ambassador**. They delivered an excellent multi-faceted talk looking at how patients can change the focus of research in the field of rheumatology and Sandra shared her

experiences of the trials she has been involved in to date, despite only having a diagnosis of RA since 2018. One attendee said: 'Thank you so much for arranging this event, I found it very informative and I liked the relaxed atmosphere and the chance to ask questions'.



The next Rheum for You mini conference is coming to Exeter on Saturday 9th November. To book your place please visit our website: [www.nras.org.uk/rheum-for-you](http://www.nras.org.uk/rheum-for-you)

A great way to meet others living with RA and make new friends

## Other ways to give

### Company Giving

No matter how big or small your company is, there are several ways it can support the National Rheumatoid Arthritis Society (NRAS) and the work we do to help all those in the UK living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA). With a charity partnership company colleagues can have fun and take part in fundraising, volunteering activities and sport/challenge events with charity places in prominent runs and cycle rides across the country including Ride London 100, Brighton Marathon and Royal Parks Half Marathon. To discuss becoming a corporate partner contact our fundraising team on **01628 823524** or email us at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk).

### Payroll Giving

Payroll giving is the most tax-efficient way to donate to NRAS. For example, a

£10 a month donation would only cost you £8 because payroll giving donations are deducted before tax. You can donate any amount and can stop your donation whenever you like. To find out how you can sign up to payroll giving contact our fundraising team on **01628 823524** or email us at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk).

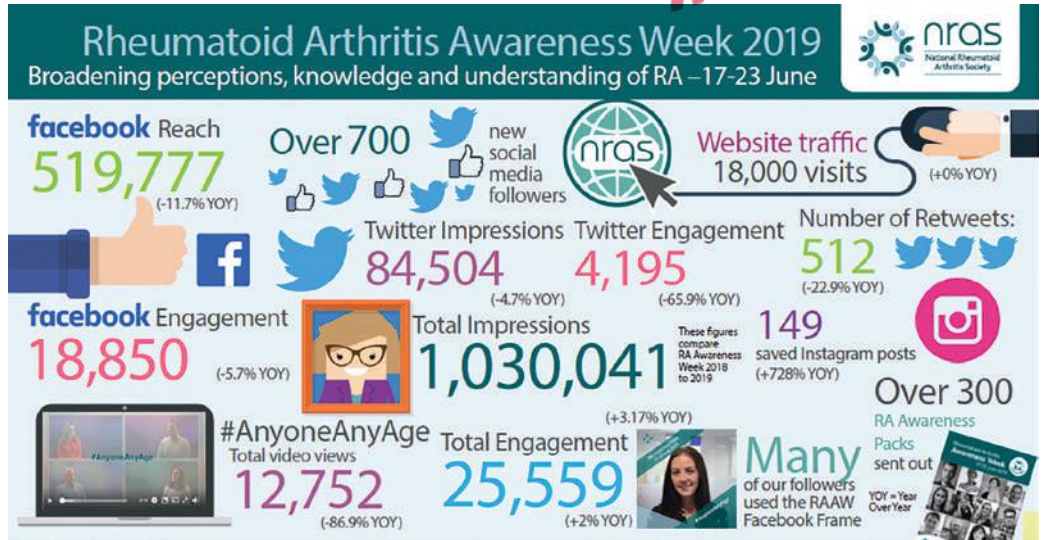


Tickets bought in the NRAS lottery help the charity to continue supporting those with RA and JIA in the UK and give you a chance to win £25,000 each week! You can sign up to the NRAS lottery online at [www.nras.org.uk/lottery](http://www.nras.org.uk/lottery) or call the Unity Helpline on **0370 050 9240**.



# RA Awareness Week 2019

## #RAAW



Julia Matthews and her husband organised a beach run on Gwithian Towans in Cornwall

Throughout RA Awareness Week (RAAW) 2019 we challenged the misconceptions of 'arthritis' being a condition of the elderly or associated with ageing. This is the 6th year RAAW and we would like to say a huge thank you for spreading the message far and wide, making a significant impact on people's understanding and perception of RA.

Many of our NRAS groups, healthcare teams and supporters also held Fundraising events and together have raised £3,780 so far with money still coming in. There were tea parties, street and supermarket collections, Facebook Fundraisers, street parties, beach runs at much more! Lots of you sent some fabulous photos in of your activities but if you haven't yet done so, do send them into us at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk) as we are always looking for images that may inspire others!



Worcester Group RA Awareness Group stand at Worcester Hospital



Altnagelvin Hospital & North West NI NRAS Group

Four hundred and thirty four RA Awareness Week packs were requested and sent by both individuals, NRAS groups, healthcare professionals and rheumatology units. Thank you to everyone who held an information stand and helped raise awareness of the disease and the services that NRAS provides.

Thank you to our social media followers who interacted with our posts, shared infographics, added the RAAW frame to their profile picture and shared their image of when they were diagnosed – there were some many amazing stories!



Eleanor and the North East Group had their big red bus return to the centre of Newcastle







Julia Mathews' beach run



Ria Bedford organised an awareness and fundraising event at the Avenues Pub in Great Yarmouth



BSR colleagues with the Facebook frame



Connie Cluderay and the Facebook UK Rheumatoid Arthritis Wonky Group held their annual meet up in Wolverhampton and raised funds through a raffle, quiz and clothes swap

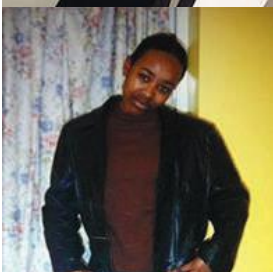
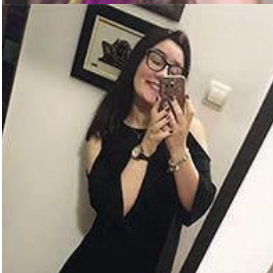


Arrowe Park Hospital



Julie Black organised a tea party in her garden





Willy Bollschweiler did a street collection in Lindfield and kindly matched all donations made.



New Cross Hospital



St Luke's Hospital



Christina sharing her story of #AnyoneAnyAge



Poole Hospital

# #AnyoneAnyAge



# Gum Disease & RA

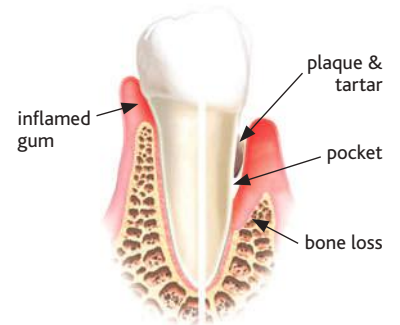
It has long been thought that gum disease might be linked to rheumatoid arthritis. Historically, this came from anecdotal reports on the levels of gum disease and other dental problems seen in RA patients. More recently, similarities in the way the diseases manifest themselves and the cells involved in the inflammatory processes of the two conditions have also been noted.

To try to determine the level of evidence for this link between gum disease (also known as periodontal disease) and RA, researchers have examined the findings of a number of studies from previous years, covering more than 100,000 participants with RA. They found that, compared to healthy controls, patients with RA were significantly more likely to have gum disease.

It is not known why gum disease is more common in people with RA. One theory is that inflammatory cells present in gum disease might get into the person's circulation, increasing the levels of systemic (meaning throughout the body) inflammation. However, interestingly, when researchers looked at studies that compared gum disease in RA patients and patients with osteoarthritis, which is not an auto-immune condition, they found that there wasn't a significant difference in the levels of gum disease between these two groups.

It seems likely that further studies will continue to take place in this area, to help scientists to better understand the correlation between RA and gum disease. To find out more about oral health and RA, please visit [www.nras.org.uk/oral-health](http://www.nras.org.uk/oral-health)

## Gingivitis | Periodontitis



# Low uptake in vaccination rates among RA patients

RA patients have a 1.5-2 fold higher risk of being hospitalised due to infection. Risk of infection is higher in RA patients due to a compromised immune system and particularly high for those on biologic therapies and vaccination is known to reduce this risk. Vaccinations, such as those for pneumonia and influenza are known to have the potential to reduce the risk of serious infection. For example, one study, which looked at over 3000 patients with RA who received regular vaccinations and the same number in a control group with RA who were not vaccinated, found that RA patients vaccinated against influenza, had a reduced risk for being hospitalised for septicemia, bacteremia, or viremia and a lower mortality risk.

Yet, a study in the US showed that only 53% of

RA patients surveyed had ever been vaccinated against influenza, and just 29% had received the vaccination 2 years in a row.

A recent analysis of studies into vaccinations in patients with RA has investigated some of the reasons for low vaccination rates. Only 5 of the 450 studies examined, met the criteria to be included in the review, which found a mean average of 17% increase in the number of vaccinations after intervention. Interventions included educational sessions, email reminders etc. However, this review was focused more on the patient's behaviour being the reason for poor vaccination uptake, and the researchers have suggested that more needs to be investigated in looking at the provider's behaviour.



# Managing osteoporosis in RA

RA patients can be at greater risk of osteoporosis, as a consequence of steroids used to help treat their RA. A study, that examined how adequate the 2003 and 2014 French guidelines were for the prevention of steroid induced osteoporosis, found that only a small percentage of those in need of treatment to prevent osteoporosis had actually received it.

The study, which found similar inadequacies for preventing steroid induced osteoporosis in postmenopausal women, looked at 776 patients

with RA. Worryingly, the study found that only 27% of those who should have received anti-osteoporosis treatment under the 2003 guidelines actually received it, and only 24% under the 2014 guidelines.

Whilst healthcare systems obviously vary from country to country, the findings of this study do show the importance of ensuring that the risks of osteoporosis to those being given steroids for RA are taken seriously and that anti-osteoporosis medication is given where appropriate.



# NRAS Challenge Events

## Elodie & Cat, two sisters take on the Kilimanjaro Trek

21st Feb-3rd March 2019

"WE DID IT!!!! By far the hardest thing either of us has ever done but wow what an incredible experience! Massive thank you to everyone who has sponsored us on this epic journey, we truly appreciate the support and the money will be gratefully received by NRAS.

RA runs in our family and we wanted to raise awareness as well as much needed funds for support."

Total amount raised **£6,145**



## Brighton Marathon

Sunday, 14th April 2019

A Huge thank you to all the NRAS Runners! It was a windy day, but the sun was shining for us!

Fraulein Smith, Matthue Levitt, Nadia Muncey, Kirsty Harmer

Total amount raised

**£2,771**



## Cerys Newman was gifted a Skydive for her 18th birthday and then was diagnosed with RA 20th April 2019

"The last two years have been filled with ups and downs, with days or even weeks where I could not leave my bed due to physical pain, fatigue or medication side effects. Now, two years on, I am slowly beginning to figure out how to deal with RA.

Therefore, to celebrate I have decided – for my 20th birthday – to do a charity skydive to raise money for the National Rheumatoid Arthritis Society (NRAS). NRAS is a charity that aims to support, educate and empower those affected by RA."

Total amount raised **£923**







## London Marathon

Sunday 28th April 2019

NRAS would like to thank all the NRAS Runners who took part in the London Marathon this year.  
**Toby Jarvis, Steve Kulski, Casey Pacitt**

"I'm going to be running/jogging/crawling the London marathon on 28th April to raise money for NRAS (National Rheumatoid Arthritis Society). Rheumatoid Arthritis runs in my family and so doing this has a lot of personal meaning for me. Both my younger sister and cousin have grown up with this widely misunderstood illness. It's well-known in older people but can also strike at an early age. It's extremely debilitating with no cure and lacks social awareness due to the invisibility of its pain to others." – Steve Kulski

Total amount raised **£6,193**

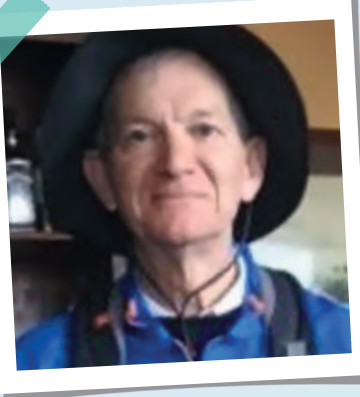


## Vitality 10k

Monday 27th May 2019

NRAS would like to thank all the runners who took part in Vitality 10k this year.  
**Kelly-Marie Staunton, Amy Davis, Mark Roberts, Anouk Milne**

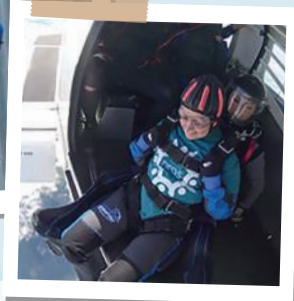
Total amount raised **£2,321**



## A great big thank you

to **Eric Rush** who took on the challenge to **walk 70 miles from Reading to Bath** for his 70th Birthday on the 13th April 2019.

Total amount raised **£4,040**



## Lowri Wynn Morgan Skydive

31st May 2019

"Jumping from an Aeroplane for National Rheumatoid Arthritis Society (NRAS) because I want to raise awareness for RA and JIA."

Total amount raised **£1,520**





Torbay NRAS Group handing over a cheque for £250 to Kim Fitchett from NRAS

# NRAS Groups

## Torbay NRAS Group

The Torbay NRAS Group would be delighted to welcome new members. The group was started by six Volunteers in 2017, all of whom have a diagnosis of rheumatoid or inflammatory arthritis.

Our aim is to bring together people who suffer from these chronic conditions. We arrange a variety of speakers as well as a chance to meet socially and support one another.

The group meets once every other month at Barton Baptist Church in Torquay, it's only a £2 entrance fee and we provide refreshments and a raffle to raise funds. Attendees are welcome to bring partners, a family member or a friend along if they wish.

Kim Fitchett, RA Services Engagement & Outreach Supervisor from NRAS recently came to speak at one of our meetings and we presented her with a cheque for £250, that we were delighted to donate to NRAS.

We have developed strong links with Dr Mackay and the rheumatology staff at Torbay Hospital and hope that our group will be able to provide some extra support and information for people living with RA. We have had some very varied and informative talks since we set the group up, ranging from managing fatigue, Tai Chi for RA, biological therapies for RA and psoriatic arthritis, mindfulness and many more!

In 2018 we consulted our members on what type of talks they would like in the future. We were pleased to be able to present a varied programme to assist in the management of rheumatoid and inflammatory arthritis. All our meeting dates and talks are at [www.nras.org.uk/groups/torbay-nras-group](http://www.nras.org.uk/groups/torbay-nras-group)

## Gwent NRAS Group

We started about three years ago after Dr Maddy Piper, a local rheumatology consultant, asked NRAS for help with setting up a local group. We now meet on a Saturday morning, alternate months from January onwards. It runs from 9.30am to around midday - and we can use the Caerphilly Library seminar room for free (and their computers too!). We often have a speaker at meetings, but it is informal with plenty of time for chat, coffee and, of course, a raffle to raise funds.

The range of subjects we have covered has been very wide. One of the best sessions was the 'laughter therapy' session which made us all feel so much better and made us realise how important it is to laugh! We have had seated yoga, Tai Chi, eating healthily, Nordic Walking, a pharmacist and the occupational therapists. We usually have interactive sessions on the various ways (both mainstream and supplementary) of dealing with

our illness and preparing for appointments. We have also used the library computers to learn how to track down reliable information.

The main benefit has been the feeling that everyone there knows how you feel – and learning about what will help. The more experienced members can give the more newly diagnosed help with navigating the tortuous avenues of the NHS, and support as they come to terms with the diagnosis.

We cover a very large area – the old county of Gwent – as much of the area is rural, and we welcome anyone from other areas. You can find details of our upcoming meetings at [www.nras.org.uk/groups/gwent-nras-group](http://www.nras.org.uk/groups/gwent-nras-group)

## Oxford NRAS Group

NRAS would like to congratulate the Oxford NRAS Group who recently celebrated their 10-year anniversary at a special meeting held on 14th May. NRAS Chief Medical Advisor, Professor Peter Taylor was the keynote speaker for the evening and presented an update on treatments for RA over the last 10 years. Well done to Group Coordinator Sue and her fellow Volunteers for reaching this milestone and a huge thank you to the rheumatology team and health professionals from the Nuffield Orthopaedic Centre in Oxford for supporting the Group over the years!

## Greater Glasgow & Clyde NRAS Group

The group was established in 2015 and we now hold our monthly meetings in the community room at Tesco in Rollox, Springburn Glasgow. Tesco supply the premises to us free of charge as well as tea, coffee and biscuits and there is a wealth of parking facilities with plenty of disabled bays as well.

We meet on the last Thursday of the month when we invite a guest speaker to come along and talk about various topics. We are well supported by the local health board promoting our group as well as attending our meetings to give practical support and presentations. In the past we have had representation from various departments including podiatry, physiotherapy, orthotics, occupational therapy and consultant rheumatologists. We cannot function without the support of our speakers and we are very grateful to all who come along.

We have a core group of around 15 people, but this can increase if a topic appeals to a wider audience. Full details of our meetings can be found [www.nras.org.uk/groups/greater-glasgow-clyde-nras-group](http://www.nras.org.uk/groups/greater-glasgow-clyde-nras-group) and we also have a dedicated Facebook page, [www.facebook.com/glasgowrasupport/](http://www.facebook.com/glasgowrasupport/)



Oxford NRAS Group have recently celebrated their 10-year anniversary



# Edinburgh and Lothians NRAS Group Launch – 3 September 2019

The launch of the new NRAS Local Group for Edinburgh and the Lothians will take place on Tuesday 3rd September 2019 in the Scottish Health Services Centre (SHSC) on Crewe Road South, Edinburgh EH4 2LF. Registration and refreshments from 5.30pm, with talks to start at 6pm and the event will end at 7.30pm.

There will be a keynote talk delivered by Naomi Scott, Lead Pharmacist for Rheumatology at NHS Lothian on 'What's New in Rheumatoid Arthritis', followed by a Q&A panel with members of the Rheumatology Team from Western General Hospital.

Kim and Tracy from NRAS will co-host the event with representatives of the NRAS Scottish Campaigns Network, who will also be presenting an update. ALL are very welcome to attend this FREE event including NRAS Members & non-Members, family, carers, friends and health professionals.

This event is now only a short time away, so if you haven't registered yet please contact Kim at NRAS as soon as possible on **01628 823 524** or email [groups@nras.org.uk](mailto:groups@nras.org.uk)



## Right Start Service

The NRAS New2RA Right Start programme was launched at this year's British Society for Rheumatology Annual Conference in Birmingham on 2nd May.

The project provides health professionals with an easy online referral form to give rapid access to NRAS support and self-management resources for their patients. The referral process is simple and quick and conforms with GDPR information sharing regulations. The programme comprises of four simple steps:

- 1. Referral**
- One of the NRAS team arranges a date and time for a **call from our Helpline** – this could be up to 45 minutes or more, as needed
- Following the call with our Helpline, a **completely tailored package** of information – both hard copy and online resources – is sent to the individual. This can include our New2RA pack, sign-posting to our apps, webinars, publications and ways of accessing our HealthUnlocked online peer support community (available 24/7)
- Finally, a **telephone call with one of our trained peer to peer support volunteers** who has lived experience of RA can be arranged.

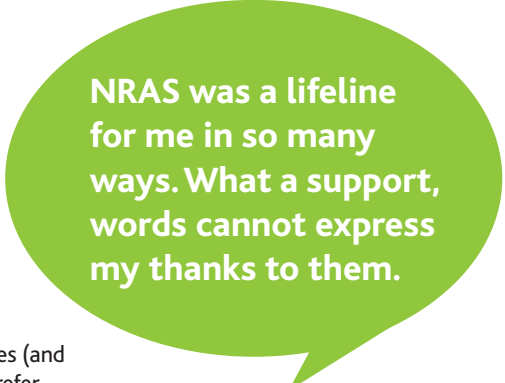
The programme has been developed to ensure newly diagnosed patients have rapid access to

support and self-management services as set out in NICE Guideline NG100 and NICE Quality Standards, which state that patients should be provided with access to education and self-management resources within one month of diagnosis.

The programme ensures that specialist nurses (and other health professionals) can confidently refer patients knowing they will be accessing high quality, evidence-based information and resources, supporting the newly diagnosed patient early in their journey.

Feedback to date has been excellent. People accessing the service have responded very positively to receiving a call, and like the fact that the service is reaching out to them, as opposed to them having to find the right sources of help themselves when they may be feeling somewhat overwhelmed by the diagnosis. This model embraces principles of personalised care, and tailors our offering to the needs and requirements of the patient. It is a bespoke service rather than a one size fits all approach.

Referrals have been steady from many hospitals, with Guys and West Middlesex topping the referral list!



NRAS was a lifeline for me in so many ways. What a support, words cannot express my thanks to them.



### BREAKING NEWS

NRAS is looking for more Telephone Support Volunteers to join the Right Start programme and offer peer to peer support. If you have been diagnosed less than 10 years and are doing well on Methotrexate alone (by tablet or injection)

then we would love to hear from you. Full training and support will be given to anyone joining this role.

Please email [volunteers@nras.org.uk](mailto:volunteers@nras.org.uk) or call us on 01628 823 524 for more information.



# Racing driver Josh Stanton

partners with NRAS to help raise awareness!



**Nineteen year old racing driver Josh Stanton, has recently partnered with NRAS, to help raise awareness in memory of his late grandma.**

Josh was incredibly close to his grandma who passed away in 2013. At her funeral she had kindly asked for donations to NRAS.

Josh felt he had overlooked the opportunity to raise awareness for a charity that was so close to his grandma's heart, a charity that had helped her in her moments of need.

Anne Stanton, Josh's grandma, suffered from Rheumatoid Arthritis and Josh saw the toll this took on her. 'She was a very athletic, enthusiastic and energetic grandma! Her arthritis really took a toll on her ability to do all the things that she wanted. She had been an amazing golfer and I wished that I could've played with her! To me, it is reassuring to know that she had the help and support from such an incredible charity in her

times of need, and for that, I can't thank you guys enough!

'It is so important to me to do anything I can for NRAS, they are a fantastic organisation and I can't thank them enough for all they did for grandma. When composing my sponsorship portfolio for my racing, I suddenly thought of raising awareness through brand representation at my races and on my car.'

Josh's JCW MINI Challenge race car bears four NRAS logos in prime positions and Josh also shares information about us at his races!

Josh's races can be seen on Channel 4, YouTube, Facebook and from next year live on ITV. He is doing well in this his first season and is looking promising for the future!

NRAS is incredibly grateful to Josh for his support. Helping to raise awareness is a vital part of what we do as a charity and his help has been invaluable.



## NRAS Trustee

# Richard Boucher takes on the Great East Swim



**Richard Boucher first came across NRAS when he was diagnosed with RA in 2015, visiting the website to understand more about the condition. Recognising the benefit NRAS gives to those newly diagnosed and living with RA and JIA, Richard was keen to support and contribute to our work.**

Richard has been working to support all those in the UK

living with RA and JIA for the past three years as an NRAS Trustee.

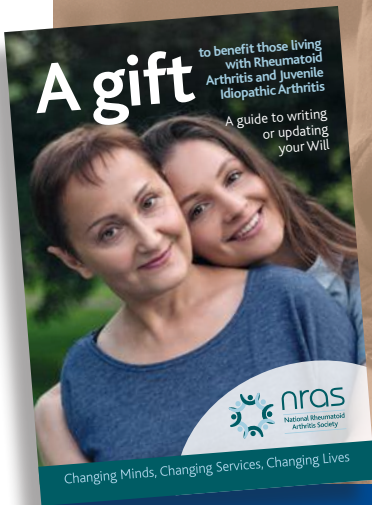
Since diagnosis, Richard has continued to try to remain fit and active as a way to maintain energy levels. Having taken up swimming again last year, he set himself the goal this year to swim in the Great East Swim. On 22nd June 2019 Richard participated in his first open water distance swim since being diagnosed four years ago, Richard has raised an incredible £1,150 in sponsorship for his swim!

Well done and thank you Richard for your continued commitment to NRAS and for all your work to help NRAS carry on supporting those living who need us.





# Remember to "Pass on something wonderful" BY LEAVING A GIFT IN YOUR WILL



## Pass on something wonderful to benefit others by leaving a gift in your Will to NRAS

Leaving a gift in your Will can have a huge impact on people's lives, ensuring NRAS services are there for all those who need us for years to come. To mark **Remember a Charity in Your Will Week** and to help you with writing your Will, NRAS has created a useful guide with the support of **Parfitt Cresswell Solicitors**. If you are thinking of writing or updating your Will we hope this guide will help you.

Wills are very important and are the best way to ensure your wishes are carried out as you would like, and that those you care about are remembered in the way you want. Leaving a gift in your Will can make a huge difference and the impact of leaving a charitable bequest means that many people will benefit from your generosity in a very meaningful and lasting way.

It is because of gifts in Wills left to NRAS by people like you that our services continue to support all those who need us and continue to adapt to best meet the needs of those we help.

If you would like to speak with someone about leaving a gift in your Will to NRAS, please contact the NRAS legacy team on **01628 823524** or [legacy@nras.org.uk](mailto:legacy@nras.org.uk)

**REMEMBER A CHARITY  
IN YOUR WILL WEEK**

**9-15 September 2019**



NRAS is hosting a one-hour webinar with a legal professional from Parfitt Cresswell Solicitors. This will be an opportunity for you to find out more about writing or updating your Will and to ask any questions you may have.

To register visit [nras.org.uk/webinar](http://nras.org.uk/webinar)



Anne with Sandra Watson

## Anne Gilbert joins a special “Taplowites” reunion

On Saturday 8th June I spent most of the day with an amazing group of people at the Genting Hotel in Birmingham. I was invited to the first reunion of the “Taplowites”. All the members were former residents of the JIA Canadian Red Cross Hospital in Taplow in the 1950s to 1980s.

I was given a booklet which all the parents of the children who were at Taplow received on admission and it's scary reading! Reading this book made me very aware of how much paediatric rheumatology has improved in every way.

It starts off... *This is about Stills' disease* (now more commonly known as systemic onset JIA, juvenile idiopathic arthritis). The first page shows two children, with very twisted and swollen joints to their elbows and knees. Here is an extract:

*John is much worse off. When he was three, he was as bonny, active and happy a child as anyone could wish, and there was no noticeable cloud on his own or his parents' prospects. He is now 14, and after an illness lasting on and off for 11 years he is stunted in growth, crippled by stiffness of his neck, hips and knees. Mentally he is very much alive, and able to develop his intelligence at a special school.*

*He is lucky that the disease has not injured his eyes, so he can learn by reading more easily than some of his fellow patients. Though bed-ridden for much of his life, he can now, after intensive treatment, walk with the aid of sticks. But he still needs some help with his eating, washing and dressing. And his future is uncertain.*

*Where his joints have fused, they will remain fixed. He will not grow normally; he will not enjoy the full independence in everyday life that most of us cherish. Still's Disease can do all that and worse.*

The booklet goes on to describe how children who are spoilt at home or come from broken homes suffer more with flare ups and mental health issues; to some degree, this is still relevant today as we know that stress and anxiety can cause inflammation and have a big effect on the level of pain people experience.

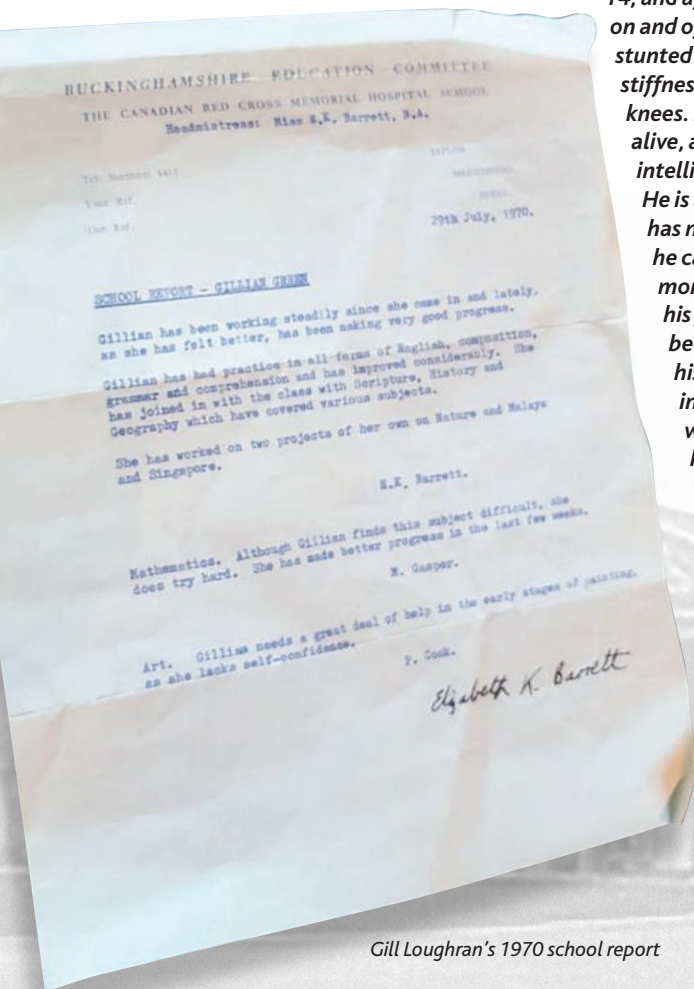
During the afternoon at the reunion I had the opportunity to talk with most of the 'Taplowites' and I was truly humbled. All of them had suffered greatly but recalled their experiences with humour and gratitude, in particular when remembering Dr Barbara Ansell. Dr Ansell was the founder of Paediatric Rheumatology and responsible for the advancement of knowledge and the improvement in treatment pathways we see today. Some referenced Dr Ansell's 'no nonsense' approach and her strict manner, but everyone remembered her and her colleagues with fondness.

When Gill and I were discussing her residential stay at Taplow she described how difficult it was for her parents to visit her; they lived in Middlesbrough and the costs to come down to Taplow as often as they would like were unaffordable. I can't imagine how I would have felt, as the child or the parent. But I do know that when you have a very unwell child, you will grab every opportunity that comes your way to help them get better.

A typical day at Taplow included as much exercise as possible, visits to the hydrotherapy pool, and school if you were old enough. Physiotherapy was regarded as one of the most important sessions to attend and medications included gold injections and Aspirin.

Luckily for children and young people today who are diagnosed with JIA, the treatment plans and medication available mean that most will not have to have many joints replaced or be reliant on a wheelchair and almost certainly they won't have to spend years in a hospital, far away from their family and friends.

I left Birmingham realising that although they didn't know it at the time, this lovely, resilient group of people were much part of the development of the treatment and care pathways we have for children and young people today with JIA and they deserve our utmost respect and gratitude. Thank you Taplowites!



Gill Loughran's 1970 school report





*Anthony Biggs*



*Gill Loughran*



*Elaine Ramanouski*



*Janet Mason*



*Jo Woolnaugh, Louisa Sommerfield & Denise Hayes*



*Joycelyn Daroux and Verona*



*Lynda and Keith Sisson*



*Marj Burden and Philippa Henry*



*Miriam and Terry Quigley*



*Philipa Randles*



*Sara Richards and Robin Coles*



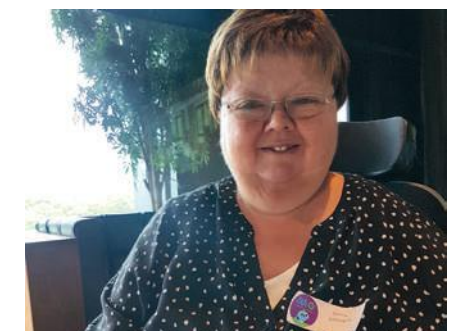
*Sarah and Samatha Clark*



*Lynda Hesketh, Kate Handey, Mathew Husband and his wife*



*Sue and Pete Dainty*



*Gail Loynes*





By Anne Gilbert

# EULAR

## “The European League Against Rheumatism”

**EULAR is an organisation that represents people with arthritis/rheumatism, health care professionals and scientific related societies.**

Every year rheumatology specialists from all over Europe, come together at this 4-day conference and launch new scientific findings from trials and studies, share knowledge and information on successfully completed projects.

This year the conference was in Madrid and I was lucky enough to be able to go, although only for one day, I did enjoy the experience. Around 14,000 people from all sectors of rheumatology attended this year including rheumatology doctors, specialist nurses and other allied health care professionals with specialisms in research, physiotherapy, occupational therapy, psychology and podiatry as well as industry professionals. I was impressed by their commitment and thirst for knowledge, as this conference was on a huge scale and required plenty of stamina! There were hundreds of sessions available to attend and a lot of networking opportunities.

One of the sessions I attended was a discussion on the importance of challenging how paediatric and adult services work for young people with JIA. Some hospitals have great transition services, and when a young person transfers to adult services, the hospitals know how to achieve good outcomes, but more can be done and rather than just trying to improve on the current model, the standards discussed in the session included proactive listening and learning from young people themselves. Sophie Ainsworth, a young lady from the UK, talked about how the simplest things can have an impact on a smooth transition, for example, she described her first experience in the adult services waiting room where even the magazines about gardening and home help were very depressing and made her feel out of place! Sophie also shared with the audience the importance of being listened to. Traditionally during the transition between services, young people are encouraged to attend

their consultations on their own. Whilst this can encourage independence and problem solving, not all young people feel the same way about this. In her initial meetings with her new consultant Sophie revealed that she quickly realised she didn't know enough about her disease or its treatment (a consequence of parents taking responsibility for her disease and treatment up to that point). Sophie left the conference with a simple message – “you must get it right for us”. Sophie's talk highlighted the need for more discussion and more funds to enable paediatric and adult rheumatology services to develop facilities that assist young people to feel empowered and championed as they go forward into their adult lives.

Another session facilitated by Professor Steve Ball from Central Manchester University Hospitals NHS Trusts opened a discussion on how we change as people, asking, do the services that support us, change as we progress along our journeys with disease? If the services are not right there are consequences for future health and our related behaviours and this is why some young people get lost in the system, their engagement dwindles and all chance of supporting illness prevention, self-care and resilience is gone.

It was truly enlightening, and I am sure that this and all the other seminars promoted a lot of reflective thought.

Conferences like EULAR inspire healthcare professionals and patient organisations like NRAS to listen, grow and make changes and I am looking forward to taking what I have learnt and putting it into practice!

eular

EUROPEAN  
CONGRESS OF  
RHEUMATOLOGY  
2019 | 12 – 15 JUNE



# Healthy summertime recipes for families



## Pea and Apple Salad

### Ingredients

2 apples, cubed  
 170g of any hard cheese  
 400g fresh peas or cooked frozen peas  
 70g chopped red pepper  
 Low calorie salad dressing  
 Salt and pepper

### Instructions

Cut cheese and apples into small cubes. Toss into a bowl with remaining ingredients. Cover and refrigerate for at least 2-3 hours before serving.

Serves 4

## Whole Wheat Blueberry Muffins

### Ingredients

180g flour, whole wheat  
 1 teaspoon baking powder  
 1/2 teaspoon baking soda  
 75g butter, unsalted  
 32g granulated sugar  
 2 large eggs  
 2 teaspoon vanilla extract  
 125g yogurt, plain  
 100 g blueberries  
 12 standard cupcake liners

### Instructions

Preheat oven to 350 degrees F.

In a large mixing bowl, stir together flour, sugar, baking soda, and baking powder.

Make a well in the dry ingredients and add eggs, vanilla, yogurt, and melted butter. Stir until wet and dry ingredients are just combined (don't over-mix!). Gently fold in the blueberries.

Line a muffin tin with paper liners and spoon batter evenly into muffin liners.

Bake on middle rack for 20-25 minutes, or until the tops are a light golden brown and a cocktail stick inserted into the middle of the muffin comes out clean.



Does your child have arthritis?  
 Come and join us at Leicester Racecourse



[www.jia.org.uk](http://www.jia.org.uk)  
 01628 823 524  
[jia@nras.org.uk](mailto:jia@nras.org.uk)

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FREE  
 ENTRY!

# FAMILY DAY

FREE  
 ENTRY!

Saturday, October 19th 2019 | 11am - 3pm

Leicester Racecourse, The Racecourse, Oadby, Leicester LE2 4AL

In addition, have the opportunity to listen to paediatric rheumatology experts and join us for lunch. Everyone in the family is welcome.

FULLY ACCESSIBLE AMAZING INDOOR ACTIVITIES FOR CHILDREN  
 AND YOUNG PEOPLE, ALL SUPERVISED BY CENTRE STAFF

To register your FREE place, visit [www.jia.org.uk/leicester2019](http://www.jia.org.uk/leicester2019)

# #WearpurpleforJIA 2019



2019 has been an amazing year for our #wearpurpleforJIA at NRAS campaign – reaching out to all corners of the UK and even with requests for fundraising packs from as far afield as the USA! With the rise of Facebook fundraising and online fundraising platforms we saw some brilliant achievements from all our supporters.

Planning for this year's campaign began in earnest in the NRAS offices back in August last year. Fabulous new merchandise was designed featuring our JIA mascot, Bonnie the Dog, and a clear and informative new website was designed in house by our web and digital media team. The Wear Purple Facebook page became key to interacting with fundraisers and families who wanted to share their stories and a whole array of inspiring and uplifting photos of the wonderful children sporting the all new purple T shirts, along with a whole range of other great purple outfits!



We were delighted that Lynette Haselip and her daughter Farah – the little girl who inspired her Mum to start the whole thing off back in 2015 – agreed, this year, to be Patrons of #wearpurpleforJIA at NRAS. It was back in 2016 that Lynette donated £1763 from her first event when she chose to support JIA services at NRAS and, since then, with her support, it has gone from strength to strength.

This year as we go to press, the total is standing at over £39,000 – please don't forget if you held an event and have money to pay in there are various ways to do this, so please contact the NRAS offices or visit the Wear Purple website and use the Pay in Funds button.

So a huge thank you to all who got involved, who got a piece in their local press, who swam, baked cakes, ran, walked or cycled, who got their school or workplace wearing purple or to anyone that purchased merchandise and wore it with pride on the day – you are all truly amazing. With your support we can get more people to understand what JIA is and, going forward, you have all helped to raise funds for our JIA services at NRAS. You have helped to support our free family fun and information days and free adolescent activity days – such as Bushcraft days. The money will help us to continue to produce free educational materials and resources for schools and healthcare professionals and campaigning to improve the services in Paediatric Rheumatology.









Order your guide to writing or updating your Will at [legacy@nras.org.uk](mailto:legacy@nras.org.uk)



# Events Diary

9-15 September	<b>Remember a Charity in Your Will Week</b>
11 September	<b>Helping you to Pass on Something Wonderful – Webinar</b>
11 September	<b>Cross-Party Group: Arthritis and Musculoskeletal Conditions, Scottish Parliament. Edinburgh, Scotland</b>
14 September	<b>JIA Family Day – Exeter, Devon</b>
18 September	<b>Time to Work event – London</b>
19 October	<b>JIA Family Day – Leicester</b>
9 November	<b>Rheum for You – Exeter, Devon</b>
20 November	<b>Managing Fatigue – Webinar by Professor Sarah Ryan</b>
4 December	<b>A yearly update on medicines/treatments for RA – Webinar by Professor Peter Taylor</b>
6 December	<b>NRAS Christmas Show. Maidenhead, Berkshire</b>

*Save the Date*  
**NRAS Christmas Show**  
 Friday 6th December 2019  
 St Peter's Church, Maidenhead

*This magazine is based on currently available knowledge and information provided by third parties that has been accepted in good faith, but has not been verified independently. NRAS cannot be held responsible for any consequences arising from reliance on such information.*

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