

Members' MAGAZINE

SPRING 2019



nras

National Rheumatoid Arthritis Society

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By Ailsa Bosworth, MBE

Chief Executive

Dear Members

Well the beginning of 2019 didn't start off very well for me and so I'm glad that we're now into March as I write this!

It started with a spontaneous bleed into my right eye which then proceeded to leak into the surrounding tissues, so I ended up looking like a one-eyed Panda, rather more alarming for others than for me as I didn't have to look at it. This was then followed by admission to hospital through A & E with what was initially thought might be meningitis, except that it wasn't! Turned out to be a 48 hour weird virus. Everyone in hospital kept getting confused by my black eye, thinking I'd hit my head. Then when attending a round table meeting in the City on biosimilars, I went to the loo and didn't see the step in the middle of the corridor and went flying, badly bruising and damaging my right elbow which is replaced, so not clever! Less than a week later I caught my toe on the uneven pavement outside my house and broke my big toe in 3 places so am now sporting what looks like a black flipper on my right foot – very stylish! The numerous bruises on various bits of my body are now starting to fade and my elbow has almost healed.

This might all seem relatively minor to those with RA who are currently experiencing a difficult time, but it leads me onto a subject that I suspect affects many of us who have lived with this horrible disease for many years. Balance and falling. In the hospital they kept asking me why I was falling and if I was feeling faint or dizzy. The answer was no I wasn't feeling faint or dizzy but if I trip, which is not that difficult given replaced ankles, knees, hips and fused wrists amongst other things, I can't right myself easily and I can't put my hands out to save myself for fear of doing something awful to my wrists, so I instinctively put my arms down by my sides and am then like a skittle and hit the ground shoulder/head first. It's quite scary really and does leave you feeling somewhat vulnerable when on uneven or unfamiliar ground, especially in the dark. I think with a long-standing disease and lots of damage, we all get a bit wary about falling badly and fracturing something.

On another subject, I'd like to remind you about the National Audit on early inflammatory arthritis/RA which is currently running in England and Wales. The audit opened in early May 2018 and is collecting data on patients with a diagnosis of rheumatoid or rheumatoid pattern arthritis at three time points across 12 months, assessing waiting times, time to treatment, clinical response to treatment, provision of education and patient reported outcomes. The audit will continue to recruit patients through 2019 and possibly beyond.

The first annual report will be issued shortly after May 2019. If you have been enrolled in the audit, you will have received an email from the audit team and asked to fill in questionnaire/s. The patient portal for the Audit is www.myarthritisaudit.org.uk and you can find all the information you need and the different questionnaires there. We would really encourage everyone who has been enrolled to support the Audit fully and fill in the questionnaires when prompted. This data is going to be incredibly helpful in improving standards of care and reducing the variability of care across England and Wales and ultimately improving patient outcomes. So far over 16,000 people have been recruited which is significantly higher than in the last audit which ran between 2013 and 2016.

We have a busy and exciting year ahead at NRAS but a year of change, as I shall be taking on a new role as NRAS National Patient Champion with effect from September, 2019. I shall be standing down as Chief Executive at our June AGM and inducting a new CEO into the role between July and September 2019. The Trustees have initiated an internal recruitment process which we shall be following over the next few months. Handing over the reins of the organisation I founded in 2001 won't be the easiest thing I've ever done, but we have solid foundations - a strong, committed and passionate team of people to take the organisation forward, a wonderful body of members and volunteers who support their patient organisation consistently and award-winning, innovative resources and services which all contribute to our aim to improve the lives and outcomes of all those living with and affected by Rheumatoid Arthritis and Juvenile Idiopathic Arthritis. I am sure that NRAS will go on to do so much more in future.

I still feel I have more to give and more to do and as 'National Patient Champion', working part time, I shall continue to support NRAS in a variety of different ways such that my experience as CEO and as a long-term patient can continue to contribute and be of value. I want to have more time to commit to my family as my daughter is expecting her second baby at the end of August.

There will be a major piece in the next magazine about my time as CEO and an introduction to the new CEO. In the meantime, I look forward to meeting some of you over coming months at various events and seeing our health professional friends at the BSR 2019 congress in May.

Warmest wishes

Are you wary of falling?

I'd be interested to know from members if falling is something you have concerns about. If so, please answer the following questions and send your responses by email to enquiries@nras.org.uk

Are you concerned about falling either inside or outside home? Yes / No

How many years have you lived with RA? yrs

Do you do any form of exercise to help with balance/strength? Yes / No

Would you be interested in info to help you tackle the problem? Yes / No

Members' MAGAZINE

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

Editor of this issue;
Tracy Bracher

Special introductory membership offer

NRAS Membership for a friend or relative

If you are introducing a friend or relative, they can benefit from a special introductory offer of just £15 for the first year when paying by direct debit. As a thank you to you for recommending them, we will send you either an NRAS Lapel Badge or NRAS Wristband, whichever you prefer.

Call us on 0845 458 3969 or email us at membership@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 to check we have your up to date email address and contact preferences.

"I find your magazine, emails and publications invaluable and they have helped me in my diagnosis of RA. I'm better informed and I feel that I am managing my condition so much better because of the support NRAS gives its members!!"

Kate Goodwin, NRAS Member



Kevin, Devan and Dylan pictured in New York in 2018 when Kevin was making better progress

Dear Dad

A daughter's letter to her father, who lives with RA



Devan and her brother Dylan pictured with their Dad, Kevin in Disneyland Paris 2011

You were the first person to hold me the moment I was born. The tears ran down your radiant face with the most intense happiness, everyone in the room could feel it. You examined my face for all the features I took after you, and any of mums, embracing the reality of creating a life.

From then you took care of me within your strong arms until I could walk, then embraced me in hugs every day after, keeping our connection forever strong. You took care of me, and you still do, but I want to talk about the time where this case was inversed. To look back on when I had to take care of you, and when we met Arthur.

My old-fashioned battery powered alarm clock rang, 6:50am. It was a Thursday morning on a chilly November day. I did my usual routine, climb out of bed with no hesitation, walk down the creaky hall to the kitchen where I poured a massive bowl of cereal and then added about 6 spoons of sugar to the top of it. I got myself comfy on the sofa and with my left hand flicked through the TV channels looking for my usual show and with my right, rammmed the cereal down my throat.

At 7:05am I heard a deep yet soft call from you. I quickly went through to your room and saw

you sitting on the edge of your bed in your usual uncomfortable manner. You needed me to put on your socks today as it was just too hard. With a smile and a, don't worry its fine, I sat on the floor and rolled the sock down in my hands and slid it onto your stumpy foot with ease. I did it with the other foot, then like clockwork repeated it again but with larger socks, for the warmth. Afterwards I grabbed your huge BFG shoes, which fitted perfectly to your oddly, deformed feet and loosening the laces as much as possible, slid them on and tightened them like a second skin. Immediately you sat up in the 'ready' position and I stood directly parallel to you with my arms out forward, not too far from your branched arms you reached forward to meet my fingers. With no words, you began your three sways like a race car revving it's engine in preparation. 1, 2,...3 and with a launch threw yourself up, with the support of my 10 year old strength. My hunchbacked, six-foot giant now towered over me like a tree, a forever comforting sight to me. Your strange

feet out at 60 degree angles from anyone's normal body alignment, you crippled your way to the kitchen to take your meds. "Paracetamol, Tramadol, Prednisolone, Methotrexate, Folic Acid..." calling through the long list of pills you needed for that morning I scrambled through the boxes in order to pop them out into the cute little white tub. About 6-7 pills later I picked up the tub and wriggled my fingers through each one, making sure they were all there, then I would let you check again. Then back through to the sofa I continued with my TV watching and breakfast eating.

By about 7:20am, unconsciously my senses were enhanced waiting for the clunk of the taxi over the ginormous speed bump outside the window. When it arrived I'd be the role play hand rail we didn't have to support you as you struggled down the steps to the car.

In the summer of 2009 you were diagnosed with rheumatoid arthritis, a debilitating disease which attacks your joints. It is known as the most severe type of arthritis. At first it was only found in your feet. Being a keen golfer and an ex-footballer you were clearly accustomed to being on your feet so this news wasn't exactly great, to say the least. "I'll just get an operation and it'll be gone, sorted". However, it was not to be that simple and straightforward in your case. Me being 8 years old and my brother being 6, we were never really told about Daddy's feet "issue", we didn't really need to know, until we really found out.

After the operation in September of 2009 the sea seemed calm, until the tsunami hit and nearly drowned us all. No warning, no protection, no idea. Everyday no easier than the day before and no better than the next as your immune system attacked you and the arthritis reigned terror on your joints – 'Arthur' as we named him, had arrived with a vengeance. Your entire body was drenched in the disease and Arthur was suffocating you to the point just before death – he was just taking you over, my Dad. Within a matter of months most of you was gone, lost to the depths of the disease. The muscle torn from your body in an instant and the little fat you had washed away. Your beige skin now turned grey and your face hollow and black, but the worst part, your joy slowly faded with it. The concept of an entire household waking up in the dead of the night to comfort a 40 year old man, in tears because he was sore inside and out was something no one could ever imagine. What do you say to a sobbing man who is just getting too sore to live anymore? You just gently wrap your arms around their aching body until the tears are no more for both of you and life must go on. Honestly, death seemed more peaceful right then.

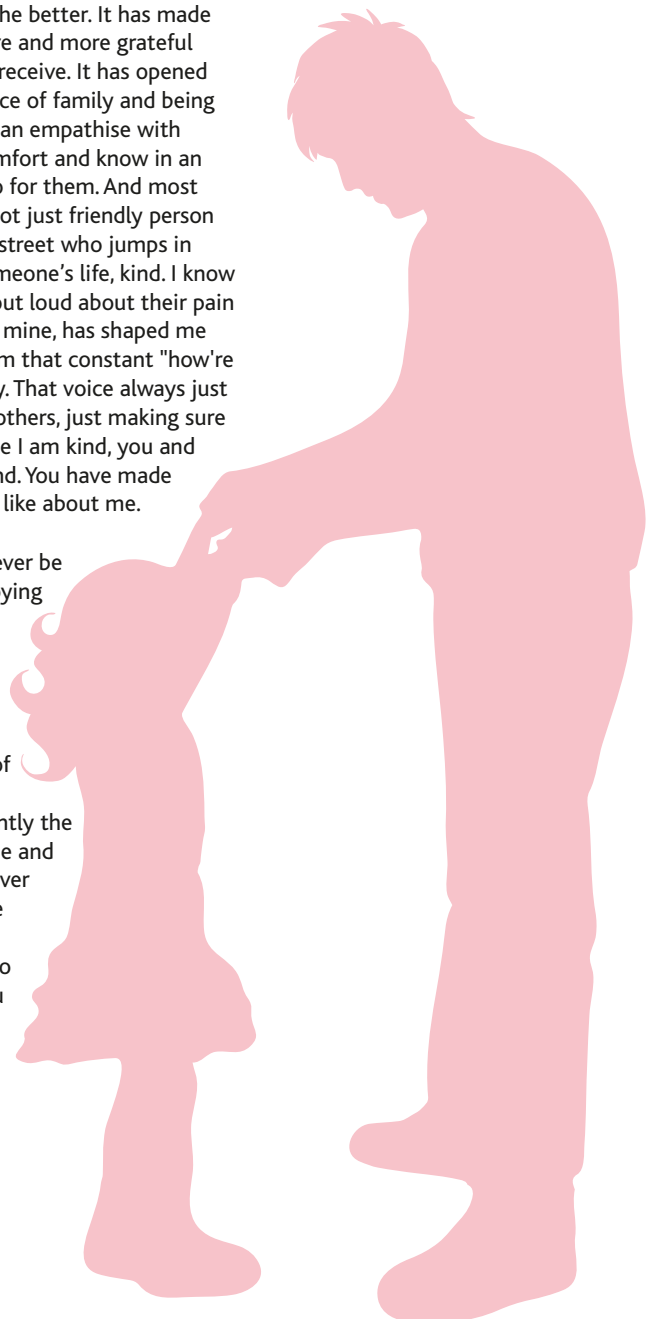
But now we are here.

You're still ill, although we always knew it was incurable. Yes, you're still so much weaker than any man of your age and still nothing like you used to be, but mentally, you're thriving. I have most of my Dad back and that means the world. Your witty jokes and inappropriate songs ring around our ears once more. Bullied by us about your new found love of lawn bowls against all the oldies in the village keep you way too busy but we wouldn't have it any other way.

Through the whole process of the past 8 years we've been living with Arthur, we are slowly building bridges with him and becoming one again. I frequently wonder what life would be like if Arthur had never moved into our lives. What we would be like as a family, the things we could have done and experienced. But he did and we survived. Of course it would mean the absolute world to all of us if someone found a cure to this God awful disease that is hurting my Dad, but apart from that I could confidently say it has changed my life for the better. It has made me stronger, more mature and more grateful for the things I earn and receive. It has opened my eyes to the importance of family and being there no matter what. I can empathise with people in pain and discomfort and know in an instant what I need to do for them. And most importantly, I am kind. Not just friendly person kind but stranger on the street who jumps in front of a bus to save someone's life, kind. I know that not everyone talks out loud about their pain but your experience, and mine, has shaped me for the better and now I'm that constant "how're you doing" in the hallway. That voice always just checking up on you and others, just making sure everything's okay because I am kind, you and Arthur have made me kind. You have made me, me and what people like about me.

Now Daddy, you will forever be the strongest, most annoying and resilient man I know. You will always be the BFG whose shoulders I sat upon and felt higher than the clouds and the man that will scare any of my future boyfriends to death, but most importantly the gentle giant that loves me and Dylan beyond belief, forever and a day. The day I leave home, never forget, I will always be the daughter to care for you and love you with all my heart until it stops beating. Forever and always Dad.

You will always be the BFG whose shoulders I sat upon and felt higher than the clouds.





By Will Gregory

EULAR grant visit report

Myositis Rehab., Karolinska Institute, Stockholm – April 2018

Will Gregory is the UK Physiotherapy Advisor to NRAS and whilst his article is primarily related to another serious rheumatic disease, myositis, this is another autoimmune condition affecting adults and children across Europe, and so we thought this article about Will's visit to the famous Karolinska Institute in Stockholm would be of interest. *(Myositis means inflammation of the muscles that you use to move your body. An injury, infection, or autoimmune disease can cause it. Two specific kinds are polymyositis and dermatomyositis. Polymyositis causes muscle weakness, usually in the muscles closest to the trunk of your body. Dermatomyositis causes muscle weakness, plus a skin rash).*

Introduction

You may have heard of the European League Against Rheumatism (EULAR). It is an organisation which represents people with arthritis/rheumatism, health professionals (HPR) and scientific societies of rheumatology of all the European nations. The aims of EULAR are to reduce the burden of rheumatic diseases on the individual and society and to improve the treatment, prevention and rehabilitation of musculoskeletal diseases. To this end, EULAR fosters excellence in education and research in the field of rheumatology, including a huge body of work on rheumatoid arthritis. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with musculoskeletal diseases by the governing bodies in Europe, something to which NRAS contributes significantly through PARE, the part of EULAR which represents patients and patient organisations.

EULAR offers educational visits for Health Professionals to share best practice. At Salford Royal, in work started by Professor Cooper and now taken over by Dr Chinoy, we have a specialist interest in the diagnosis and management of myositis. This inflammatory muscle condition is rare; whilst RA is reported at 1 per 100 of the population, myositis is thought to be around 1 per 10,000.

Like RA, myositis is a chronic, progressive, inflammatory disease. It is most often indicated

by symmetrical proximal muscle weakness (the muscles closest to the trunk of your body) and skin rashes, and for some, chronic pain. Other symptoms may include fatigue, trouble swallowing, shortness of breath, lung disease, fevers, and weight loss. People with myositis often have difficulty climbing stairs, rising from a seated position, turning over in bed, raising their arms over their head, and may become prone to falls. Symptoms can appear gradually, over a period of months or even years, or they may develop more rapidly, within days or weeks.

Myositis can overlap with RA, as one of the components of what may be called 'Mixed Connective Tissue Disease'.

As myositis is a rare condition, the research into rehabilitation techniques to benefit people with myositis is even rarer. Working at a UK specialist centre for myositis I have more recently been involved in seeing these patients for assessment, measurement and rehabilitation. I soon realised that our practices here in Salford could be enhanced by learning from the world-renowned myositis service at the Karolinska Institute, Stockholm. (Ailsa has visited the Karolinska in the past with EULAR to understand more about how their RA pathways operate).

Description of the Experiences

In discussions with Dr Helene Alexanderson, rheumatology physiotherapy lead at the Karolinska, we had identified 3 days as the optimal visit period.

We started with a tour of the department, informal discussions on the research base in myositis rehabilitation, the database I had collected thus far in Salford and the service at the Karolinska. We had lunch with the clinical lead for the service, Dr Ingrid Lundberg, and her second in command Dr Mariam Dastmalchi; it was very nice to see how highly Helene was regarded by the medics and the easy relationships between different professions in the myositis team.

I was fortunate to get hands on (or at least leg on) experience of the testing protocol for the latest trial the team are undertaking. I performed the 13-repetition muscle fatigue testing (for quadriceps muscles) – this active learning really appeals to

Myositis can overlap with RA, as one of the components of what may be called 'Mixed Connective Tissue Disease'

me. Later in the afternoon I discussed with Helene the paediatric / juvenile services in each of our countries and our shared contacts at Great Ormond Street Hospital. Myositis is a very difficult disease to diagnose in young children.

We had three, hour-long myositis exercise groups. It was great to consider how a rare condition could fill a full afternoon in group exercise, and even greater to see this in action. The three groups were similar, with a mix of newer and more established patients. It was great to see the role that Helene had – acting as a go-between for the patients wanting to interact with the rheumatologist, their local physios and local GPs. Helene managed to facilitate a supportive, but undeniably patient-led and patient-motivated session.

My final morning started with the weekly myositis research meeting which included two patient representatives. All members were kind enough to conduct the meeting in English for me. There are a large cohort of PhD candidates and a broad range of areas being researched. The patient representatives were kind enough to stay on after the meeting to discuss with me their experiences of rehabilitation, both at the hospital and in their local exercise services. I then returned to the physiotherapy gym and saw the application of the Astrand cycle ergometer protocol (used as a cardiorespiratory fitness test) for an annual review patient. The other components of this 5-year annual review were familiar from the patient observations earlier in the visit. The visit finished by chatting through with Helene the UK services, my plans for implementing some changes on getting back to the UK and a potential future research project – both to review myself and to consider as a collaborative international project.

I have spent time reflecting on how this incredibly helpful visit might influence our practice in the UK. This kind of visit with a specialist unit in this particular field can influence best practice and care, and I think may give NRAS members an idea of the need for European and international collaboration in the rarer diseases, where specialist centres are few and far between.

Summary and relevance for RA

With the National Health Service, we have a fantastic healthcare service here in the UK. But, things can be learnt from how healthcare is delivered in different countries. When managing people with rare diseases it can be hard to find guidelines and to establish best practice: national and international centres of excellence can help with this. Whilst reading about what happens elsewhere is very useful; for me the possibility to visit and see the application of what I had read about was invaluable. EULAR offers a fantastic opportunity to expand our knowledge and to use that extra knowledge to improve the work of our NHS here in the UK.

Whilst I have written about myositis, there is clearly some application to RA; either from those patients with overlap of both conditions or in considering muscle strength and muscle strength rehabilitation for those with RA. Whilst the muscle issues that are present in RA are usually not inflammatory, muscle weakness and loss can be an issue for many people with RA (see the article by George Metsios in this issue). We have started to consider measuring strength, and particularly grip strength in our RA clinics to see if this data can better help us with the RA service, as it has done with the myositis service.

EULAR offers a fantastic opportunity to expand our knowledge and to use that extra knowledge to improve the work of our NHS

Snowdonia challenge

Raising funds for Juvenile Idiopathic Arthritis

A big thank you and well done to Angharad who took on the very challenging path Crib Goch on her Snowdon challenge on the 25th November 2018!

Angharad, has rheumatoid arthritis (RA) herself, and wanted to raise awareness of Juvenile Idiopathic Arthritis (JIA), she raised £361.25 including the Gift Aid - fantastic!



£305 Raised For JIA

Healthcare champions



Rt Hon Theresa May MP and Ailsa Bosworth MBE (centre) with the award winners from 2016

At the end of 2019, NRAS will be hosting an event to celebrate healthcare professionals across the country who have gone above and beyond in their care for people with RA and JIA. This high profile event will be held in London, and further details can be found on our website: www.nras.org.uk/healthcarechampions

If you would like to nominate one of your healthcare professionals who you feel deserves to be recognised for their work, please fill out a nomination form on our website: www.nras.org.uk/healthcarechampions

Alternatively, if you'd like to discuss this with us over the phone, please call **01628 823524**.

JIA Family Day

Yorkshire – Saturday 29th June 2019

The fun day at Nell Bank in Ilkley, brings children and families together, and often it's the first time that a child with JIA meets another child with juvenile arthritis! Parents and carers also get the opportunity to chat and share, and ultimately feel less alone about the condition.

We also share with families our latest news, and how we support children and young people with JIA and their families, including how we raise awareness about JIA.

We love meeting all the families and listening to children laughing

and watching them interact with each other, if you didn't know, no one would believe these children had a life changing long-term condition.

This year we have staff from Leeds Paediatric Rheumatology unit coming along to share some facts about JIA and answer any questions; we also have a lady who is going to share her JIA story, and Chloe who has supported us many times. Chloe is doing an informal demonstration and chat about how drama therapy can help and how it works at home.

The Ilkley Family day is free and open to anyone with JIA and their family. Lunch is provided.

For more information, please get in touch with Anne Gilbert at NRAS **01628 823524** or email anne@nras.org.uk

Looking after yourself

... and why it's important



By Anne Gilbert

We can all be guilty of putting others before ourselves too often, and this is especially common for those who are parents and/or carers of children with long-term health conditions like JIA. Here are some of the common warning signs, that might mean it's time to seriously start thinking about yourself:

1. You're on edge and easily troubled. You feel crushed or trampled from all angles
2. You feel more tired than usual, and this can't be explained by an increase in activity
3. You're finding you pick up colds and illnesses more than usual
4. You don't feel inspired or stimulated to try anything new or creative
5. You can't remember the last time you went out with friends, or enjoyed your favourite ice cream or read a good book
6. You get irritated easily and snap for no reason
7. Relationships with friends and loved ones are falling apart
8. You are misusing substances to get you through the day
9. You dread going into work and just can't be bothered with your work load.

Many of us feel guilty about "me time". You might be asking for a day off from work and taking yourself somewhere for the day on your own or locking the bathroom door and having a long soak with your headphones on; whatever it is, it can feel wrong to take time out for ourselves.

How to Recharge

Don't underestimate how much better, stronger and able to cope you will feel once you start to regularly look after yourself as well as others.

Having a brief mental break can help you feel more refreshed and look at the jobs ahead with a more positive outlook.

Humour is a great stress buster. Watching something on the TV, listening to something that really makes you laugh or catching up with friends will not only help your mood but also the stress hormones that can build up. Laughter also releases endorphins, the body's natural feel-good chemicals.

Social time is particularly important for happiness; if you have strong relationships with

friends and family you are much more likely to be able to handle stressful situations. As we get older and take on more responsibility, the opportunity for coffee dates and catch-ups in person or on the phone get less. Good connections give us a sense of wellbeing and contentment and being able to give and receive a hug from a good friend or family member will give you a sense of belonging, being loved and valued.

A key part of looking after yourself is engaging in activities that bring you pleasure. Activities that seize your attention, whether in a calm and quiet way or exciting way. Here are some examples to think about, and if there are some you haven't tried, why not give them a go?

Treat yourself and ignite your senses, give yourself permission to enjoy, have some fun and feel satisfied and remember that when you take care of yourself, it puts you in the best position to look after others.

Reading
Writing stories
Journaling about your thoughts and feelings

Taking pictures
Drawing or Painting
Colouring
Dancing

Cooking / Baking
Swimming
Walking / Biking
Yoga

Running
Hiking
Gardening
Building something

Sewing
Singing
Writing letters
Fishing

Golf
Tennis



Community Fundraisers



Kids Planet Day Nursery

Kids Planet Day Nursery in Warrington held a Christmas Fayre and raised an amazing £821.91. Staff and children were delighted to present the cheque to Chris Lowe, an NRAS Ambassador, who kindly went along to meet them all and receive their donation.



Donna Moore

Donna decided to 'Brave the Shave' at the end of January to raise awareness of RA and funds for NRAS. Donna raised an amazing £802.10!



Things to look out for...

If you live in and around the Milton Keynes area do look out for Angela Fretten and her husband who will be out and about at local Fairs and charity events with her wonderful homemade jams and chutneys. Last year Angela raised £1500, so please support her fundraising for NRAS this year.

Here are just some of the events she will be attending:

- 15th June: **Thame Carnival** – 1pm-4.30pm
- 22nd June: **The Big Food Festival** at Milton Keynes Rugby Club, MK4 2DN – 12pm-7.30pm



Big Lakes Challenge

Canoe. Trek. Cycle.



Register your interest for 2020!

Big Lakes Challenge
Based in Keswick, this exciting challenge will see participants canoeing, cycling and trekking through the beautiful scenery of the Lake District while raising funds to improve the lives of those in the UK living with rheumatoid arthritis and juvenile idiopathic arthritis.

To register your place, email fundraising@nras.org.uk or call **01628 823524**

For information on other events, visit www.nras.org.uk/events



Registered with FUNDRAISING REGULATOR

nrAS is a registered charity in England and Wales (1134859) and Scotland (SC039721). A company limited by guarantee. Registered company in England and Wales (7127101).



RideLondon 100

4th August 2019



Join and raise funds for **NRAS** at Prudential RideLondon 100

Cycle a 100-mile route on closed roads and help the National Rheumatoid Arthritis Society to improve the lives of those in the UK living with rheumatoid arthritis and juvenile idiopathic arthritis

To register your place, visit www.nras.org.uk/cycle or call **01628 823524**



For information on other events, visit www.nras.org.uk/events



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CAN YOUR COMPANY HELP?

NRAS needs YOU

We're looking for new corporate charity partners for 2019

Supporting NRAS as your chosen charity of the year goes further than just raising money and awareness for a worthwhile cause, it can also help:

- Demonstrate your Corporate Social Responsibility strategy and your organisation's commitment to supporting worthy causes
- Increase staff morale and motivation through fundraising and volunteering activities

What we can offer from a partnership:

- Bespoke social media coverage, inclusion on our website and a variety of PR opportunities
- Feature in our members' magazine
- Charity places for prominent runs and cycle rides across the country including the Great North Run, the Royal Parks Half Marathon, the Vitality London 10K and RideLondon 100



By Connect Health
Rheumatology
Community Team

East Kent Community Rheumatology service

Outpatient provision for patients with inflammatory arthritis has changed dramatically in East Kent this year.

In 2016 a year long pilot study of patients with stable, uncomplicated disease was undertaken. The objective of the pilot was to establish whether patients would be satisfied to receive their care from an experienced nurse consultant with no routine medical consultant reviews.

As part of the pilot patients were provided with monthly education sessions, covering a wide range of subjects, from a variety of speakers which were held at a local theatre. The pilot used a leadership approach designed to incorporate education to local GPs and health professionals and encourage a more integrated way of working, keeping patients at the centre of all decisions made about their care. The pilot evaluation was extremely positive and the continuation of the service highly recommended by patients and GPs.

As a result of the pilot South Kent Coast Clinical Commissioning Group tendered for a community service and, in February 2018, Connect Health was awarded a 12 month interim contract.

Connect Health is the largest musculoskeletal (MSK) provider in the UK. The majority of its contracts are for physiotherapy but, in more recent years, they have moved into orthopaedics, pain and rheumatology services.

Patients allocated to the community service have non-complex rheumatological conditions which include rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and self-limiting conditions such as polymyalgia rheumatica. For the first phase of the service, patients on biologic drugs have been excluded, whilst agreement between the community and hospital service on how to best manage these patients is agreed.

Removing routine medical reviews is not the only change made to the service:-

- Care is now delivered closer to patients' homes, mainly in GP practices but also community centres, where parking is free. The rheumatology specialist nurses can now liaise easily with the primary care team who look after patients. The service provides a comprehensive annual review which ensures an assessment of all areas of risk, such as heart disease and osteoporosis which can affect those with inflammatory conditions. This information is shared directly with the GP and entered into the patient record, thereby removing the need for patients to attend their GP for an annual check on their RA.
- Monthly education sessions are delivered across East Kent offering patients an opportunity to improve their knowledge and help them to self-manage. The groups also offer patients an opportunity to share experiences and support each other. A specialist nurse attends all sessions to enable patients another opportunity to discuss any health issues which are worrying them.
- An advice line which is monitored to ensure a call back within 24 hours Monday – Friday is available.
- 48 hour guaranteed "flare" appointments are available
- The choice of a telephone consultation is provided when appropriate
- Each patient will be provided with a handheld record. This is a resource of information regarding things such as drugs and the relevance of blood results. It is also a tool for patients to keep a record of information which is important to them such as, dates of a "flare", amount of steroid taken, drug reactions and vaccine dates. There is a section to keep a record of all investigations including blood results and x ray reports, and a diary section including space for any health professional to make a comment, if the patient so wishes. This also provides a central place to keep information about local education events and national events such as webinars.
- There are a range of exercise classes planned for East Kent including seated exercise, Tai Chi and yoga.



The new rheumatology service feels 'plugged in' to the local community and will be a huge factor in managing our disease.

Assessment and recording information

For the first time the assessment of a patient's condition will be entered onto an electronic template which allows easy identification of all activities and outcomes for patients to be monitored and measured. For example, it is possible to plot a patient's DAS score over a period of years or identify the number of patients who were escalated for a biologic therapy. It also helps identify any trends that clinicians display, for example, a health professional who uses more steroids than her contemporaries. A copy of the assessment can be provided for the handheld record.

Evaluation of the service

Every aspect of the service is open to patient assessment. This includes the face to face and telephone consultations, urgent advice line responses and the patient education and support sessions. Patients are asked to complete questionnaires and make comments, both positive and negative, to help to maintain and continually improve the service.

So far, so good.....

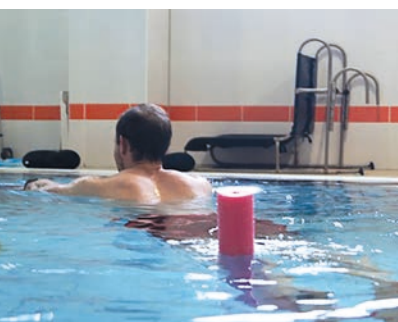
The first reviews took place in early September 2018, so the service is still very much in its infancy. However, patient feedback has been very positive. I could include many examples but this one sums things up really well.

"We are so lucky to now have a rheumatology service that has truly been designed around the patient. It's as if someone has asked us exactly what support we need and have made sure that it is available. Of course that is in fact what happened and it is difficult to name which is the most important aspect. The nature of inflammatory arthritis means that it is constantly fluctuating so thank goodness the new service is so flexible. A quick and responsive telephone help line is a life saver, and local appointments make such a difference as mobility is a huge issue for us. It's so important that we can see someone quickly and locally if we have a flare as well. The local support groups bring a whole new level of care as we learn how to cope together, sharing tips and advice. We also have expert speakers to help us take responsibility and the best possible care of our own health."

Save our Pools

By Will Gregory

The NHS is a service under threat



In these times of austerity the way the NHS uses its resources is under the microscope. Services are being reviewed and often cut. This is an issue across many areas. But the area that concerns me and many of my colleagues is the threat to our hydrotherapy pools. For that reason we are in the process of starting a "Save Our Pools" campaign.

Recently a proposed decommissioning of the pool at Whipps Cross Hospital, London was fought against by patient groups and staff; but still closed. Our focus now shifts to the pool at Heywood Hospital in Stoke-on-Trent. For further details, please see www.change.org and search for Heywood Hospital.

So, why should we care? What does a hydrotherapy service offer for people with inflammatory arthritis?

People have been bathing for health in man-made warm water pools since the Roman times, and no doubt earlier where there are natural warm water springs. The history of rheumatology care is quite closely linked to the UK's spa towns. Until quite recently Buxton had a rheumatology hospital based around previous links to the spa there. But, most famously our Royal National Hospital for Rheumatic Diseases remains in Bath Spa but its services will be moving out of the iconic Georgian Hospital and into the Royal United Hospital in Bath. These days of course we have heated pools. It has been estimated that around 50% of NHS Trusts have access to a hydrotherapy pool. A recent survey, funded by the National Ankylosing Spondylitis Society, attempted to map UK hydrotherapy pool access. Whilst finding this a near impossible task the figures are worth reviewing. They had 100 respondents, 68 had on-site hydrotherapy pools, 11 had access to such facilities off-site. I would speculate these are the only 79 pools in the country, but it is probably as close to the number as we could find out.

Hydrotherapy pools in the UK now tend to run at 34-37degrees Celsius. This is considerably warmer than the 29 degrees C most swimming pools are run at. The depth of a hydrotherapy pool is designed such that exercises can be undertaken standing. Exercises of course are also undertaken lying, and in sitting where pool appropriate stools are available. The Aquatic Therapy Association of Chartered Physiotherapists have recently updated guidelines for the maintenance and running of NHS hydrotherapy pools – so most NHS pools will offer a similar environment for rehabilitation.

The hydrotherapy pool offers a unique environment for rehabilitation. It is used by many specialties, from children's sessions, to neurology, orthopaedics, learning disabilities and of course, rheumatology. All hydrotherapy pools will offer NHS treatment sessions, but some also offer out of hours classes and self-management sessions. NHS treatment is usually 4-6 sessions each of 30 minutes or so, supervised by a trained physiotherapist. Classes and self-management sessions allow on-going access to the pool for some people to extend this 4-6 session allowance.

Research has shown that people with RA who attend regular hydrotherapy tend to have fewer hospital admissions and a lesser reliance on other medical care, and we know from the parents of children with JIA what the great benefits are to using a hydrotherapy pool. This may well be true for all forms of regular exercise; but it should be noted that most RA and JIA patients do find the hydrotherapy pool an easier environment to exercise in. A recent study in Brazil reported improved disease activity and easier walking after 16 sessions of hydrotherapy. A 2012 review of all studies up until that date concluded that "there is some evidence to suggest that hydrotherapy has a positive role in reducing pain and improving the health status of patients with RA compared with no or other interventions in the short term. However, the long-term benefit is unknown". This is not saying hydrotherapy is needed by all. It is certainly not recommend to overdo it in one of the heated pools during active joint flare.

**BREAKING
NEWS**

Since this article was written there has been news of a further NHS hydrotherapy pool under threat, at Charing Cross, London

Reeling in new research finds

Fish intake may not have a protective effect against developing rheumatoid arthritis

It has previously been suggested that frequent fish consumption may reduce the incidence rates for rheumatoid arthritis, perhaps due to the anti-inflammatory effect of omega-3 fatty acid found in fish (which some people feel has a positive effect on managing their RA symptoms).

However, researchers analysing food frequency questionnaires (at baseline, then every 4 years) found no difference in the number of people diagnosed with RA, who had less than 1 serving of fish a month, compared to those who had 4 or more servings a week.

The survey looked at data from female patients in 2 studies, one covering 1984-2014 and the other covering 1991-2015, looking at over 150,000 women. Within these groups, 1080 incidents of RA diagnosis were found, and then analysed for their levels of fish consumption.

One, perhaps surprising, result from the study was that people who smoked but had a higher level of fish consumption seemed to have a lower risk of developing RA than people who smoked but had a lower level of fish consumption. However, the researchers determined that this would require further investigation to examine the possible link.



NRAS Rheumatoid Arthritis Awareness Week (RAAW)

17th -23rd June 2019

With RAAW, our aim is to educate and inform the public about exactly what rheumatoid arthritis (RA) is and how it impacts those living with the condition. We also raise awareness of the importance of an early diagnosis. Throughout the week we shall share your stories, raise awareness, challenge misconceptions, and fundraise to support the essential work of NRAS... your society with you every step of the way with RA.

To play your part in RA Awareness Week you can order your free RAAW information pack with lots of hints and tips for raising funds and awareness by emailing

enquiries@nras.org.uk
or call **0845 458 3969**



Order the RA Awareness Week Pack from our website www.nras.org.uk



Spread the word by sharing our posts. Use the hashtag **#AnyoneAnyAge**



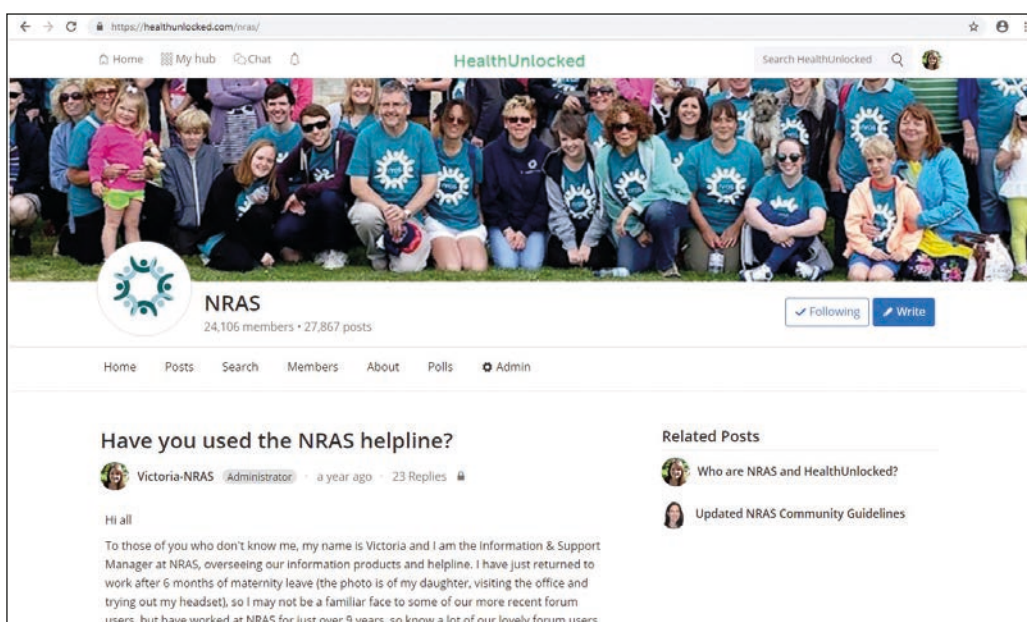
Organise your fundraising activity for RAAW 2019



Dear Helpline

I have recently been diagnosed with rheumatoid arthritis (RA) and I don't know anyone else who has it. Are there any forums I can join to connect with people who also have RA?

Just to have another voice that's not medical that can talk you through things, Helpline were just brilliant.



Rheumatoid arthritis affects around 1% of the population, so it is not uncommon for us to speak to people who have never (to their knowledge) come across anyone else with the condition. It is also a largely invisible condition of course, so it is possible that you may have known people with RA without realizing it. Unfortunately, it is not a widely understood condition. Friends and family may not fully understand what you are going through, and that in itself can feel quite isolating.

NRAS moderate a forum on a platform called 'HealthUnlocked' (HU), that has forums for a wide range of health conditions, including

rheumatoid arthritis, as well as one for parents of children with JIA (though many of our JIA parents use our JIA Facebook forum for support). Both of these HU forums are moderated by NRAS.

Our RA forum has nearly 4000 active members, many of whom use the forum regularly. As a result, questions are often answered quickly, and it can be a good place to go to for support. Not everyone feels comfortable posting on a forum, and that's fine too, as many people just read other people's posts and get support that way. It's quick and easy to set up a profile on HealthUnlocked all you need is an email address and to create a password, and you can make it as anonymous as you like.

Helpline
0800 298 7650



I'm off on my holidays shortly for the first time since being diagnosed with RA. What are the key things I need to consider when travelling abroad?

Packing

- It's a good idea to pack a supply of your regular painkillers or anti-inflammatory drugs. Consider the worst case scenario of needing the maximum dose every day of your holiday and then you definitely won't run out!
- If you think you may need it, ask your rheumatologist or rheumatology nurse specialist about the possibility of getting a steroid injection before you go, to help to see you through the holiday period with minimum pain. You could also ask about getting a supply of oral steroids just in case you get a flare up during your holiday and cannot access medical help. Ask your team about dosage to take in this event.
- Remember to pack some comfortable footwear, particularly if you'll be doing more walking than usual or the terrain of the area is rough.
- Don't forget cold or hot pads to ease painful or stiff joints if you use these regularly at home.

Travelling with medications

- If you are flying, check in advance with your airline to see what preparations you need to make to take your medications on board the plane. This will obviously vary depending on which RA meds you are taking. Some airlines may require a doctor's note to allow you to take your medications on board, particularly if you are travelling with syringes.
- If medications need to be kept cool it would be worth contacting your home delivery company for advice. It is unlikely that you will be able to use the fridges on board the plane to keep drugs cool but some home delivery services are able to provide a cool bag device and should be able to advise on the best way to travel with your medications. A cool bag with an ice-block in a tea towel can be effective in keeping medication cool for short periods. If you are flying, however, you will not be able to take an ice-block on board the plane so will need to pack it in your hold luggage before going through security. Ensure that you refrigerate your drugs as soon as possible upon arrival at your destination.
- Make sure you have a large enough supply of your drugs for the duration of the holiday and keep all medications in your hand luggage if allowed.

Flying/airports

- Travelling around some airports can require walking very long distances. If you do struggle with mobility it would be worth contacting the airline you're travelling with in advance to see if they can offer help with transportation around the airport. They may not be able to offer you assistance on the day if you have not prebooked in advance.
- Once on board the plane remember to do the range of motion exercises with your legs that are usually recommended on board and try to get up and move around from time to time to prevent joints from stiffening up.
- Perhaps think about taking an extra pillow for your neck if you're on a long haul flight and tend to find the airline pillows uncomfortable. This can usually be purchased at the airport.

Sun/heat

- Some drugs can make your skin more sensitive to the sunlight so take precautions to protect yourself from harmful rays. This is good practice for everyone whether you have RA or not. It is recommended in Cancer Research UK's SunSmart campaign to regularly re-apply sunscreen (factor 15+ ideally) particularly after swimming, try to stay out of the sun during the hottest part of the day (usually 11am – 3pm), and to wear a wide-brimmed hat and some good quality sunglasses to protect your eyes. It is also a good idea to drink plenty of water and cool drinks when in the heat to prevent dehydration.

Insurance

- Make sure you have a good holiday insurance policy and that your insurance company are aware of your medical conditions. Over the years NRAS members have made us aware of a number of insurance companies they have used to purchase travel insurance and while we do not endorse any companies in particular, please contact the helpline if you would like a copy of this list of companies (0800 2987650 or helpline@nras.org.uk).



Make sure you have a large enough supply of your drugs for the duration of the holiday and keep all medications in your hand luggage if allowed.

Useful sources of information on travel can be found in the 'Holidays and Transportation' section of the NRAS website under 'Useful Links'.

Female Sexual Dysfunction (FSD)

More common in women with RA

The study assessed whether there is a correlation between physical disability caused by disease and sexual functioning



Results from a recent study have suggested that female sexual dysfunction (FSD) is common in women with RA. Sexual dysfunction is defined as having persistent, recurrent problems with sexual response, desire, orgasm or pain during sex, any of which can prevent an individual from enjoying sex. The survey was conducted via anonymous surveys which were returned by 203 patients with RA and a control group of 169.

Using the Changes in Sexual Function Questionnaire (CSFQ-14), a well-established and validated questionnaire comprising of 14 questions, investigators sought to gauge the effect RA has on women's sexuality, with regards to desire, activity and satisfaction. Additionally, the Health Assessment Questionnaire – Disability Index and the Clinical Disease Activity Index questionnaires were distributed as part of the study to assess disease activity, depression and disability. The study additionally assessed whether there is a correlation between physical disability caused by disease and sexual functioning.

The results showed that 47.8% of the women with RA had a CSFQ-14 score of 41 or less, indicating FSD, whereas only 14.2% of the control group had results in this score range. Even after adjusting the data to compensate for the difference in the mean age of the two groups,

the results suggested that women with RA were significantly more likely to experience sexual dysfunction in comparison to the control group. Furthermore, the survey showed that 31.4% of the women felt their RA had affected their sexuality, with 86% reporting a lack of sexual desire, 25% reporting dryness as an issue and 14% experienced pain during intercourse. The scores from the disability and disease activity indices, however, did not show an association between the level of severity of RA and FSD.

The survey concluded that the data suggests sexual dysfunction in women who have RA is probably underestimated in daily clinical practice, as only 6.8% of the women with RA had sought professional help for a sexual problem. The report further added that more research should be carried out to identify interventions for women who have RA and who may be experiencing sexual problems.

Smoking linked to higher disease activity in Rheumatoid Arthritis

A recent study, published in The Journal of Rheumatology, has once again shown an association between smoking and increased disease activity in rheumatoid arthritis.

A total of 282 individuals (83% women, average age 59 years) diagnosed with RA, were observed every 3 months for 27 months. Data was collected at each hospital visit, on disease activity and smoking status along with variable data on age, race or ethnicity, use of medications, sex and obesity.

When comparing smokers to non-smokers two main measures of disease activity showed an

increase; an increase of 0.64 units in the patient global score and an increase of 2.58 more affected joints in the swollen joint count.

No association was found between smoking and CRP levels (a measure of inflammation in the body) and an opposite association, with smoking, was shown in the results for tender joint count.



Smoking can make RA medication less effective, and people with early RA who smoke are 50% less likely to respond to treatment.

People with RA who smoke may have a higher risk of heart diseases and lung cancer.

Smoking can cause the body to produce antibodies which are strongly associated with the development of RA.

Smoking is associated with the most severe forms of RA.

Patients are not meeting low disease activity targets

Study suggests patients are not meeting low disease activity targets, due to a lack of changes to their medication.

A recent study in the US has concluded that medication is not being altered when it should be, to meet low disease activity scores.

The study looked at information from the 'CORRONA' registry (a national database) and concentrated on the US healthcare system, which of course, is very different to the UK. However, the concern is universal for the successful treatment of rheumatoid arthritis, as it shows that the principles of 'Treat to Target' are not always being followed.

'Treat to Target' is a treatment approach that is often used in the treatment of many conditions, including rheumatoid arthritis. The basic principles of this approach are that a target should be set, a means of measuring whether it is achieved should be established and treatments should be altered accordingly, in order to achieve

that goal. In rheumatoid arthritis, the ultimate goal is, of course, remission, but this will not be achievable for everyone, but the ultimate aim will be to get the lowest possible levels of disease activity.

The study looked at RA patients at the beginning and end of a 7-12 month period and found that many had not had any changes made to their medication, despite continually high levels of disease activity. The study's lead, Dr Curtis, has concluded that these results show that rheumatology teams should be doing more to address the barriers to accelerating a patient's RA treatment and doing more to engage patients in helping to set their treatment goals.





Ailsa Bosworth, CEO (right) and Donna Saunders, Worcester Group Coordinator

Worcester NRAS Group 10 Year Celebration Meal

When I agreed to set up a local group for NRAS I didn't expect it to be still running 10 years later....

So, it was certainly a reason for celebration!

Worcester group attendees at our celebration meal were eager to hear our guest speaker Ailsa, talk about the work of NRAS. We felt privileged and honoured that Ailsa Bosworth and husband Brian travelled from Maidenhead to join us. I also said a few words to express my thanks to the group for their support, without them the group wouldn't exist.

In 2011 NRAS invited me to their 10 year celebratory meal. I remember feeling very lucky to be the chosen member to attend as guest speaker and to cut the cake with Ailsa. Those feelings were relived when Ailsa and I cut the Worcester NRAS Group 10 Year celebratory cake, baked and donated by Jenna Nicole Bailey.

My involvement with NRAS has certainly taken me on a path I would never have imagined. I have been involved in various projects and travelled to places I would not have been otherwise, but my biggest sense of achievement is setting up and running the Worcester NRAS Group...

As far as I was aware there was not a group in Worcester for people living with RA, so I felt certain that there was a need for it. I know I would have appreciated something similar when I was diagnosed in 1996.

I had been volunteering as a peer to peer support caller for NRAS for a little while. After learning to accept and cope with this disease I began to think that I could start to turn the negativity of living with RA into a positive. I wanted to raise awareness and understanding of this debilitating disease, while giving people the opportunity to speak to others with the same condition, to share stories, tips and concerns.

After attending a Coordinators workshop in Leeds, with lots of support from NRAS and the local Rheumatology team, Worcester NRAS Group began in January 2009.

I felt nervous and a great sense of responsibility at that very first meeting and still get those same feelings at the start of each meeting all these years later. Yet, the feeling of achievement and satisfaction at the end of a meeting makes it all worthwhile.

Over the years we have had an array of guest speakers, ranging from rheumatology consultants, physiotherapists, pilates instructor to a fireman!

I always try to keep a positive atmosphere within the group and find that the attendees are so supportive of each other. We also get together for social and fundraising events. It's been lovely to see so many friendships that have been formed through this. I personally have made new friends, seen people blossom and learn how to accept and cope with living with RA. I've seen families grow, find love, get married, have babies. Plus, sadly we've known of people who have passed away.

A lot has happened in 10 years, I feel thankful that NRAS took me on this pathway and proud that I may have made the RA journey just that little bit easier for others.

NRAS Groups

Oxford NRAS Group – Visit to Waterperry Gardens, Oxfordshire

As a change to their regular January Group meeting and to beat the January blues, the Oxford NRAS Group decided to take a trip to Waterperry Gardens in Oxfordshire as entry is free to the gardens in January.

A group of 16 people attended the day out. After touring the gardens they stayed for coffee and delicious cakes and then lunch in the tea rooms, chatting about all sorts of things in addition to members' experiences of their own RA. Waterperry is a perfect meeting place, with lots

of parking and excellent food in the tea room; it has something for everyone. For those just wanting a short stroll, there is a craft shop, a gift shop, a garden centre and a little rural museum; for a longer stroll, the large gardens have lots of interesting planting and sculptures.
www.waterperrygardens.co.uk

It was a lovely social outing to offset our normally formal talks. For a group like ours, it was the perfect venue and a valuable opportunity for members to get to know each other better.



NRAS 3 Counties Group

Our group was set up as 3 Counties in 2013 because we are on the borders of Surrey, Hampshire and Berkshire. We are very fortunate to have the support of the RA Department at Frimley Park Hospital. As the hospital is our focal point, we meet at a nearby church hall, it's not too big and has easy parking all on the flat. We meet every two months on a Tuesday 7.00-9.00pm.

We try to have speakers with a good knowledge about RA so that we can ask questions or try things that might either explain things or encourage us to do different activities to help ourselves. Our Consultants and Specialist Nurses come to explain the hospital treatment, procedures and related diseases. Other speakers tell us how biologics are being developed and what their function and methods are within our bodies. RA pharmacists on our medications and possible interactions. Optometrists on the impact of our treatments on the eyes, and Citizen Advice for benefits. The many speakers are clear and very helpful in the Q&A sessions and

very interesting. The sessions that might amuse spectators are when we try to do the physio and Tai chi exercises, when everyone is joining in and moving about, maybe not the most fluid of movements but an opportunity to learn tricks to help ourselves.

At the end of the meeting there is a chance for socialising and discussing the topic of the evening or getting helpful hints which makes for an enjoyable end to the evening. Our group feel that our audience benefits from having the chance to interact with others locally. Often we have people who are coming off treatments to biologics or completely new to RA, so the opportunity to see the NRAS literature and hear members' insights can be a source of relief.

During RA Awareness Week we tend to go into Frimley Park Hospital, on a clinic day, to promote NRAS and let people see the literature we have available and to inform them that there is a local NRAS group available for them.



NRAS Swansea Group

NRAS Swansea Group coordinator Cynthia Rees, spearheaded an independent fundraising initiative, with the help of Swansea NRAS Group members and local health professionals, during 2017 and 2018 with the aim of funding the purchase of a new state-of-the-art infusion chair for the local rheumatology unit. The chair has now been delivered to Neath Port Talbot

hospital's Rheumatology day unit. It is in regular use and being very much enjoyed by patients receiving their RA medication by infusion. NRAS would like to extend huge congratulations to Cynthia, members of the Swansea NRAS Group and everyone that supported this fundraising initiative!



NRAS Groups, continued from page 21



NRAS North East Group (Newcastle)

The National Rheumatoid Arthritis Society N.E. Volunteer Group was the first group to be set up in the Country in November 2005, with the support of Musculoskeletal Department and the management of the Hospital Trust at The Freeman Hospital.

We have had speakers from just about every Directorate in the Hospital and I am sure we are all grateful for all that tremendous information in helping us to live with our long-term condition.

Periodically we have held an information stand within the hospital where we can chat with patients and visitors about RA and what the group does to help people. They can take information booklets and information sheets we have to help themselves or someone they know suffering from RA.

On the social side we have been on coach tours to various places, one in the summer months and one to a Christmas Market each winter plus an annual event on the London Routemaster along the coast in the North East which is beautiful. We also have a monthly coffee morning and a monthly stall within the hospital selling crafts and other items along with NRAS badges, wristbands and pens.

RA Awareness Week is something we look forward to, and following on from the first one in 2013 where we had a London Routemaster bus in the centre of Newcastle as an information stand. We have continued to do this as it is a very big attraction and allows us to make everyone aware of RA. For the last few years we have had specialist nurse, Lesley Tiffen join us on board in the afternoon and this has been invaluable to us. I think she also enjoys helping us as she offers to join us every year. This year we will be taking the Routemaster to Northumberland Street on Tuesday 18th June 2019.

This year we will continue to arrange the meetings and events for everyone and carry on helping each other as we always have done. The support and information we get from NRAS with their wonderful publications and the support of the hospital is tremendous and we are so grateful. What has been achieved over the years of the N.E. Group are wonderful friendships. Hopefully the group will continue to grow and be there for whoever needs us in the future. I personally am very proud of the group.

Eleanor Houlston
N.E. Co-ordinator

ebay
FOR CHARITY

Recycling
FOR GOOD CAUSES

Are you looking to **DECLUTTER** or do your drawers need a spring clean?

Why not do some recycling or selling and help improve the lives of those living with RA and JIA at the same time!

With this magazine you will have received a freepost recycling envelope. Simply fill with any unwanted items of jewellery (plastic or metal), any old foreign or UK banknotes, then pop it back in the freepost envelope to **Recycling for Good Causes**. They can even recycle broken or damaged jewellery! Any funds raised will be sent directly to NRAS. If you need extra envelopes or have friends/family who would like one too, call the Fundraising team on **01628 823524** or email fundraising@nras.org.uk

Recycling for Good Causes can also recycle a range of larger electronic items, gadgets and collectables (e.g. old bank coins, stamps,

laptops, mobile phones and cameras). Simply request a free recycling box or sack by calling them direct on **0800 633 5323**. Involve your family, friends or workplace, and then arrange a free collection, at a convenient time for you, when it's full.

Have you received some unwanted Christmas presents? Selling on **eBay for Charity** is fun, easy and will put some extra cash in your pocket (as well as helping your favourite cause).

When selling on eBay for Charity, you can choose how much of your profits you would like to give to your chosen charity and Ebay rewards your support by offering you a fee credit based on your donation percentage. Why not give it a try? Go to www.ebay.co.uk/ebayforcharity and search for NRAS under 'Find a Charity.'



Best Value Biologics

Update on our work with NHS England

As many of you will be aware the biologic drug adalimumab (Humira) no longer has exclusivity as there are now 4 other biosimilar alternatives available. This will lead to a significant number of patients being switched from the originator product (Humira) to an alternative biosimilar, depending on the contracting deals that have been negotiated in specific areas.

Ailsa and I have been working with NHS England alongside other patient organisations i.e. National Ankylosing Spondylitis Society, RNIB, Birdshot Uveitis Society, Psoriasis Association and Crohn's & Colitis UK, to ensure that patients have adequate and appropriate communications around the biosimilar switching process.

We have all been really pleased with how NHS England has listened to our input and taken on board our suggestions for the various documents being made available to patients and health professionals. These documents include the Frequently Asked Questions, Nurse Briefing, patient template letter for clinical units to use when communicating with individuals about the switching process.

The patient organisations group now plan to survey our respective patient populations over the coming months, to understand how the adalimumab best value biologic process is being managed across the UK. If you have been affected by switching your adalimumab treatment, I would urge you to complete the survey questionnaire when it goes live in early April. The findings will be presented back to NHS England and we will share the report in due course via this magazine and our website.

For information on biosimilars you can visit www.nras.org.uk/biosimilars to find the latest information on biosimilars as well as links to our updated NRAS Position Statement and the Specialist Pharmacy Service where all the previously mentioned resources are available to download.



By Clare Jacklin

Deputy CEO, NRAS



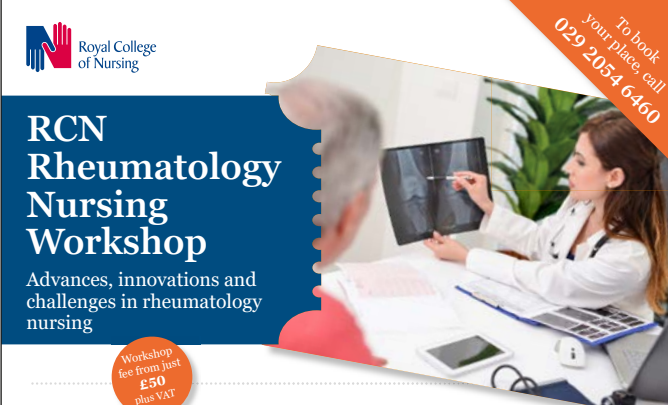
Give as you Live™

amazon smile


Shop and raise!

Did you know you can shop and raise funds for NRAS at no extra cost to you? Over £10,000 has been raised for the charity simply by supporters doing their usual shopping online! Shop through Amazon smile and 0.5% of your purchase is donated to NRAS. Shop at over 4,000 stores via Give as you Live to raise anything from 1% to 5%! Think of NRAS next time you order your food shop or book your next holiday and raise valuable funds for those living with RA/JIA.

Visit www.nras.org.uk/ways-to-give to find out more



To book your place, call 029 2054 6460



RCN Rheumatology Nursing Workshop

Advances, innovations and challenges in rheumatology nursing

Workshop fee from just **£50** plus VAT

Whether you are an experienced or aspiring rheumatology nurse specialist wanting to stay ahead of the curve, attend this one day workshop to get those all-important updates to support your professional development, as well as an opportunity to network and share best practice with like-minded professionals.

By attending this workshop you will:

- hear from leading experts on current issues and challenges facing rheumatology practitioners
- gain an in-depth understanding of emerging drug therapies and the importance of drug monitoring
- advance your knowledge and skills to deliver and promote excellence in care.

Workshop topics include

- Understanding the JAK pathway
- Demystifying the BSR DMARD guidelines
- Understanding vasculitis and impact on inflammatory arthritis patients
- What's new in managing the telephone advice line

Programme timings

10.30am - 11am	Registration
11am - 3.15pm	Workshop

“ What our past delegates said:

Thank you for an informative meeting, the speakers were all very knowledgeable and experts in their field as well as passionate about their subject matter

Very informative, very relevant, very beneficial



Really enjoyed the study day - it provided a good balance of science, clinical and professional development topics

A thoroughly enjoyable day with great speakers - I came away feeling very inspired

For further information, to view the programme and book, visit www.rcn.org.uk/rheumatology19

Friday 28 June 2019
 RCN HQ, 20 Cavendish Square, London, W1G 0RN

Accrue up to 4.5 hours of CPD



Huge thanks to our NRAS Fundraisers!

Great North Run – 8th & 9th Sept 2018

The Great North Run is the largest half marathon in the world which takes place annually in North East England every September. Participants run between Newcastle upon Tyne and South Shields.

A huge thank you to all the runners who took part in the Great North Run on 9th Sept and

the Mini run on 8th Sept 2018 raising funds to support NRAS services.

The total raised was **£3,944** which is fantastic! Well done!



Galadriel Ruck-Keene



Karen Gibson



Michelle Scorer & Jennifer Lee



Kate & Lukas Flynn

Royal Parks Half Marathon, Sunday 14th October 2018

Starting and finishing in Hyde Park, with the crowds cheering you on every step of the way, the stunning 13.1 mile route takes in the capital's world-famous landmarks on closed roads, and four of London's eight Royal Parks – Hyde Park, The Green Park, St James's Park and Kensington Gardens.

A big thank you to all who took part in the Royal Parks Half Marathon, it was pouring down with

rain, which didn't dampen their spirits, it was such a fun day!

With a fantastic overall fundraising total of: **£3,348**

Katy Pieris, Natalie Bennett, Ignacio Fiestas, Massimo Fusato, Andis Mema, Team Tom-Tom (Tom Minter & Tom Waring).



Natalie Bennett



Katy Pieris



NRAS Team supporting on the day! Raman Fenech, Bronwen Cranfield, Olivia Cranfield



Andis Mema

Halloween Walk, Saturday 27th October 2018

A huge thank you to all who took part in the Halloween Walk this year!

15km walk starting at Putney, South West London with a Zumba Style warm up then an amazing scenic route finishing off with a medal and a fortifying hot meal.

Kay Legge and her partner raised an amazing **£650.00**

How fantastic they look in the scary spooky costumes...



Kay Legge and friends



Kay Legge



NRAS Carol Concert 2018!



Clare Jacklin, Deputy CEO, NRAS our compere, with Voices Anon



NRAS Ronettes – Ailsa, Lorraine and Emma

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

We were delighted to welcome some special guests:

The Prime Minister, The Right Honourable Theresa May MP, The High Sheriff of Berkshire Mr Graham Barker and The Mayor of Windsor & Maidenhead Councillor Paul Lion.

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

Every year we are supported by the local businesses with donations or refreshments for the night, so thank you again to Shanly Foundation, Michael Burbridge Creative, The Handmade Cake Company, Maidenhead, Marks & Spencer, Maidenhead, Tesco Extra, Furze Platt and Sainsburys, Wootton Way.

NRAS raised a fantastic total of **£2,912.00!**

NRAS: How Brexit may impact you



Over the last few months, NRAS has asked its members and supporters to contact their MPs to raise various issues about the UK's departure from the European Union and any impact this may have on people with RA and JIA. Over 750 emails were sent to MPs from across the political spectrum, raising issues including:

- Sufficient rheumatology workforce
- Future innovation for research into treatments
- Access to treatment and care in EU countries
- Access to medicines

Regarding workforce issues, some MPs have raised concerns about recruiting staff from EU Member States once 'freedom of movement' ends. Currently, over 5% of staff working in the NHS are EU nationals. However, other MPs have stated that this may not be an issue, as healthcare professionals, such as doctors and nurses, have been taken out of the 'Tier 2 visa cap', meaning that there is not a limit on the number of skilled healthcare professionals coming into the UK.

Many MPs have raised concerns about the future of innovation and research into treatments for diseases such as RA, particularly in light of the UK's close scientific relationships with neighbours in the EU. The UK Government launched its Industrial Strategy in 2018, and Ministers have pledged to build on existing relationships and open up new opportunities.

Millions of people in the UK have a European Health Insurance Card (EHIC), which entitles people to medical treatment when in an EU member state (also referred to as 'reciprocal healthcare'). NRAS understands that if the UK leaves the EU without a deal, the EHIC will no longer apply in EU member states. However, if a deal is negotiated and the UK enters a 'transition period', the EHIC will apply during this period.

Access to medicines has been one of the most important and contentious issues, and NRAS has seen a wide variety of responses from MPs on this issue. The Government has stated that it is committed to ensuring that patients have safe and timely access to medicines and that it is prepared for all exit scenarios. The Government has asked pharmaceutical companies to stockpile 6 weeks' supply of prescription-only and pharmacy medicines, over and above their business-as-usual buffer stocks. However, the

Government has not released the lists of medical supplies for which it is seeking to develop stockpiling arrangements, and therefore it is unknown as to whether RA drugs are included within this scope.

NRAS asked its Members to raise concerns with their Members of Parliament about the Government's 'serious shortage protocols', which indicated that medicines could be automatically switched by a pharmacist without discussing with the prescriber. This was a serious concern, as any changes in medicines for people with RA could cause a flare. The Government has confirmed that this protocol will only apply to suitable medicines, which does not include biologics, where the medicines need to be prescribed by brand for clinical reasons. This will come as a relief to many people with RA. However, concerns remain around other medicines (with the exception of biologics) where no such confirmation has been received. It is worth noting, however, that there is currently a motion to overturn these regulations by the Opposition, particularly in light of concerns raised by the Royal College of General Practitioners and the British Medical Association.

It has also been noted that, although the devolved administrations (Wales, Scotland, Northern Ireland) are responsible for Health and Social Care, the UK Government's Department for Health and Social Care has overall responsibility for ensuring the continuity of the supply of medicines, and devolved nations have opted to utilise the UK Government's contingency arrangements.

Whilst NRAS remains politically impartial, the charity's Chief Executive co-signed a letter on 22nd February 2019 urging the Prime Minister to prevent the UK leaving the EU without a negotiated deal, due to the impact that this could have on people with RA and JIA. This is available to read on the 'News' section of the NRAS website.

We are grateful for so many people getting involved in our campaign to ask MPs about the implications of the UK leaving the EU in relation to RA. The high volume of correspondence to the Minister for Health has ensured that we have obtained all of the above information, and NRAS is therefore able to pass this on more widely. A big thank you to everyone who participated.

The UK Government's Department for Health and Social Care has overall responsibility for ensuring the continuity of the supply of medicines



Shaping the rheumatology service in Scotland – the patient voice

Survey of patients with established disease

The Scottish patient experience survey of people with established disease was carried out in RA clinics across the country over the winter of 2017/18 with an excellent response rate and geographical spread. Results were very encouraging, expressing an overwhelmingly positive view of the service we all use. Possible areas of weakness highlighted in the findings included poor co-ordination between secondary and primary care, inadequate access to self-management training, too little signposting to patient or other organisations offering information/help, and some delays in offering appointments in the case of unexpected cancellation or additional clinical need arising.

Representatives of NRAS have been involved throughout in this exercise and we continue to take part in discussions with the Scottish Society for Rheumatology (SSR) about exploring the scope for real improvements which might be made in the service in response to survey findings.

You may see an outline of the findings here in the form in which they were presented to the SSR conference last November: <https://www.nras.org.uk/shaping-the-rheumatology-service-in-scotland-the-patient-voice>

Scottish Quality Registry (ScotQR)

NRAS members and supporters in Scotland will already have heard something about this initiative which will be trialled for a twelve-week period, beginning later this month, in two areas of Scotland, NHS Greater Glasgow and Clyde and NHS Lanarkshire. The project is being organised by Healthcare Improvement Scotland with the help of a grant from the Health Foundation. Patient views have been taken into account throughout planning and implementation stages. The system, inspired by arrangements used successfully in Sweden for some time, is designed to offer and strengthen patient-centred care, to make a reality of the doctor/patient partnership

and shared decision making, to support informed self-management and to promote continuity of care through symptom-tracking and measurement of outcomes.

The focus of the consultation in clinic will be an online tool or 'dashboard' which will combine patient-reported wellbeing outcomes with validated clinical information. Patient and clinician will use this as the basis and framework for their conversation, matters raised and shared decisions will be logged, as well as printed out for the patient to retain. In a fully operational system this online resource would be available to patients between routine appointments as a means of recording information and two-way communication; the pilot, being time limited, will not yet include this. Participants at the two pilot sites – both members of the clinical team and patients – will be asked for feedback. The testing of the ScotQR is designed to inform the construction and evaluation of a business case for the further roll out of the registry approach across Scotland within rheumatology as well as possible extension to other specialties.

The benefits to be gained from a quality registry approach; better communication, smoother continuity of care, more timely interventions when required, stronger patient voice both in individual care and in pathway redesign, availability of useful data and, above all, better outcomes, (in Sweden a 50% reduction in the effects of disease has been claimed among people with RA) make this an exciting initiative. If you live in one of the pilot sites you will probably have received information already – or will be given all you need ahead of participation. Elsewhere, we will keep you in the picture in the hope that this scheme will be available to everyone in Scotland in the near, or at least the foreseeable future.

Greater Manchester – Pathways to Better Care

NRAS has been working in Manchester to empower patients

On 7th March, NRAS held a 'Pathways to Better Care' roundtable meeting in Manchester, involving clinicians and patients.

Over the last couple of years, NRAS has been working in Manchester to empower patients and ensure that rheumatology is at the forefront of the development of Greater Manchester's 'Integrated Care System'. RA still has an unmet clinical need, and with Greater Manchester's healthcare devolution deal in mind, this meeting provided an excellent opportunity to gain a better understanding of what care for people with RA in Manchester is like, and how this can be improved going forward.

Discussions focussed on what currently works well across different hospitals in Greater

Manchester and what the existing challenges are, including the existence of 'early arthritis clinics', access to different members of the multi-disciplinary team (MDT), access to a nurse-led helpline, group consultations, access to supported self-management, and many other topics.

Attendees were then presented with a patient empowerment toolkit, which explains how the healthcare system operates in Greater Manchester and in the UK more widely, as well as how people can influence the decisions that affect people with RA.

If you'd like more information and are interested in joining our next meeting, please contact us at campaigns@nras.org.uk.



Event in the Assembly for Wales

NRAS will be holding an event in the Welsh Assembly later this year to raise awareness of RA amongst Assembly Members and the general public in Wales. We are hoping many of our Members, supporters and fundraisers will join us for this exciting event. NRAS will also

be releasing a new policy briefing for Wales on mental health, and will be exploring issues relating to RA, JIA and work. If you are interested in attending, please contact campaigns@nras.org.uk for further information.



My Story ~ Jennifer Lee

Let's start at the beginning then...

2011 and I've been in my new job for a couple of months, it's going ok but the commute is tough (3 hours a day) and they're not the most welcoming of people – the new boss brought me in and that makes me an outsider.

I'm struggling with my feet and have been for a while now; I do have a penchant for high heels so have decided that I must just limit the distance I walk in some of the more towering efforts. It's funny though, because the time when they are worst is when I'm barefoot. In fact over about 6 weeks it's become pretty unbearable so I've relented and booked in to see the GP.

'Hmm', he looks at them and then asks about my hands and says he's going to refer me to the hospital for some tests. I don't know what he did, but since then my hands have been sore, and my knees, and my elbows, and my wrists and... well just about every part of my body.

I can't get up the stairs.

I can't get down the stairs.

I can't change my bed.

I can't fasten / unfasten my bra.

I can't squeeze toothpaste out.

I can't exercise.

I can't get out of bed.

What is wrong with me?

You've got rheumatoid arthritis. I don't even know what that is. But I've got something, I'm not going mad, I have something they can treat: but I don't understand, I've only just turned 27.

My mum and I walk slowly out, I will not use the lift, I will use the stairs even if it takes me all day. I get home and spread my loot on the coffee table:

- Steroids (they're for the immediate pain, I'll have to carry a special medical alert card)
- Methotrexate (DMARD) (I'll obviously google that one, I will entirely confuse my google search with this very nice doctor's medical degree)
- Buccastem (for the effects of the above)
- Diclofenac (NSAID) (for the pain but not as immediate as the steroids)
- Omeprazole (for the effects of the above)

36 hours later; 'Why doesn't everyone just take steroids, I think I might be the happiest person in the world right now'.

3 months pass and the steroids reduce. It turns out that whilst they have a lovely smoothing effect normally the result of botox, they do unfortunately turn your face into something resembling the moon. I feel like I'm back at square one and here is where I hit absolute rock bottom. I can no longer cope, the pain is as bad as ever and I'm just supposed to carry on. These horrible drugs that are making my hair fall out are doing nothing. What is the point in any of it? On many journeys to and from work (power steering is the only way I managed this), I am picking out spots where it might be a good place to crash. Things to consider; must not cause actual death, as maiming would suffice, must not cause a tailback or injure anyone else, nobody else needs their day ruined and must happen on route to work rather than spending a further



Jennifer with her husband Martin and their daughter

minute in pain at work pretending to be ok and not the sick new girl.

I didn't do it, I instead pulled over, had a panic attack and spent a week with my mum. Which was spent sleeping, slow dog walking on the beach and eating macaroni cheese.

So from what has just happened you have probably gathered the methotrexate isn't quite cutting it, cue more 'sweeties' to add to the mix:

- Hydroxychloroquine (DMARD) (yes I googled that too, malaria – excellent, high occurrence of malaria bearing mosquitos in Scotland)
- Fluoxetine (turns out I'm now depressed as well – wouldn't you be?)

I have to sort this out. I read everything, I tried every diet: no dairy, no nightshade, drinking cider vinegar and molasses because it will cure me. I then turned to alternative and after they see me coming, I am recommended a course of various herbs and spices (that tasted like an old foot) and told to stick with it and in a matter of months I'll be off the toxic drugs and onto a natural, herbal drug induced remission. Obviously if something comes from a plant it can't be toxic. Everyone knows that.

I have also tried a hyperbaric chamber, meeting a lovely group of people in the process but not too much physical improvement. I've tried swimming, horse-riding, ballet, acupuncture, cupping therapy; there has to be something?

Three months passed and turns out turmeric and herbs won't cure this, nor will avoiding tomatoes.

I've failed two DMARDS so now I qualify for a fancy new drug:

- Certulizomab (biologic)

It's an injection, which does terrify me but please just let something take away this pain.

I'll jump forward again, those next three months seemed much the same but slowly, without me noticing, something started to change. I wasn't sore every day, I was starting to bend again and my feet, my lovely feet were back to their former size.

It has taken a year and goodness, many of you will be thinking, I had those symptoms for years, so what can I say? I was lucky I suppose. Not lucky at getting this horrible disease, but lucky that it didn't take years of trying different things, hoping that one day something would work. You see RA isn't like having a headache, where you know that generally a paracetamol will work for the majority of us. They (those higher beings) don't know what causes it, and they don't have a one size fits all, it's all about luck I suppose.

Now in a physically better place, it's time to look at my life and my work. What makes me happy and more importantly what doesn't. Since I spend so many hours at it, work is a good place to start; I've only gone and found a job 5 minutes from my flat in Edinburgh – with underground, on-site parking. This is the stuff dreams are made of. Next, I've met someone, he understands my disease, tolerates my cat and hasn't run a mile; he has strange taste in films but we can't have it all.

And whilst all these changes in my life are happening my joints have been very quiet, the odd ache and injection here and there but strangely absent from pain. It is one of those diseases that seems to drop you into boiling water but then as it does cool down, you're still in that haze of earlier shock that you don't necessarily notice the gradual improvements until suddenly you're out of the water and dry.

What has changed is that I am more aware these days that I can't do everything I used to, I do have to accept that I have to pace myself more and give myself time to rest, and also remember to be kind to myself!

Fast forward 7 years and I'm married (to a rheumatologist – not mine, I met him when he was on sabbatical raising money for NRAS and I was working in radio). We have a 2 & ½ year old daughter (turns out you can do that when you have RA, you just have to plan it a bit more). I volunteer to run courses at the local hospital helping people newly diagnosed with RA. I've just completed my first half marathon (raising money for NRAS) and last year I got invited by the PM to 10 Downing Street in recognition of the previous two points.

I can do what anyone else can do: I love cycling (when it's dry), I sometimes love running, I hate swimming in the UK (it's wet, it's exhausting and just no), I love cooking and in the summer am desperately trying to be like Monty Don in our little garden by the sea. I also like to lie on the sofa and watch a film with a glass of wine and family pack of maltesers.

So what can I say, my life is very different from the one it was 7 years ago. I'm a different person and have grown and learned so much, not just about my condition but about myself. Whilst I would love not to have RA, I wouldn't be where I am now if it wasn't for it and I cannot imagine my life without what I have now. My husband and my daughter mean everything to me, and if you'd asked me 7 years ago to imagine where I'd be now, I would never have dreamed that it would have all just turned out.

Jen, aged 35 (and clinging to it).

Those next three months seemed much the same but slowly, without me noticing, something started to change.



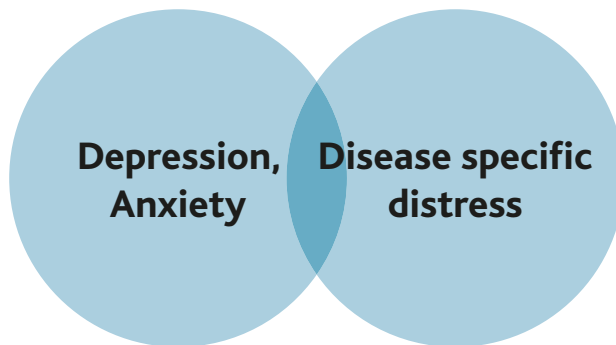
By Linda Silke

Disease-Specific Distress in Rheumatoid Arthritis

Living with rheumatoid arthritis (RA) can be physically challenging, with joint pain, fatigue and functional disability, being common difficulties facing people living with the condition. It can be psychologically or mentally challenging also, and increased rates of depression and anxiety have been reported in people with RA.

A different type of psychological difficulty has emerged from the scientific research called 'disease-specific distress' (DSD). This is a form of psychological distress specific to the impact and burden of living with a long-term condition, its symptoms and/or treatment. People experiencing DSD may report that they don't feel depressed or anxious but feel frustrated with the demands of living with their condition. This means that people with DSD may not necessarily have a diagnosis of depression or anxiety, although there may be some overlap in some cases (See Fig. 1). Research has shown that DSD is well established in other conditions like cancer, diabetes and irritable bowel disease, and it also seems to exist in some people with RA.

Figure 1.



Previous research that analysed interviews of patients with RA found various so-called themes of DSD. For example, some people appeared to report 'physical-related distress' e.g. from the pain experienced with their condition, while others reported 'social distress' e.g. the impact having RA has on personal relationships. This study confirmed that DSD was indeed a real and important issue in RA and highlighted some of the aspects of living with the condition that can cause concern or frustration. The next step was to develop a tool that would help identify people with RA who are experiencing this DSD.

This tool took the form of a questionnaire. It was developed as part of a research study using the previously reported themes of RA distress mentioned above. These were used to help form statements for the questionnaire (e.g. 'I feel frustrated because my RA pain limits my mobility'). This was then presented to a patient group who made suggestions on the relevancy, wording and structure of the tool. The final draft was presented individually to members of NRAS, who kindly volunteered their time to assess if the questionnaire was relevant and made sense to people living with RA. The interviews provided a unique insight into life with RA, and their expertise was invaluable in the creation of this tool.

The final version of the questionnaire was called the Rheumatoid Arthritis Distress Scale (RADS). Overall, participants in our study reported that the RADS was clear and relevant. It is hoped that in the future, after further testing, this measure can be used to help identify people with RA who are experiencing DSD. Identification is the first step before potential treatments can be developed. Effective treatments have already been developed in people with diabetes who are experiencing DSD, and, importantly, treating this diabetes-specific distress also seems to improve clinical outcomes like blood sugar levels. This demonstrates there may be a link between the psychological well-being and physical well-being in some conditions. Whether this is the case for RA remains to be seen, but the important first step in trying to identify DSD in people with RA has been made.

I would like to thank everyone in the patient group and all members of NRAS who participated in interviews for their time, expertise and enthusiasm.

Amelie's story

Amelie is 9 years old and has JIA

By Helena Jones

Amelie was a difficult pregnancy and was early diagnosed as an IUGR (Intrauterine growth restriction) baby with severe complications.

My waters broke at 27 weeks and Amelie came early at 34 weeks weighing just 3lbs. It was clear from birth something wasn't quite right. Amelie was born with club feet and a slight displacement of the hip.

Amelie was a very unsettled baby and cried constantly day and night. She struggled to feed and was sick continuously. Eventually being diagnosed with chronic lactose intolerance and acid reflux. Whilst symptoms improved after medication it was becoming clear Amelie was not meeting any physical milestones. She developed severe plagiocephaly (also known as flat head syndrome) and her neck was dropping to one side.

We were treated very poorly by our local Paediatrics team who insisted nothing was wrong. She was eventually diagnosed with Hypermobility Syndrome but my pleas to investigate further fell on deaf ears.

Amelie took her first step at the age of 2½. But didn't walk unaided or confidently till she was well over 3 years of age. She seemed in constant pain and cried and cried. It was impossible to leave her which created a bond between her and I which is so very special. A positive to come out of what was to be a devastating diagnosis.

When Amelie turned 4, "choose and book" came into practice in our area and I demanded an appointment at Sheffield Children's Hospital, a specialist hospital with phenomenal reviews. They couldn't refuse. Amelie met with a joint specialist for the first time a few months later. Lots of tests and scans were arranged and we were booked in with a physiotherapist.

I'll never forget that day. Amelie's little joints were measured and moved, and she played happily along unaware, but I knew something was dreadfully wrong. I pleaded for just a snippet of what was happening, and arthritis was mentioned as a strong possibility.

When we went to meet with the rheumatologist, he confirmed what we knew really but had been dreading. Amelie's inflammation markers which should have been below 10 were at 78. She had large amounts of fluid on both knees and was unable to properly move lots of other joints. The

effect on us as a family was devastating but also one of relief, we knew something was seriously wrong and in some ways an air relief knowing why she had struggled for four years.

That was the start endless hospital visits to try and dampen down Amelie's arthritis. She quickly had to start Methotrexate which alone made her so sick and poorly. Sadly, this didn't work so Amelie started on Etanercept along with Methotrexate but again this didn't work so Amelie switched to Adilimumab.

You hold out so much hope when a new drug is tried but 2 years down the line sadly this too has failed to keep the constant flares at bay. She has recently tried Tocylimumab but the side effects were so severe she had to stop after just one injection. Amelie must have regular steroid injections and blood tests and has had to miss so much school, it is heart-breaking to see.

Despite this she remains a grade A student and works hard to keep her education at that level. She is a very determined little girl.

She has consequently developed a fear of hospitals and hospital procedures. This has also led her to suffer with extreme anxiety and panic attacks. This is a side which we as a family are very concerned about especially as she grows up into a teenager with life's normal worries.

Amelie struggles day to day. She can't do PE, she can't go to sleepovers, she can't walk long distances and gets so very tired. It's hard on all the family, my husband and I and her little brother. It's so upsetting for her to see children her age running around and playing tag, she often sits on the side-lines. She constantly picks up infections from being immune suppressed and we must be so very careful if she goes near anyone with serious illness.

People also don't understand. I've lost a lot of friends as we are unreliable and cancel constantly; flares come on so quickly some people don't see it, so can't understand it. Whilst others are our friends for life and I don't know what we would do without them.

Amelie is a sensitive kind caring bright little girl whom I wouldn't change for the world. She has an infectious laugh a huge heart and a beaming smile despite her daily challenges.

We remain in hope that one day there will be a breakthrough and Amelie can live without pain.





By Dr Yeliz Prior

Living with arthritis

Dr Yeliz Prior is a Clinical Academic Researcher at the University of Salford, Advanced Practitioner in Occupational Therapy and the founder and lead of the www.MSKHUB.com and online self-management platform for people with rheumatic and musculoskeletal conditions.

I feel as if arthritis has played a part in my life from an early age. I was diagnosed with Acute Rheumatic Fever soon after my 7th birthday. I remember coming back from summer holidays, where I spent the majority of my time by the seaside; swimming, playing on the beach, building sand castles and getting sun burnt. On my return home, I had streptococcal pharyngitis and couldn't get out of bed for the rest of the holidays. This was followed by various red spots and bruises appearing around my knees, ankles and foot, which were tender and painful to touch, so prevented me from walking. Following a series of visits to various doctors and specialists, my treatment involved using long-term antibiotics to avoid recurrent infections to prevent progression to rheumatic heart disease. I had monthly penicillin injections at a local Italian Hospital in Istanbul for years to follow. It stung and

temporarily numbed my lower limbs, causing me to limp for the rest of the day, which was not the image I was trying to portray at school! The distinct scent of the antibiotics is etched into my memory to this day, and I used to get anxious when entering a pharmacy until my late teens, as I came to associate the scent with my traumatic visits to the hospital. On the upside, we always stopped by the fancy stationery shop by the hospital afterwards and I was allowed to buy a nice pencil or a scented eraser to stop me feeling sorry for myself.

Since then, I have been diagnosed with other types of arthritis to include Juvenile Idiopathic Arthritis, Undifferentiated Spondyloarthritis (USpA), Osteoarthritis and Fibromyalgia, all of which have common symptoms of widespread chronic pain, fatigue, sleep difficulties and dyscognition. I have learned that arthritis is here to stay and if I am to have a 'normal' life, I have to learn to live with it. So, I continue my life, pursuing my goals with a sense of resolve to not give in, by adapting the way I do things. As and when it tried to stop me in my tracks, I developed my own self management strategies.

What is your gut telling you?

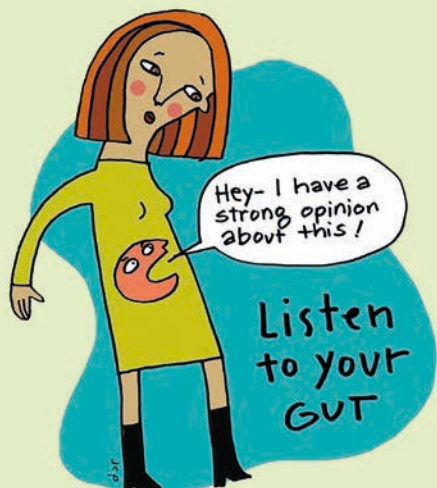
An extract from Dr Yeliz Prior's November 2018 blog

Did you know that your gut is practically your second brain? Yes, indeed the enteric nervous system is often referred to as our second brain and it houses a complete ecosystem of microbiome [a diverse range of bacteria, yeast, parasites, and other single-celled organisms that live in and on our bodies] which is as unique to us as our fingerprint. The gut is also lined with a vast neural network comprises some 100 million neurons. To put this into perspective, our gut has more neurons than our spinal cord and it gives more information to our brain than it receives. So, our gut is not only the main portal to our external environment, but also runs the complex procedures such as processing food, absorbing nutrients, dealing with infectious agents and toxic substances and finely tuning our immune system pretty much by itself. Ok, our gut is not our thinking brain, it does not help us to pass an exam or to multi-task, but there is a growing evidence to suggests that our gut strongly influences how we feel. I am not simply referring to times that when we feel bloated and uncomfortable, and therefore not in the mood; the gut-brain axis -the biochemical signalling that takes place between the gut and the central nervous system (CNS)- is so sophisticated, changes in the composition of the gut flora causes changes in levels of circulating cytokines, some of which can affect brain

function. Cytokines act through receptors and are especially important in the immune system. Considering the fact there are at least 80 types of autoimmune diseases such as Juvenile Idiopathic Arthritis (JIA), Rheumatoid Arthritis (RA), Inflammatory Bowel Disease (IBD), and Systemic Lupus Erythematosus [SLE], which are commonly chronic, debilitating and sometimes disabling, it is about time that we start to pay attention to what our guts are telling us.

Because our gut is so sophisticated and interconnected with our entire body, multitude of factors can affect its balance. If our lifestyle choices lead to stress and anxiety, poor dietary habits, illness and sedentary behaviour, which we often try to fix with taking cocktail of drugs, these can lead to abdominal pain, bloating, nausea and vomiting, indigestion, constipation, diarrhoea and flatulence (wind). Moreover, we know that the gut produces more than 90% of the body's serotonin, a hormone that helps regulate our mood or emotions. If the gut is not functioning well, regulation of such vital hormones are also affected.

To cut the long story short, if our gut is not happy, it is unlikely that we can be happy and contented.



The Beneficial Effects of Physical Activity

on Cardiovascular Function in Rheumatoid Arthritis

Strong evidence, that has emerged over the last 10 years, suggests that physical activity can significantly improve the way that both our heart and our arteries function. Our cardiovascular system comprises our heart and our vessels [arteries that deliver the blood to internal organs and muscles] capillaries where the exchange of oxygen and nutrients occurs between the bloodstream and our organs, and the veins that drain carbon dioxide and metabolites (any substance that is created during metabolism) from our organs. The structure and the function of our cardiovascular system changes significantly and beneficially, in response to physical activity.

Work that we have done in our laboratory has confirmed some very positive results in the cardiovascular systems of people with rheumatoid arthritis (RA) who engaged with physical activity. This study, that has been published in the *Annals of Rheumatic Diseases*, investigated the effects of physical activity on both cardiac and vascular function in RA. This study investigated two groups over a six-month period:

- The exercise group: this group engaged in medium-to-high intensity exercise (e.g. walking on the treadmill, cycling, weight training after the 3rd month) which was co-developed with our RA patients according to their functional ability, needs and preferences, three times per week.
- The control group that followed standard practice: this group received information about the benefits of physical activity at baseline but were not given any exercise intervention.

As expected, just providing physical activity information to our control group did not result in any beneficial changes to the cardiac and/or the vascular systems. We know that providing support to engage in physical activity as well as having experienced/knowledgeable exercise professionals involved, is key in getting people with RA to engage with physical activity. In contrast, significant beneficial changes were observed in our exercise group. Specifically, people that engaged in our exercise program improved their cardiorespiratory fitness markedly as well as their vascular function. To assess

vascular function we used different methods: we investigated changes in the large as well as the small arteries (macro- and micro-vascular function, respectively), with both sized-vessels demonstrating a significant improvement i.e. a reduced risk for developing vascular dysfunction. Vascular dysfunction can promote atherosclerosis (this is the narrowing and stiffening of our hearts' arteries which is what causes heart attacks), a function that we saw could be markedly improved through exercise.

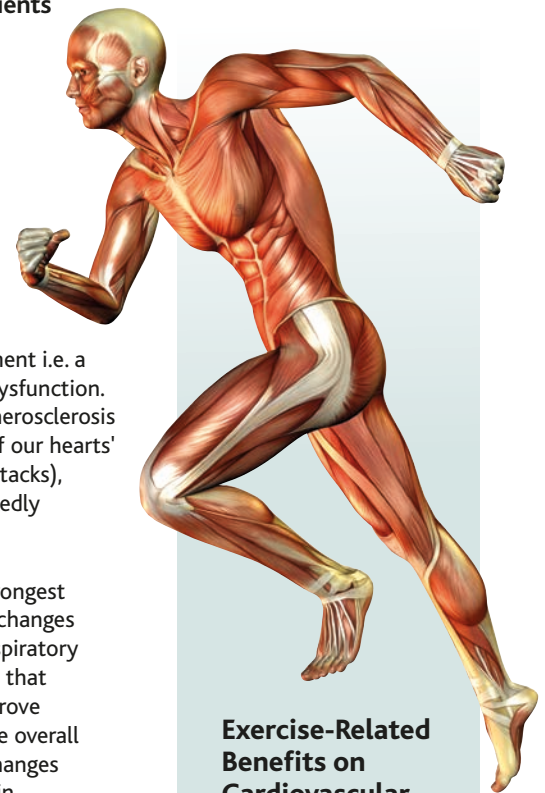
Our results demonstrated that the strongest predictor of these beneficial vascular changes was the improvement in the cardiorespiratory fitness. This confirmed our hypothesis that exercise and physical activity can improve cardiovascular health in RA and reduce overall cardiovascular risk. These beneficial changes coincided with significant reductions in inflammation, since exercise can also have anti-inflammatory effects.

Despite the multiple different beneficial effects of physical activity in RA, including reductions in fatigue, pain and inflammation, its implementation in clinical practice and its overall use for better management of RA in routine outpatient clinics is currently lacking. We are currently trying to identify ways of using physical activity for improving the health of people with RA. NRAS is also engaged with studies in this area and is supportive of these recommendations.

For more information about exercise, please visit the NRAS website: www.nras.org.uk/exercise



By George Metsios



Exercise-Related Benefits on Cardiovascular Health in RA

- ↑ Cardiac output: more blood ejected from the heart per minute
- ↑ Stroke volume: more blood ejected from the heart with one heart beat (more efficient heart)
- ↑ Cardiac and respiratory fitness
- ↑ Vascular function (both macro- and micro-vascular)
- ↑ HDL (good) cholesterol
- ↓ Resting heart rate
- ↓ Cardiovascular 10-year risk
- ↓ Risk of Diabetes
- ↓ Blood pressure
- ↓ Fatness

Wear purple for JIA at NRAS



#wearpurpleforJIA

#wearpurpleforJIA



Wear purple for JIA at NRAS

Friday 7 June 2019

- ▶ Raise awareness about Juvenile Idiopathic Arthritis (JIA)
- ▶ Raise funds for JIA at NRAS
- ▶ Get your school, friends or colleagues at work involved
- ▶ Wear purple to show you care

For help with ideas, get in touch with the team
jia@nras.org.uk



Order your fundraising pack from

www.wearpurpleforjia.com



JIA-at-NRAS is a part of the National Rheumatoid Arthritis Society (NRAS). NRAS is a registered charity in England and Wales (1134859) and Scotland (SC039721). A company limited by guarantee. Registered company in England and Wales (7127101).

Looking for a Challenge? for 2019



Raise funds for National Rheumatoid Arthritis Society
To support everyone living with RA and JIA
www.nras.org.uk

Looking for a Challenge for 2019?

Order your Events brochure at fundraising@nras.org.uk

Events Diary

30 May	NRAS Open Day. Frogmore Gardens, Windsor
7 June	#WearPurpleforJIA
17-23 June	NRAS Rheumatoid Arthritis Awareness Week (RAAW)
22 June	Rheum for You. London
29 June	JIA Family Day. Ilkley, Yorkshire
30 July	JIA Bushcraft Day for Teens. Cornbury Park, Oxford
1 August	JIA Bushcraft Day for Teens. Castle Howard, Leeds
4 August	Ride London 100. Places available
14 September	JIA Family Day. Exeter, Devon
19 October	JIA Family Day. Leicester

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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