

Members'

MAGAZINE

AUTUMN 2016



nras

National Rheumatoid
Arthritis Society



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By Ailsa Bosworth, MBE

Chief Executive

Autumn 2016

Dear Members

As usual, the year seems to be speeding by far too quickly. We have had an extraordinary summer politically with the BREXIT vote etc. – what a fascinating time for historians! And then followed by the most successful overseas Olympics ever for UK athletes excelling across the board. As you read this I will be on holiday, it's two years since we last went away for a break and I'm looking forward to some reliably hot weather and a bit of R & R!

There are a number of things which concern me at the moment not least of which is the state of the NHS. The second year audit data from The National Rheumatoid and Early Inflammatory Arthritis Audit, commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP) and carried out by the British Society for Rheumatology (BSR) was published at the end of July. Year two's data echoed the first year's results with a little improvement against some standards, but overall, the picture of rheumatology services across England and Wales remains hugely variable. 97% of Trusts and Health Boards took part in year 2 of the audit and patient recruitment improved with over 5,000 new patients being added. What did not change however was the number of units reporting compliance with NICE Quality Standard 2 which relates to whether people referred by their GP have been seen in specialist care within 3 weeks. This remains at a disappointing 37%. For some health providers, this wait is over 20 weeks for a quarter of their patients. Also, disappointingly, only 20% of GPs referred in line with NICE Quality Standard 1 (3 working days). You can read the British Society for Rheumatology's press release on page 13.

I am pleased to tell you that we shall be working closely with the BSR to see how we can best support units in regard to easy ways for them to sign-post their patients to NRAS for tailored patient support services. This audit and other research has again highlighted delays in getting people into the system in a timely way. We are currently exploring further ways to address these issues.

It was with these thoughts in mind and with some concern that I listened to an interview on Radio 4 this morning (16th August) with someone from the Patients Association who

was highlighting the results of their Freedom of Information investigation with NHS Trusts which revealed lengthening waiting times for certain elective surgical procedures (e.g. hip and knee replacements). In the same interview, the CEO of one of the Trusts was advocating for less referrals from primary care so that consultants only dealt with patients who absolutely needed to be in front of them (in order to save money where hospitals are in financial difficulty). They were primarily talking about surgical referrals, however, in the last 12 months we have heard of areas where GPs have been 'discouraged' for limited periods, to refer patients into secondary care more broadly.

Given the lack of public awareness of the early symptoms of RA, and the low rate of referrals in line with the NICE Quality Standard 1, we want more GPs to be referring in line with the NICE quality standard, not less and the current climate isn't helping to support rapid referral. We know that people diagnosed and treated within the "12 week window" provides greatest opportunity of gaining rapid control of disease and sustaining minimum damage to joints.

You all need to be aware of this. If anyone you know suspects they may have RA, they should ask for a prompt referral from their GP to see a rheumatologist in line with NICE Quality Standards and Guidelines. If they are not being referred and symptoms continue, suggest they take someone with them and insist on a referral, asking that possible inflammatory arthritis is clearly mentioned in the referral letter. I've never yet met a Consultant Rheumatologist who wouldn't prioritise such a referral.

I am all too aware of the financial hardship of many hospital trusts around the UK and yet we know that good care is, in the long term, cheaper than poor care.

There are tough choices to be made and I do not envy the commissioners having to make them, however, taking a longer term view of healthcare relating to earlier diagnosis and treatment of people with long term conditions would be very welcome.



Sally Wright

New kid on the block!

Sally Wright is the right woman for the job

NRAS are delighted to welcome Sally to the NRAS staff. Her role will be challenging as she will be instrumental in helping all areas of the society achieve the aims set out in the 3 year strategic plan.

"Joining NRAS in August as Head of Marketing and Communications, I am effectively, the 'New Kid on The Block'. My background essentially is voluntary sector, starting my career at operational level in the field of learning disability and ASD. I also gained marketing and business development experience in both corporate and charity sectors, so I am more than excited to begin a new journey with NRAS and privileged to be part of an organisation brimming with personality, drive and determination."

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;
Clare Jacklin, Director of External Affairs

Meet the Team

Anne on Conn

Conn joined NRAS just about a month after I started, we were newbies together and as we sit almost opposite each other it was easy to start the interrogation of the newbie! Conn's family moved to Yorkshire when he was in primary school and although he says he never quite got over it, he clearly is very fond of this part of the country and rightly so. But luckily for us the attraction of London and his first love, politics brought him to NRAS.

The first thing to say about Conn is that he is quite the most delightful young man; and over the last year he has proved to be very knowledgeable on so many subjects that he is often the "go to guy" for assistance.

His young years do not reflect his grown up attitude, and even when he is the subject of jokes about his collection of croc shoes or his fascination with owls he still manages to enjoy the banter and maintain the attitude of a more mature self-confident person.

Conn has established himself as an integral part of the whole team here at NRAS and he has immersed himself in all aspects of the organisation. Amongst other things, he has spoken and shared his insight on policy and public affairs with NRAS patient groups across the country; he has supported the continued campaign with Welsh ambassadors to influence the establishment of a specialist JIA unit at Cardiff's children's hospital and continues to raise the profile of NRAS, RA and JIA at every opportunity in government and with other stakeholder organisations.



Conn O'Neill

Policy & Public Affairs Officer

Nikki on Shivam

Shivam joined the team in November 2015 as the Web and Digital Media Officer after graduating from the University of Hertfordshire. He is responsible for growing the NRAS online community which includes Facebook, Twitter, Instagram and Health Unlocked. He also plays a key role in updating and developing the NRAS website. He did a brilliant job this year of our online social media campaign for RA Awareness Week. He is always helpful and on hand to support his less tech savvy colleagues with IT related queries and that is pretty much most of the office!

Shivam is a keen sports and gym fan and regularly cycles to work. He also likes to watch his favourite football team Manchester United. We have heard he is learning guitar, so the office is looking forward to his first performance – roll on the Christmas party!



Shivam Arora

Web and Digital Media Officer



Membership

Member Events 2016!

There are still two more NRAS events this year

In May we were delighted to welcome many Members and guests to our Rheum for You South Gloucestershire event held at the stunning Eastwood Park Conference Centre.

We were delighted to be joined by Sarah Collins, Psychotherapist and Counsellor, who has lived with RA for more than 30 years, as our keynote speaker. Those attending also enjoyed presentations by our Director of External Affairs, Clare Jacklin, and Chantal Watts, General Manager of South Gloucestershire Citizens Advice. Unfortunately, we didn't have the weather to enjoy the grounds but Members did have the chance to chat over a delicious afternoon tea!

There are still two more NRAS events planned for 2016 including our Rheum for You Nottingham which is being held at the Novotel Nottingham/ Derby on Thursday 29th September from 1pm to 5pm with the keynote speaker being Dr Chris Deighton, Consultant Rheumatologist and long

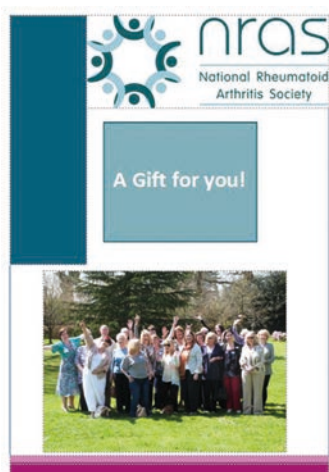
term supporter of NRAS. Register to attend online at: www.nras.org.uk/rheum-for-you-2016

NRAS Scottish Ambassadors are also hosting the 'Gathering' at Forth Valley College in Stirling on Tuesday 4th October from 10am to 4pm. They have an excellent agenda including the keynote speech by Dr Anne McEntegart, Consultant Rheumatologist and Clinical Lead of the Greater Glasgow and Clyde Managed Clinical Network. Further agenda details and registration details can be found here: www.nras.org.uk/gathering-in-scotland-2016

Don't forget that all NRAS Members, plus one guest, can attend for free. You can also register by calling **0845 458 3969** or email emma@nras.org.uk. We look forward to seeing you soon!

If you are not currently an NRAS Member you can still attend for just £10 per person or join today and come for free!

Don't forget that all NRAS Members can attend for free



NRAS Gift Membership

The perfect gift that keeps on giving

If you're struggling to find the perfect gift for a loved one, then why not give the gift that lasts all year? If you have a family member or friend who lives with rheumatoid arthritis, why not consider buying them a gift of NRAS Membership?

For just £25 for the whole year, they will receive all the benefits of Membership plus a gift card which has a space for a personal message from you. We can arrange for the gift card to be sent directly to the recipient or we can send it to you so you can give it to them yourself.

If you have RA yourself and are being pestered by family and friends to give them some ideas what you'd like for a birthday, anniversary or Christmas present, why not put them out of their misery and

suggest they buy you the gift of NRAS Membership. NRAS Membership is a thoughtful and unique gift that will not only benefit you but thousands of others like you as well.

Membership of NRAS is the best way to hear the latest RA news and enables us to better support you, your family, your health professionals and others living with this disease. Equally as important is that the more Members join the society the greater the NRAS voice is on your behalf to influence change for the better across the UK. If you are interested in Gift Membership, then please call the Membership team on 01628 823524 or visit our website www.nras.org.uk/gift-membership to print off the Gift Membership form and send it back by post.

General Article

Fashion design meets medicine

How can such collaboration help patients with musculoskeletal conditions?

By Alexa Chan

A recent graduate from the MA Fashion Futures course at the London College of Fashion.



Co-design Sessions: Understanding dress habits (Left), Fabric handling and selection (Right)

I am a recent graduate from the MA Fashion Futures course at the London College of Fashion. I am interested in designing clothes for a better life. With fashion being such an intrinsic part of people's lives, I could not remove its meaning from my rationale that clothing is the ideal vehicle for positive well-being.

As part of my master's thesis I proposed clothing as an interventional tool to improve patient esteem and self-management. For future health tools to be integrated in clothing, garments must be designed to accommodate a variety of bodies and physical capabilities when it comes to dressing. Garments should therefore be mobility positive.

People living with long-term musculoskeletal conditions often have difficulty with dressing due to pain and restricted joint mobility. Furthermore, mainstream garments do not consider these requirements and leave the person to devise their own alternate methods of dress. To create a new set of garment design methodologies that is mobility-friendly, I worked with the Rheumatology Department at Kings' College Hospital London to conduct co-design workshops with musculoskeletal outpatients who contributed their insight and took part in design decisions over a six-month period in 2015.

For this pilot study, I looked at the importance of considerate design in clothing for better ease of wearing, comfort and versatility. The input from the participating outpatients was invaluable; their experiences and first-hand knowledge guided the design process and enabled the establishment of new approaches to garment-wearing mechanisms.

The key aim of this study was to develop a toolkit that attempts to encourage and guide future fashion designers to rethink their design and development process to allow for universal wearability without limiting their creative inspiration.

Applying the toolkit to actual practice resulted in 5 garment outcomes designed in accordance to the patients' lifestyle experiences. The outcomes of the project have been presented as a poster during the 2016 European League Against Rheumatism Conference. I have also received a cultural partnership from Kings College London to further the project research on inclusive design for garment wearables. Thus, greater insight on how one adapts to current fashions as well as practical trials would be vital to this research – If you are interested in participating in my further research you may contact me by email at alexa@aaikai.com.



The capsule collection: Wearable for all abilities

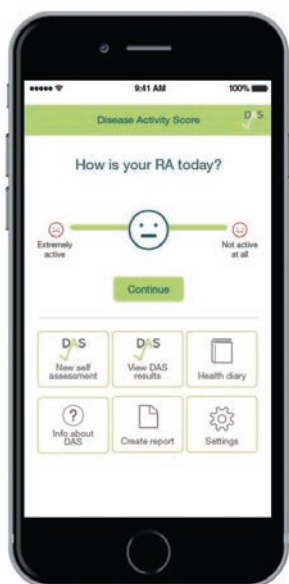


By Dr James Galloway

Kings College London

Download the NRAS DAS App

www.nras.org.uk/publications/know-your-das



Rheumatoid: more than just a single disease!

I am a rheumatologist – that is to say a doctor who has trained in managing 'rheumatic' disease. The word 'rheumatic' is an old term, originally used to describe illnesses that affect the joints. However, to say that I only manage problems that affect the joints would be misleading.

Let me tell you about rheumatoid arthritis as an example of a condition that is far more complex than you might have thought. The term 'rheumatoid arthritis' was first used in 1859 by a London doctor called Garrod (see the picture of the stern looking man below). Even as long ago as the 1800s, doctors realised that rheumatoid arthritis affected far more than simply the joints of the body.



You may well have heard rheumatoid arthritis described as an 'autoimmune' condition. This is correct. The body has a complex immune system, comprising cells and proteins that work to keep you healthy, by fighting off infections and protecting against cancer. The 'auto' of autoimmune disease implies that the immune system has made a mistake and is attacking its own body. In rheumatoid arthritis, this is apparent with inflammation (pain and swelling) appearing within joints.

When a doctor helps treat rheumatoid arthritis, it is vital to recognise that what is visible in the joints may not represent the whole story. In fact, we usually use blood tests to measure inflammation inside the body. You may be aware that when you have your

regular blood monitoring, something called the 'ESR' or 'CRP' is included in the list of things that the doctor looks at. These both relate to measuring the amount of inflammation in your body.

If you have rheumatoid arthritis, hopefully you may keep a personal record of these results as they are needed to calculate your Disease Activity Score (DAS) – for more information about the DAS score and to download the NRAS DAS App, see www.nras.org.uk/publications/know-your-das

The CRP and ESR are very similar tests, and in practical terms it does not really matter which is used. What is important is that these tests show that the inflammation is not only in the joints, but actually present in the blood stream - or serum – confirming the 'systemic' (affecting the whole body) nature of the illness. Anyone living with rheumatoid will attest to the fact that the whole body feels involved, with almost everyone finding they become very tired. Sometimes (thankfully not often with good treatment) signs of inflammation can develop in places other than the joints, e.g. the eyes, skin or even lungs.

As it is the whole person that is affected, it makes sense that our most effective treatments are given as tablets or injections that work throughout the body. Although we used to give medicine directly into the joints, this is much less common nowadays, as we have discovered that medicines that work on the whole body are more effective.

The last 20 years have seen massive changes in the treatments for rheumatoid arthritis. We have learnt how to better use medicines that have been in use for a long time, (often in combinations) and have also discovered many pioneering new drugs (e.g. biologic therapy) that can not only suppress the visible inflammation in the joints, but also completely switch off the inflammation in the blood.

However, despite sharing this good news, our work is not finished by any means. When I start a patient on a new treatment like an anti-TNF, I know that approximately a third of people won't feel any better and their joints will still be painful and swollen. In practical terms, this means I need to try a different medicine, and thankfully there are many

to choose from now. The reason I mention the issue is that it highlights a very important feature of the illness: not all rheumatoid is the same and it is therefore not 'one' disease – there are different sub-types.

As research started to unpick why some people have different immune systems to others, it actually transpired that one of the oldest tests for rheumatoid is the most useful.

Rheumatoid Factor

The 'Rheumatoid Factor' (which predates ITV's the 'X-Factor' by some 64 years!) is a blood test that



we request on all patients with rheumatoid arthritis. The test detects whether the immune system is attacking itself. Unfortunately, it is not a perfect test. It is positive in almost 10% (1 in 10) of healthy people. Around 1% (1 in 100) of adults will develop rheumatoid arthritis. In addition, we know that approximately 80% (1 in 5) of people with rheumatoid arthritis, have the rheumatoid factor in their blood. What should we conclude from this? Well, it is likely that the rheumatoid factor itself is not harmful – if 10% of people can walk around with it in their blood and are healthy. There were actually some studies in the late 1950s that showed injecting rheumatoid factor in healthy people didn't cause rheumatoid arthritis. However, in people with rheumatoid arthritis, the presence of the rheumatoid factor does have important clinical

implications: it is linked to more serious disease and it can help predict which drugs are likely to be helpful. For this reason, it is now routine for rheumatologists to classify people with rheumatoid arthritis into those with (termed 'seropositive') and those without (the 'seronegative') the rheumatoid factor in their blood. Many of us now believe that seropositive and seronegative rheumatoid arthritis are in fact two distinct diseases.

Around 10 years ago now, a new version of the rheumatoid factor was discovered called the CCP test, which some of you may have heard mentioned or seen written in clinic letters. This is effectively the same test, although more accurate; it is found in fewer than 1% of healthy people. In fact – if you have a positive CCP test, research suggests that you are at an increased risk for developing rheumatoid arthritis in the future. This discovery is exciting, because if we could identify people before they actually develop rheumatoid, we might be able to prevent the disease altogether! You may be interested to know we are actually trying to study this in the UK at the moment in a number of clinical studies (visit NRAS website for more information about the Apippra study and others). See more about research on page 20.

So, what should you take away from this article? I hope you will have gained a better understanding that rheumatoid arthritis is not simply a matter of having painful joints, but actually an illness affecting the whole body. If you suffer with rheumatoid arthritis, I hope this explains why rheumatologists are so keen on prescribing you drugs! In addition, maybe you will be inspired to download the NRAS 'know your DAS' app – and even ask your own rheumatologist, if you don't already know, to tell you if you are seropositive or seronegative as it can impact on your outcomes and medication choices.

80%
(1 in 5) of
people with
rheumatoid
arthritis,
have the
rheumatoid
factor in
their blood.



HealthUnlocked (HU)

In July, some of the NRAS team were invited to HealthUnlocked's offices in London for a workshop.

This enabled us to share ideas and look at ways in which our two HU communities can be improved. In July we also reached the massive milestone of 12,000 followers on our RA community and it is growing every day so if you haven't already signed up, why not take a look and connect today!

RA: <https://healthunlocked.com/nras>

JIA parents/guardians: <https://healthunlocked.com/jia>



Fundraising



spring
chicken®

An EGGcellent partnership: Spring Chicken and NRAS

Helping to make tasks simple for people with RA

NRAS is delighted to announce a new partnership with the online shop, Spring Chicken.

A funky name yes, but who are they? Spring Chicken, formed by duo Anna and Sarah, exist to provide solutions to everyday life that some of us can have difficulty completing. NRAS are delighted to be working with them to provide you with access to the latest and most suitable products to help you with your RA. With Spring Chicken, we have our own NRAS shop, to showcase all of these great products in one easy to use area. Spring Chicken will still administer and provide your order, but NRAS will get a small proportion of the sale to support our work, and at no extra cost to you.

We've selected a range of products that we think help best support people with RA, products such as: Easi Twist® Jar Opener; Ring Pull Opener; Adjustable and Folding Walking Stick; Trolley Bags; Automatic Needle Threader; and the Rolling Garden Work Seat to name a few.

Visit us here and see what we can offer
www.springchicken.co.uk/nras

Anna James, from Spring Chicken:

"We started Spring Chicken two years ago in 2014. We wanted to create a brand which promotes the most positive aspects of getting older and living longer. We're determined to find or develop a whole range of practical solutions to some of the challenges of ageing and/or living with restrictions.

For me, the catalyst for all of this was the real need to find tried and tested, innovative and well-designed products and services to help my father- who'd just been diagnosed with Parkinson's disease. Sarah also came at it with a very personal motivation- having cared for her mother at home for several years with dementia.

The Spring Chicken team are themselves aged from 18 to 82 and we spend every day trying to find products and ideas that make life easier. We get most excited when we find something which our customers tell us makes a real difference- whether it's a gadget to help put your socks on without bending down, an electric bed that makes it easier to sleep, or something to help thread a needle – anything that helps people overcome an obstacle- however large or small.

We are delighted to be working with NRAS, supporting their work and to be helping to make life a little easier for people with rheumatoid."

Spring Chicken are looking for suggestions for products you want, but can't yet get hold of. Drop us a line at enquiries@nras.org.uk to share your thoughts.



Fundraising

Ride London

NRAS Prudential Ride London team did us proud!



On a beautifully sunny morning at the end of July some of the NRAS fundraising team made their way to the leafy suburbs of Weybridge in Surrey to wait for our fantastic team of riders who were taking part in the 2016 RideLondon 100.

Eleven cyclists took on the 100-mile route, with some starting in the Queen Elizabeth Olympic Park as early as 6am!

Weybridge is around mile 34 of the course and our 'cheerers' were lucky enough to see most of the NRAS riders go by. Some were on a mission to complete the race as quickly as possible so waved and cheered as they went by, others stopped to introduce themselves to the staff team from NRAS

and take a well earned stop! Val, NRAS Events Fundraiser, said of the day *"it really is an incredible event, watching so many bikes racing by on the closed roads. The highlight for us was every time we saw an NRAS cycling jersey coming towards us, our noise level increased significantly! We had yet another fantastic team take part this year, so far they have raised over £8,000 with more still to come – way to go Team NRAS!"*

A huge thank you to everyone who took part. If you feel inspired to sign up for next year's ride the good news is we have guaranteed places, visit our website at www.nras.org.uk/cycle or email fundraising@nras.org.uk, Val would be happy to give further details of this incredible event.

So far they have raised over £8,000 with more still to come – way to go Team NRAS!

Foot Problems in Rheumatoid Arthritis

By Christian Pankhurst

Clinical Specialist Orthotist,
Guy's and St. Thomas' NHS
Foundation Trust

Matthew Collison

Lead Musculoskeletal
Podiatrist, Guy's and St.
Thomas' NHS Foundation
Trust

Matthew McShane

Clinical Specialist Orthotist,
Guy's and St. Thomas' NHS
Foundation Trust

How Orthotics Can help



Orthoses can be used to redistribute weight; support unstable or painful joints and compensate for weak or absent muscles

The feet are often one of the first areas of the body affected by rheumatoid arthritis (RA), which can get progressively worse if unmanaged, and can have a big impact on quality of life. Most patients with RA will experience foot problems at some stage, with up to 80% reporting problems with footwear, 90% complaining of foot pain and 70% reporting difficulty walking.

The foot and ankle contains 26 bones and 33 joints, resulting in a highly developed, complex structure that serves to bear body weight as well as forces many times the weight of the human body during normal gait. Long-standing inflammation due to RA can lead to structural deformity and soft tissue damage in the worst cases. This process can lead to skeletal changes, displacement of bones, pain, and loss of movement. This in turn can cause areas of pressure that may result in foot ulceration leading to pain and immobility. Early diagnosis and correct treatment of problems in the feet due to RA is therefore crucial to being able to stop these kinds of long-term complications.

Management

The use of orthoses in people with RA aims to improve function and comfort. An orthosis is an externally applied device used to support, align, prevent, or correct deformities or to improve function. With regards to feet, orthoses can be used

to redistribute weight; support unstable or painful joints and compensate for weak or absent muscles.

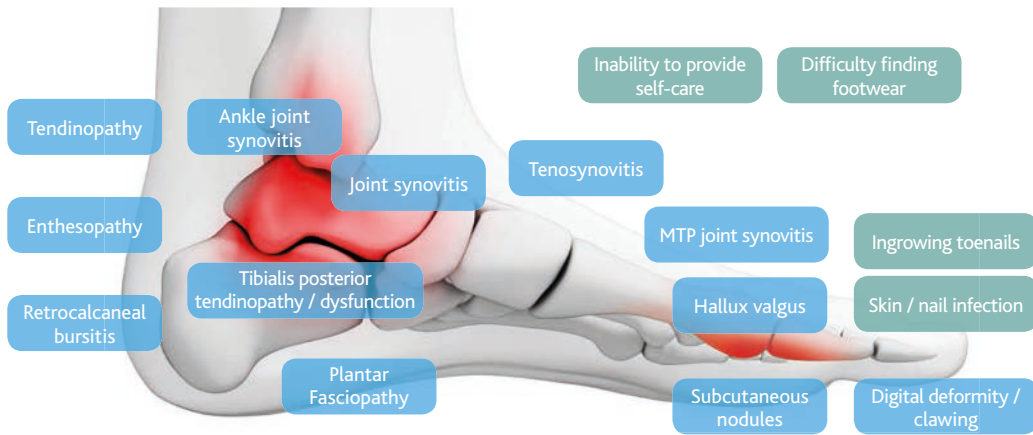
Various types of orthoses can provide pain relief and improve function including:

- Insoles
- Footwear
- knee orthoses
- wrist braces
- elbow sleeves
- shoulder supports
- spinal/lumbar supports.

It has been suggested that early intervention through the provision of foot orthoses has the potential to prevent major functional and structural foot problems. However, because foot changes have the potential to occur within 2 years of disease onset, it is essential that patients are referred to have their foot function assessed upon diagnosis. Studies have shown that when foot orthoses have been used in RA patients, the foot structure and stability of the joints of the foot has improved. This has resulted in a reduction in pain and deformity and improved mobility.

Foot orthoses (insoles) are often issued to RA patients for foot pain and to reduce pressure on the sole of the foot. They are also often used to reduce progression; accommodate deformity; alter the mechanics of gait; and protect the joints in the

Early intervention through the provision of foot orthoses has the potential to prevent major functional and structural foot problems



Common foot complaints in RA

longer term, though further research is needed in this area.

Finding suitable footwear is often cited by patients as being a problem for those with foot deformity, along with a lack of good information on where to find suitable retail footwear, or issues fitting into footwear. Custom made footwear is often very effective in accommodating deformity, but some patients are reluctant to wear them due to issues of aesthetics or weight. Often patients with deformity can find retail footwear to fit and advice from their Podiatrist or Orthotist can be helpful.

Recommendations

The National Institute for Health and Care Excellence (NICE) and the *Scottish Intercollegiate Guidelines Network (SIGN)* agree that all people with RA should have access to foot health services. Similarly, NICE guidance recommended that functional orthoses and therapeutic footwear should be available for all people with RA if needed.

All patients with RA should have access to footwear advice. Referral to Podiatry or Orthotics service should be available to all RA patients so that they can provide foot orthoses.

Improved pathways from NHS primary and community care to acute care, including the provision of foot orthoses which could potentially prevent major functional and structural foot problems. It could also result in earlier diagnosis of structural problems, better treatment and improved

management. This could also result in estimated productivity gains to the economy of £31 million from reduced sick leave and lost employment.

What should you do?

If you have problems with your feet, make sure that your rheumatology team are aware of this, and keep them updated if foot symptoms get worse or you have new symptoms in your feet. Where appropriate, they may also recommend referral to a podiatrist or orthotist. RA affects people in a variety of ways, and support from the Multi-disciplinary team, not just your rheumatology team, can have a huge benefit in getting the disease and its symptoms under better control.



General Article



BSR Press Release

Four in every five patients with early inflammatory arthritis at risk of long-term disability and reduced life expectancy due to delays in NHS treatment

Nationally, fewer than half of patients who are referred are seen by a specialist within three weeks



Up to a million Britons are at risk of preventable, long-term disability and reduced life expectancy due to delays in referrals to specialist advice and treatment services, according to the most comprehensive audit of rheumatology services carried out across England and Wales.

The first weeks and months following the onset of rheumatic disease symptoms are known as the 'window of opportunity', and it is crucial that patients get appropriate treatment in that time period to maximise their chances of avoiding lasting complications. Early referral to, and assessment by rheumatology services is therefore vital and the report reveals that for four out of five patients in England and Wales, this does not happen.

The National Rheumatoid and Early Inflammatory Arthritis Audit report was commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP)* and carried out by the British Society for Rheumatology (BSR). The report reveals that nationally just 20 per cent of patients who see a GP with suspected rheumatoid and early inflammatory arthritis are

referred to specialist services within the three-day limit recommended by the National Institute for Health and Care Excellence (NICE). For some health providers, this wait is over 20 weeks for a quarter of their patients. Nationally, fewer than half of patients who are referred, are seen by a specialist within the three-week time limit recommended by NICE. For some providers, a quarter of patients are waiting more than 12 weeks.

The report reveals considerable differences in achievement rates for the standards across England and Wales. A 'postcode lottery' means that depending on where a patient lives, they are far more or less likely to access treatment at an early stage and hence prevent the disease becoming more advanced and life-shortening. For example, patients in Wales are half as likely to see a specialist within three weeks as those living in London.

The audit data points to several reasons for the delays in accessing services including the overall number of rheumatology specialists needed to diagnose and treat the disease. The BSR calculates that consultant levels are 21% below Royal College of Physicians recommended levels, and the number of additional consultants needed is likely to increase as the demand for rheumatology services increase. The latest report also shows a link

between numbers of specialist nurses and an ability to commence treatment in a timely manner and achieve treatment targets.

Research has highlighted a lack of awareness of the symptoms of disease and of the need for quick referral amongst GPs. Most patients will initially present to their GPs.

There are significant personal and society costs linked with inflammatory and rheumatoid arthritis. These are some of the most common debilitating medical conditions in the UK. Around 10 million people have a form of arthritis, of which almost 700,000 have rheumatoid arthritis. Around 12,000 children suffer from juvenile idiopathic arthritis, the childhood equivalent disease. The arthritis can be so severe that those with the disease cannot bathe or dress themselves or perform simple tasks such as walking a short distance. Rheumatic conditions do not only damage joints but can also damage vital organs, including the lungs, heart, nervous system, kidneys, skin and eyes if not adequately treated.

One third of sufferers will have stopped working within two years of onset, and half will be unable to work within ten years. Rheumatoid arthritis is a major cause of sickness absence and unemployment, and this is estimated to cost around £1.8 billion per year. It has been estimated that reducing work limitations and loss of work, can save the UK economy around £31 million a year for rheumatoid arthritis alone. Patients are twice as likely to experience depression and have similar risks of cardiovascular disease as patients with diabetes.

The audit's recommendations include:

- Increase awareness amongst the general public of the symptoms of inflammatory arthritis and the need for quick treatment to prevent it progressing
- Increase GP's awareness of the varied symptoms and in particular the need for referral within the NICE guidelines in order to maximise the efficiency of treatment programmes and prevent the disease progressing into more serious, later stages.
- Analyse and understand variation in performance against the key standards
- Review the adequacy of specialist nurse provision, given the strong association between

staffing levels and timely delivery of intensive treatment.

- Support national audit data collection.

Clinical Audit Director, Dr Jo Ledingham said:

"Inflammatory arthritis is a widespread medical condition with higher linked mortality rates than some cancers. But, with appropriate and quick treatment the disease and its consequences can be controlled. GPs understand the need for speed when it comes to diagnosing and referring cancer patients, yet many still don't understand that they need to treat inflammatory arthritis with the same urgency.

"Remission is a realistic aim with modern management, allowing patients to live a longer and more fulfilling life, benefiting themselves, their families, their employers and ultimately costing the government less in benefit payments and more costly drug treatment. Rapid access to specialist services is needed, however, to facilitate this. I hope this report serves as a wake-up call to everybody involved in referring, diagnosing, treating and commissioning services for inflammatory arthritis – from GPs to specialists. In particular, far quicker, and more consistent referral and treatment times need to be achieved across England and Wales."

BSR President, Dr Peter Lanyon, added:

"It's now very clear from the consistency of the data, that important variations in standards for people living with inflammatory arthritis still exist. This has implications for both primary and secondary care clinicians and commissioners. We all have a role to play in working towards reducing this unwarranted variation, at local, regional and national level. I would urge all those commissioning or delivering services to read the report in detail, reflect on the results, and decide individually and within respective teams, what the implications are and what actions are required."

For more information or for a copy of the clinical or patient reports, contact BSR Communications. Email Neil Walsh – nwalsh@rheumatology.org.uk

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Around
10 million
people
have a
form of
arthritis,
of which
almost
700,000
have
rheumatoid
arthritis

Fundraising

Community Fundraising

Community Fundraising has been busier than ever over the past 4 months and through the summer

It has been full on hectic fundraising with a real spectrum of events around the UK from all our wonderful fundraisers. A huge thank you to all of them – NRAS couldn't do it without their help and dedication.

From running various distances, to swimming, cycling, climbing the Three Peaks or trekking. Getting covered in mud in tough mudder style events or holding a quiz night or tea party, they all take time, effort and commitment to organise. Here is a brief snapshot of some of the fundraisers over the past few months to give you a taste of what they do for NRAS and people living with RA and JIA.

Sue Wigmore – Onward and Upward

Sue was diagnosed with RA over 20 years ago and has suffered from extreme pain, fatigue and bouts of depression due to the disease. Her consultant at the Great Western Hospital put her on a specially devised physiotherapy plan two years ago and this has helped her enormously. Sue is currently in a drug maintained remission. However a few years ago her RA flared up so badly that bones in her feet and toes became dislocated, she then struggled to even do simple things like turn on a tap or light switch, or even get herself dressed.

Sue has always been fiercely independent and determined and although her life has changed for the better dramatically with her medication and physiotherapy she still has days when she struggles. Sue says 'I still have bad days, but hey, doesn't everyone? I have also learnt to properly accept that RA is an integral part of me that I can manage and control rather than live my life around it.'

So with that attitude it was no surprise when Sue contacted us in the fundraising team to let us know she was planning an 800-mile solo cycle challenge,

starting in Brittany and tackling the Pyrenees to Spain. Sue's only companion was her trusty hand built bike 'Bob'. Part of the month long cycle took in the Col du Tourmalet, a legendary section of the Tour de France. Sue had an eventful and very challenging month but already has itchy feet to get out there and do something else again.

Sue raised a fantastic £601.79 and awareness in abundance as she tweeted and blogged her way through the gruelling 800 miles! Sue told NRAS *"I'm not an athlete, just a normal person who wants to do stuff. I hope that maybe my story and trip will give a glimmer of hope or inspiration to others who are or have been in my position or similar. It's not always going to be the bad times, you don't have to do something huge, just push yourself to be the best you can and want to be. NRAS staff were wonderful on a number of occasions, I'm not sure I would be here without them and their support."*

To read more about Sue's adventure visit onwardandupward.co.uk or to donate visit her Just Giving page at www.justgiving.com/fundraising/Sue-Wigmore2

Karen and Nicola just keep on running

Karen Anderson knows first-hand the impact of RA and living with someone who has been diagnosed with the disease. Karen's husband, Kevin was diagnosed in 2009 – at the age of 38! So as Karen said *"definitely not just a disease that only older people have to live with."*

He has steadily, sometimes rapidly, gotten worse and in the last few years has had to have two full hip replacements and a knee replacement. This has impacted quite considerably on his life, but fortunately things seem to be on the up! He's now more mobile and getting some of his independence back, which is equally important to a man of 45.



Sue Wigmore



Karen and Nicola



John Griffiths, pictured on the right.

Karen decided she wanted to do something in 2016 to really raise awareness about RA and her good friend Nicola pledged to join in the challenge – ten 10K runs over the 12 months.

She said, *“So while we are still fit ourselves – sort of – we thought we would take on a challenge of our own to help raise awareness of the charity and raise funds for the good work they do to support RA sufferers, as we have discovered this impacts all ages and more people than we even realised.”*

The ladies have now completed seven 10K events all around the glorious scenic routes of their homeland Scotland! With just three more to go to complete their 2016 challenge, the girls seem to have got the running bug! So far they have raised £1920.98, if you would like to make a donation please visit their Just Giving page: www.justgiving.com/fundraising/Karen-Nicola

John Griffiths – 3 Peaks in memory of his Mam

John has been a supporter of NRAS, a charity close to his heart, for a number of years and he makes a regular gift to us every month. However, this year he decided he wanted to really challenge himself and decided the National Three Peaks was the one for him. John wanted to do something memorable and his inspiration behind it was his late Mam, Eirlys Griffiths, who was diagnosed in her late 30s with RA.

John had been one of six children under the age of 12 when his Mam was trying to cope with bringing up her family in a small village in North Wales, along with all the affects that RA was throwing at her. In later life she had knee and hip replacements, and struggled for over two years with kidney problems, as well as many other serious health issues. John remembers that she never complained, only praised and put everyone else first. Sadly, Eirlys passed away in 2002, aged 72.

John along with two friends took on the Three Peaks on a very warm June weekend. Ascending Ben Nevis and Snowdon was particularly tough in the warmer part of the day, with Scafell Pike in the somewhat cooler night air. John told us afterwards, *‘it was an amazing experience and the feeling of achievement on completion was one not to be forgotten.’* It was obvious the commitment to training up and down Snowdon and workouts in the gym and circuit training, were well worth it. What helped his focus over the weekend was his memories of his Mam who he says, *‘will always be my true inspiration in life.’*

John has raised a fantastic £1083 and if you would like to donate please visit his Just Giving page: www.justgiving.com/fundraising/Johnnygriffwales

Ask the helpline

Should I stop taking my medication for surgery?

I am due to have surgery and someone has suggested I may need to stop my RA medication. How long do I stop it for?

RA medication affects the immune system, which can make people more vulnerable to infections.



This is a very hard question to answer, as there are many variables to it. The simple answer is that you should always make your rheumatology team aware when you are due to have surgery and ask them when and if to stop and restart medication.

Hopefully the following information may help to explain why there isn't a straightforward answer to this question, and your healthcare team will need to consider/be aware of this to answer your question fully.

Type of surgery

The first thing to note is the type of surgery. The reason RA medication is often stopped before and after surgery is that RA medication affects the immune system, which can make people more vulnerable to infections. There is also a risk of infection with surgery, so this risk is increased, but the infection risk will vary from one surgery to another. For example, dental surgery isn't likely to be as much of a concern as hip replacement surgery.

Medication

The level of infection also varies between the different types of RA medication. Biologic drugs are thought to make people more prone to infection than standard disease modifying anti-rheumatic drugs (DMARDs). Steroids also increase the risk of

infection when taken together with other drugs. The advice might also depend on the frequency of the drug. Rituximab is only taken every 6 months (or even longer), therefore, where it is possible to plan, having surgery in the middle period between infusions would be best, whereas for a biologic taken weekly, it might be a case of having to miss a few doses before and after surgery. How long the drug lasts in the body is also relevant, as in some cases, where a drug would stay in the body for a long time, it might not be considered worth stopping it for a short period for surgery. In summary, sometimes a medication-free period may be recommended, all depending on the type of surgery and the type and dosage of the medication.

Before or after surgery?

It is likely that if your rheumatology team want you to stop your medication for surgery, you will stop taking it some time before surgery (to allow it to start to come out of your system) and to restart some time after (when infection risk has started to reduce). This is usually when there is some sign of healing.

Other factors

Lastly, there may be factors outside of your RA, the medication you take for it and the nature of the surgery (for example other health conditions and medications) and this is why it is always important to seek medical advice about stopping medication for surgical procedures.

Ask the helpline

Why don't I feel better?

I have recently been diagnosed with rheumatoid arthritis and started taking methotrexate 3 weeks ago and am not feeling any better. Should I stop taking the tablets?



It isn't uncommon to not be getting benefit from a drug like methotrexate at this early stage, so don't be disheartened. You do not need to stop the drug (unless you are experiencing bad side effects, in which case we would suggest speaking to your rheumatology team as soon as possible).

Methotrexate comes under the group of drugs termed disease modifying anti-rheumatic drugs (DMARDs). These drugs can take between 3 to 12 weeks before you start to feel an improvement in your symptoms. Sometimes within this time your consultant may offer you steroids to help control your symptoms while waiting for the DMARD(s) to take effect. After 6 months you should hopefully feel the full effect from the drug. It is also not uncommon for other drugs to be added during this time (this is referred to as 'combination therapy'). Changes in dosage and/or administration of your methotrexate during this time could also improve your RA.

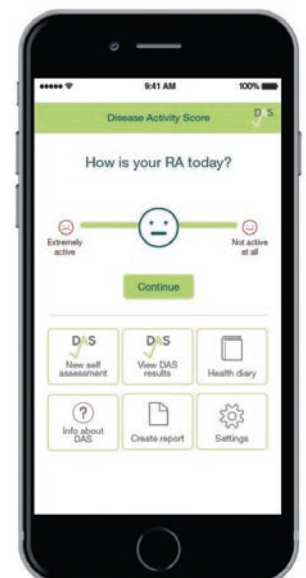
DMARDs work by dampening down the immune system, as in RA this immune system has become overactive and has started to attack the lining of the joints. By getting this process under better control, the drugs can slow or prevent damage to the joints and can also start to give you relief from some of your symptoms.

Your rheumatology team should be able to determine how well this drug is working for you by monitoring your blood tests (more specifically inflammatory markers, which will hopefully show a reduction in inflammation over time) and just as importantly by speaking to you about your symptoms and whether you feel better. They may also use a scoring system called 'Disease Activity Score' (DAS) to monitor improvements in your disease. DAS is worked out by examination of swollen/tender joints, as well as blood tests and an overall health score.

It can take time to find the right drug and dose. It is important to work closely with your rheumatology team until you find the right treatment plan for you. Hopefully the methotrexate you have started will make you feel a lot better soon, but should this drug not work for you, or not be enough on its own, the good news is that there are a lot of options currently available, so there is a very good chance of getting your RA under good control, it just may take time.

Download the NRAS DAS App

www.nras.org.uk/publications/know-your-das





General Article

Get your flu jab

One in five rheumatoid arthritis patients missing recommended flu jab

Research from The University of Manchester has found a shortfall in the uptake of influenza and pneumococcal vaccinations among those diagnosed with rheumatoid arthritis (RA), potentially increasing their infection risk.

The team from the Arthritis Research UK Centre for Epidemiology looked at data from over 15,000 patients diagnosed with the disease who were being treated with certain types of immunosuppressive drugs, and found that one in five patients received no influenza vaccinations and one in two patients received no pneumonia vaccine over a five year follow-up period.

Patients with rheumatoid arthritis have double the normal risk of infection, due to a range of factors, compared to the rest of the population. Guidelines recommend that vaccinations should be used to protect against certain infections, such as influenza and pneumonia.

Dr Will Dixon, who led the study, said: "There is no national data on vaccination uptake broken down in a way that allows us to pull out those with RA. Only one study in the US has looked at whether patients with rheumatic diseases are being vaccinated prior to starting immunosuppressive therapy."

Get up and running

in support of
NRAS and JIA

Nicola was determined her RA wouldn't stop her doing the things she wanted to do.

Will you join Team NRAS and run in the Brighton Marathon 2017?

Sign up at
www.nras.org.uk/runs

NRAS is Changing Minds, Changing Services, Changing Lives for People with RA and JIA



nras
National Rheumatoid Arthritis Society

Research Update

Pain and fatigue

High levels of pain are associated with long-term fatigue

A Norwegian study has found that people who have a greater amount of RA pain are more likely to experience long-lasting fatigue. The study was carried out to measure levels of fatigue in patients with rheumatoid arthritis who had gone into remission or very low levels of disease activity after being treated with disease modifying anti-rheumatic drugs (DMARDs).

2193 patients were treated with methotrexate, either on its own or alongside anti-TNF treatment. After 6 months of treatment the patients were assessed again and the 699 patients who were found to have very low disease activity or remission were monitored. Among these patients, people who had an increased level of pain and signs of

inflammation at the beginning of the study were found to have greater incidence of fatigue after six months despite good treatment.

Two groups in the study were identified as enduring higher levels of fatigue after 6 months; these were people younger in age and people who suffered higher levels of pain at the onset of the study.

This study gives us a better understanding of which RA patients might be more susceptible to long-term fatigue and highlights the need for better treatment of this symptom, as it can have a huge impact on the patient's quality of life and ability to carry out daily activities. It also demonstrates that low disease activity and remission could have a significant element of fatigue.



Medicine to help RA

Medicine used for cholesterol may also help with rheumatoid arthritis

A common drug called simvastatin, used for reducing cholesterol has been found to have a positive effect on the immune system when it comes to inflammatory conditions such as diabetes, multiple sclerosis and rheumatoid arthritis. Aarhus University in Denmark has carried out interesting research on how cholesterol medication may be able to help treat inflammatory diseases.

In inflammatory conditions the body's immune system starts to attack itself. This is a fault in the immune system and the cause is not fully understood. As a result, the body goes into a state of chronic inflammation which then starts to break down healthy tissue.

Simvastatin has been used to treat multiple sclerosis (where the immune system attacks the central nervous system). It has also been used in type 2 diabetes (where the inflammation damages

the kidneys, eyes and peripheral nerves). It has been found to lower inflammation in these diseases but for a long time scientists have not known the reason why.

The science behind this is simply that the drug acts as a 'plug' to stop the proteins that keep the immune cells in the inflamed areas. Therefore, with the plug in position the immune cells are unable to add to the inflammation so it is reduced and the patient feels better. This process has initially been tested in a laboratory, further tests will need to be carried out in humans to ensure the same process occurs but is felt by researchers that this is highly likely.

As statins (cholesterol medication) such as simvastatin were not originally designed for treating these conditions, this now opens up new ways to develop the drug to cater for inflammatory diseases. This may even be a better way to treat such conditions in the future as the side effects are very minimal.





By Clare Jacklin

NRAS Director of External Affairs

Research Update

Research to improve the future of treating RA

A guide to research projects in the UK

These and other studies hope to improve the lives of thousands living with rheumatoid arthritis.



Across the UK there are many research projects going on that perhaps you can contribute to however finding out about what research is going on is not always easy. A good place to start is of course the internet however not all research trials are in one place, but hopefully these sites can point you in the right direction.

NHS Choices

www.nhs.uk/Conditions/Clinical-trials

UK Clinical Trials Gateway

www.ukctg.nihr.ac.uk

INVOLVE

www.invo.org.uk

Two particular projects that NRAS is actively supporting is the MATURA trail and APIPPRA. Both are actively recruiting not only patients but rheumatology units to take part.



The MATURA (MAXimising Therapeutic Utility for Rheumatoid Arthritis) is a research project that aims to find and develop tests that will allow better targeting of the available treatments to those who would benefit most, thereby improving the selection of the best treatment for individual patients. There are two clinical trials with links to MATURA.



STRAP: (Stratification of Biologic Therapies for Rheumatoid Arthritis by Pathobiology) where biopsies of disease tissue will be taken and analysed. The biopsy will be used to investigate response and non-response of patients to three biologic drugs and identify predictors in the disease tissue.

BRAGSS: (Biologics in Rheumatoid Arthritis Genetics and Genomics Study Syndicate) where blood samples are taken to analyse the genetics' components to try and recognise markers that may lead to predicting which patients may respond better to specific treatments in RA earlier on in their journey. To find out more visit www.matura.whri.qmul.ac.uk



The Apippra study (Arthritis Prevention in the Pre-Clinical Phase of RA with Abatacept) is a UK wide study which aims to test whether RA

medication can prevent or delay the onset of the disease. www.kcl.ac.uk/lsm/research/divisions/dioid/departments/rheumatology/research/clinical/current/apippra

More units are invited to join both these studies and if you are a rheumatologist or a research nurse and would like more information about your department participating, please get in touch via the appropriate websites.



These and other studies hope to improve the lives of thousands living with rheumatoid arthritis. If you as an individual would like to know if you are able to take part in these or other similar studies the best way to find out is to "ask". It's **ok to ask** and ask more than once as often new opportunities arise all the time. Your nurse or consultant will be able to tell you if you are eligible to participate in any current studies.

.....
Your nurse or consultant will be able to tell you if you are eligible to participate in any current studies.

Research Update

Can RA prediction be a “gut feeling”?

Gut bacteria may help to predict susceptibility of RA in some individuals

According to two recent papers published by Dr Taneja and her team at The Mayo Clinic's Center for Individualised Medicine in the US, a possible link has been observed between specific gut microbiota and the onset of rheumatoid arthritis.

One study examined a group of rheumatoid arthritis patients, their relatives and a healthy control group. The study aimed to find a biomarker (a biological measure that could indicate disease). The results showed an increase of certain types of gut microbes in people with rheumatoid arthritis compared to the healthy individuals.

A second study by The Mayo Clinic involved treating a group of mice that were susceptible to arthritis with a specific bacterium (*Prevotella histicola*) and comparing them to a group with no treatment. The results found that in the mice that were treated with the bacterium their symptoms reduced along with their inflammation. There were also found to be minimal side effects as the bacterium is already part of a healthy gut. As mice immune systems and arthritis is very similar to our own, this shows promise for when trials are extended to humans.

It is hoped that further studies in mice, and later in humans, could help scientists to predict who is likely to develop RA and how severely, which could lead to perhaps finding new ways to treat or even prevent RA using manipulation of the gut bacteria.



Diabetes link

Study highlights diabetes link to glucocorticoid treatments for arthritis

A study led by the Arthritis Research UK Centre for Epidemiology at the University of Manchester has shown that those on doses of steroids higher than 5mg have a greater risk of developing diabetes with an increase in risk for every increase in steroid dose. This type of steroid therapy is often used for people with rheumatoid arthritis.

The study looked at more than 20,000 patients and compared rates of new-onset diabetes in those who were prescribed glucocorticoids to those who were not. Glucocorticoids were shown to be associated with one new case of diabetes for every 150 to 200 people treated each year.

The results were published in the Journal of Arthritis and Rheumatology.

Although low doses of prednisolone (less than 5mg) did not carry any increased risk of diabetes, higher doses increased the risk by 25-30% with every increase of 5mg.

The conclusion was that those who use steroids for long periods of time may be susceptible to an increased risk of diabetes but that this risk was not seen at low level doses.

Dr Will Dixon, Director of the Arthritis Research UK Centre for Epidemiology at the University of Manchester said: “Doctors treating people with arthritis have to make a decision how best to prescribe glucocorticoids by balancing the benefits against the risks. However, until now, no studies have considered how the risk changes with the dose and duration of treatment. This research provides important evidence for doctors to make the decision.”

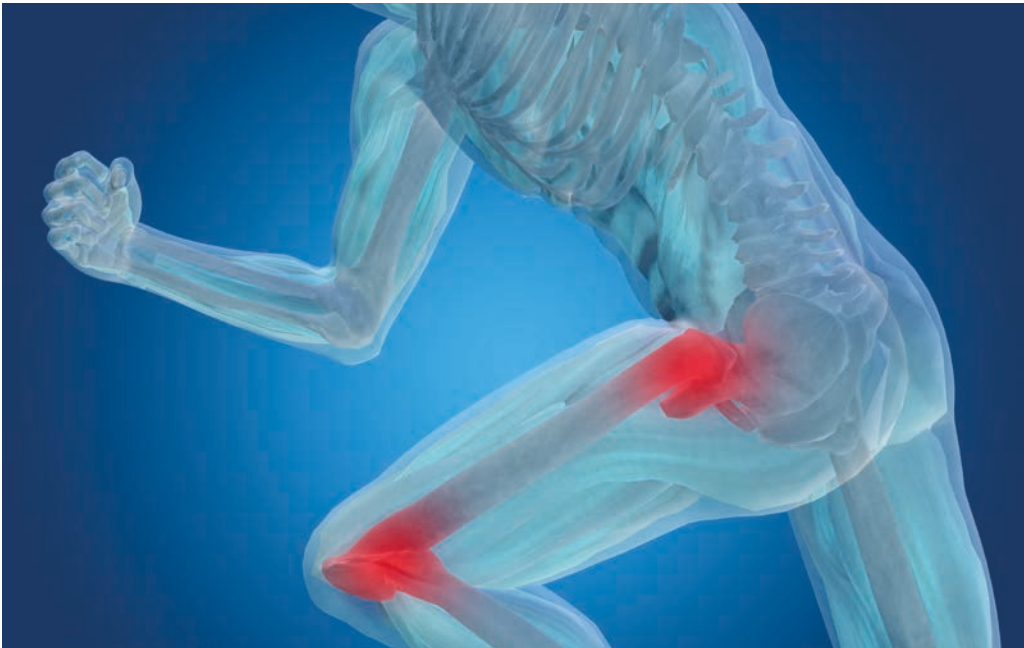
MANCHESTER
1824

The University of Manchester

Research Update

Cartilage re-growth

Re-growing cartilage with bioglass technology



Bioglass was originally developed in the 1960s to heal the bones of Vietnam War veterans and now researchers from Imperial College, London and the University of Milano-Bicocca in Italy have created a new bioglass that mimics the shock-absorbing and load-bearing qualities of real cartilage. This new bioglass technology could lead to improved treatment of cartilage damage and implant technology.

This new version is made up of silica and a plastic, or polymer, called polycaprolactone. It provides cartilage-like properties including flexibility, strength, durability and resilience and can be made in a biodegradable ink form that can be used in 3D printing. It has also shown self-healing properties when it gets damaged.

This is a step forward because it means that synthetic, bioglass cartilage disc implants can be made that perform the same as real cartilage but without the need for metal and plastic support devices. In addition, cartilage that is worn can be

replaced with this material.

The team is also looking into creating tiny biodegradable scaffolds using the bioglass ink, providing a template that replicates the structure of real cartilage in the knee. When implanted the bioglass would encourage the cartilage cells to grow through microscopic pores in the scaffold, with the scaffold disappearing over time and leaving the new cartilage in place.

One of the developers of the bioglass at Imperial College, Professor Julian Jones, has said "Patients will readily attest to the loss of mobility that is associated with degraded cartilage and the lengths they will go to, to try and alleviate the often excruciating pain associated with this.

We still have a long way to go before this reaches patients but we've made some important steps in the right direction to move this technology towards the market place."

Synthetic, bioglass cartilage disc implants can be made that perform the same as real cartilage

NRAS 2016

Some highlights of our year



Tammy + Beverley RA week at Tilehurst GP Surgery



L to R; staff nurse Susan Henry, occupational therapist Fiona McCurdy and biologics nurse Valerie Findlay. A team effort by the NHS Grampian Rheumatology department, organised by Aimee Urquhart, senior physiotherapist



Nikki + Ali out and about during RA Awareness Week (RAAW)



I've got to hand it to you, Conn - you've really had a hand in it this time!



Dr David O'Rielly dropped by the stand at EULAR



NRAS team at EULAR Congress in June at the Excel in London



NRAS Worcester group take to the high seas... well, river!



DAS app launched at BSR conference.



AILSA RECEIVES HER MBE



12 page supplement in the Guardian during RAAW



NRAS group in Blackpool, supported by their rheumatology team, raise awareness of RA.



Luton and Dunstable rheumatology team having their cake and eating it for RAAW

External Affairs

NRAS Groups' Update

The External Affairs team has been as busy as ever over the spring and summer

In March, Nicky and Val from NRAS made the trip to Salisbury and hosted an Information Evening supported by Salisbury District Hospital rheumatology team.

The group originally launched in 2011 and has been running successfully since then. To show their continued support for the group the rheumatology team came together for the evening where Alison Kent, Rheumatology Nurse Manager, gave an insightful presentation into 'How to Make the Most of Rheumatology' from a patient and healthcare professional perspective as she lives with RA herself. This was followed by a lively Q&A session. There was also an appeal made to ask if anyone else would like to help coordinate the group. NRAS would like to say a big thank you to Alison who was instrumental in making the evening happen. We wish Salisbury NRAS group many more successful years.

In May, Kim and Gill made the long trip to Kendal in Cumbria to launch a group with the help of Westmorland General Hospital Rheumatology

team. NRAS were thrilled when we were approached to start a group in the south of Cumbria as it covers such a wide geographical area. The event was held within the hospital and there were over 80 people in attendance. Gill and Kim would like to thank Dr. Eva Palkonyai, Consultant Rheumatologist, for her keynote speech. This was followed by an excellent Q&A session with rheumatology specialist nurses, a physiotherapist, occupational therapists and the ward manager from the treatment centre. A big thank you to Liz Axten, Maggie Thorne and Jenny Stockdale from rheumatology for helping to organise the evening. A very keen group of six volunteers came forward to coordinate future meetings.

Meeting dates and details can be found at www.nras.org.uk/groups/nras-south-cumbria

July saw Kim, Gill and Shivam head to the London suburbs to launch a group at Croydon University Hospital. Kim and Gill met with all the rheumatology consultants back in November 2015 who were keen to start a group in the area. Despite Wales playing in their semi-final of the European



Alison Kent
Rheumatology Nurse Manager
Salisbury District Hospital



Westmorland Hospital rheumatology team



Croydon University Hospital

football championship and Andy Murray having a late match at Wimbledon a dedicated group of approximately 80 people still attended the launch. The evening kicked off with a curry supper generously provided by the rheumatology unit before everyone headed into the lecture theatre to hear the opening address from Croydon Health Services NHS Trust CEO John Goulston. Dr. Tazeen Ahmed made the keynote presentation and was then joined by her colleagues Dhrupti Shah, Physiotherapist, Jun Liu, Rheumatology Specialist Nurse, Reginald Grant, Podiatrist and Elizabeth Butler, Hand Therapist, to form the Q&A panel generating many interesting questions. A special thank you to Justine Sharpe, Rheumatology Manager, and Dr. Ahmed for organising much of this event, especially the curry supper and the free parking.

We are hoping to announce meeting dates for the group soon, more details can be found here www.nras.org.uk/groups/nras-croydon

The busy autumn approaches with four group events taking place:

- West Wales to be held at the Queens Hall in Narbeth on the 15th September
- Grimsby to be held in the gym of Diana, Princess of Wales Hospital on the 11th October
- Stoke-on-Trent to be held in the main hall of the Hayward Academy on the 8th November
- Southend-on-Sea in the Jubilee Suite of the Saxon Hall Conference Centre on the 9th November

To find out more about these events please contact **Gill or Kim** on **01628 823 524**.

We would like to thank all the healthcare professionals that have been involved in planning and supporting these events and we wish all our new groups every success.

In other Volunteer news...



Cheshire NRAS Member and Volunteer, Lynda Hesketh recommended to the Queen to be awarded a British Empire Medal (BEM) in recognition of her voluntary work with Chester Adult Phab Social Club. Lynda was diagnosed with JIA at the age of 2 and has been a keen supporter of NRAS for many years.

Congratulations Lynda.



Donna Saunders (NRAS Member, Volunteer and Group Leader) from Worcester was magnificent in working on a two-day shoot in London for a filming project NRAS is working on with Lilly Pharmaceuticals. The title of the project is *Behind the Smile* but Donna even got behind the camera! Donna was the "authenticity" director to ensure that what was being captured was realistic of the day to day situations that someone with RA may encounter.

Watch out in the autumn for the release of the *"Behind the Smile"* video.



We're on Instagram!

Just to let you all know, we're now on Instagram! You can follow us at www.instagram.com/nras_uk if you have an Instagram account, or alternatively search **NRAS_UK** on Instagram search from your phone.

For those that haven't heard of it, Instagram is an online mobile photo/video sharing and

Find us on Instagram:
NRAS_UK



social networking platform that lets users upload photos using filters and hashtags. It has a reach of roughly 500 million active users per month. A quick search for **#rheumatoidarthritis** alone has 74,000 results. Take a look: www.instagram.com/explore/tags/rheumatoidarthritis/

External Affairs

RA Awareness Week 2016

NRAS London Event

On Saturday June 18th the very first London patient event took place at the Diorama Arts Studios on Drummond Street in Euston. Due to the London lifestyle community groups are difficult to establish in the capital therefore the NRAS External Affairs team decided to host a one off information event.

Guest speakers for the afternoon were Dr. Frances Humby MRCP, PhD Senior Lecturer and Honorary Consultant Rheumatologist, Bart's Health NHS Trust and Dr Bruce Kirkham, Consultant Rheumatologist, Guy's & St Thomas' NHS Foundation Trust, London. Dr. Humby kicked off the afternoon's presentations and briefly covered the basics of RA, then went on to talk about available medications and the future of RA treatment. Dr. Humby gave an inspired presentation that generated many questions from the audience, from what prospects there are for people that have already tried many drug options to how pain and fatigue are related and advice on

how to help alleviate them. Dr. Kirkham then went on to give a very interesting presentation about the RA centre at Guy's & St. Thomas' Hospital, which was revolutionary when it started in 2004 and has been at the forefront of improving patient care and experience ever since. Dr. Kirkham's talk also generated questions from the audience, with one patient asking if the work taking place at the RA centre could be rolled out to all units across the UK to ensure fair access and treatment for all.

The event was a huge success with very positive feedback from all attendees and NRAS hope to make this a regular feature of the NRAS calendar.



*Dr Frances Humby
PhD Senior Lecturer and Honorary
Consultant Rheumatologist,
Bart's Health NHS Trust*



Competition results

Planes, Trains and Automobiles

Top Tips for Trips Winner!

Winner of the second Cool Icebox medium travel case was Ray Howard for her top tip:

"If travelling with injections get your supplier to provide you with a letter confirming they are medication and that they must be kept cool, keep the letter with your prescription and all

medication in your hand luggage. Always inform the airline before you travel that you will be carrying injections for medical purposes, they will often inform airport security which reduces the number of questions!!"

Congratulations Ray and happy travels.



Fundraising

Could NRAS be your next Charity of the Year?

Highlights from the past year



Northup Golf Club



Night of the Stars

NRAS has been fortunate to receive great support from businesses and social clubs in the past, which provides us with a fantastic opportunity to raise awareness of RA and NRAS locally.

This year NRAS Charity of the Year supporters have raised an incredible £23,300, so our thanks on behalf of all those we support living with RA and JIA goes to them all. We're always looking for new partnerships and want to make your year the best yet. So if your sports club, business, community group are interested please get in touch today on fundraising@nras.org.uk or call 01628 823 524 and speak to the fundraising team. Some of the highlights from this year are below:

Northup Golf Club

Steve Roberts, 2014 & 2015 Club Captain, supported by his wife May who lives with RA, have both been fundraising for NRAS and raising awareness of RA at Northup Golf Club in North Wales. They have been raising money via charity raffles, Captain's Day, Ladies Day and numerous collections. Their generous efforts have raised a fantastic £2,595 and we're extremely grateful for their support over 2014 and 2015.

Night of the Stars

The Night of the Stars, a Pro Am bridge tournament, raised in excess of £67,000 for four charities on

25th February 2016; NRAS received an incredible £15,030.

This event was Night of the Stars', ninth and final year raising funds for charity, led by auctioning off opportunities to play with professional bridge players as well as other fantastic prizes. The world class line up of stars included: Andrew Robson, Zia Mahmood, Tony Forrester and Norwegians Geir Helgemo and Boye Brogeland.

Terry Hewett, Chairman of the Night of the Stars, nominated NRAS to be one of the charity partners this year and had this to say: *'When my young daughter was diagnosed with aggressive rheumatoid arthritis, it seemed like the world had ended. It turned out to be the beginning of a journey albeit one that no one would want to take. Thanks to the most fantastic medical support, my daughter is able to enjoy an incredibly full, active and productive life as a junior doctor.'*

I was delighted when the Night of the Stars Committee unanimously agreed to select the National Rheumatoid Arthritis Society as one of our 2016 charities. NRAS proved to be a popular choice as it became clear very quickly how many people have a close friend or family member with this disease.

I am sure that the money we raised will be put to great use by your wonderful organisation which gives all sorts of support, information and hope to people who have this debilitating illness.'

.....

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Fundraising

Marathon Marriage Proposal!



At the London Marathon Richard Evans, a long term supporter of NRAS, proposed to his girlfriend Luci.

Richard chose mile 9 to propose, he dropped down on one knee, Luci said yes and then he got up and ran the other 17.2 miles to complete the marathon. A real first for NRAS! Richard's mum was involved with the surprise and made sure Luci was in the right place at the right time.

Richard ran for NRAS last year and after running found out that his grandfather had passed away earlier that morning – whilst he will never forget his grandfather, he wanted to have more positive memories of the London 2016. The proposal was in the planning for a few months and definitely tops his marathon memories.

Many congratulations Richard and Luci, can't wait to hear when the wedding will be, our hats are at the ready!

Congratulations!

The latest NRAS Lottery Winner was the lovely Rebecca, who won £1,000 earlier this year



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



Playing the NRAS lottery is a great way to support the work of your society as NRAS receives 50p in every £1 directly to NRAS. Sign up online at www.nras.org.uk/lottery and the next winner could be you!



Support NRAS through Payroll Giving

Payroll Giving is a great and simple way to support people with rheumatoid arthritis and juvenile idiopathic arthritis in the UK on a regular basis.

Your donation is taken straight from your gross monthly salary before tax is deducted, so if you decided to give £5 per month it actually only costs you £4 and the taxman pays the rest!

If you would like to become a Payroll Giver all you need to do is fill out a simple form at www.nras.org.uk/give-through-your-salary

If you would like further information, please contact us on **01628 501546** or email fundraising@nras.org.uk



700,000 reasons to run Berlin 2017

That's approximately how many people live with RA and JIA in the UK.

Will you join Team NRAS and run in the Berlin Marathon 2017?
Sign up at www.nras.org.uk/runs

NRAS is Changing Minds, Changing Services, Changing Lives for People with RA and JIA

BBC RADIO 4

16 OCTOBER

Listen out for NRAS on the BBC Radio 4 Appeal on the 16th October

The BBC Radio 4 Appeal raises thousands of pounds annually for charity and on the 16th October NRAS will be broadcasting its Appeal.

Celebrating our fantastic Volunteers and NRAS' 15th Birthday, our broadcast shares the story of Amy, who was diagnosed with RA shortly after the birth of her first child. Amy's story covers the highs and lows of her journey and how an NRAS Telephone Support Volunteer 'came to her rescue' and helped her when she was at her lowest, struggling with isolation and 'the continuous struggle of living with RA'.

To hear Amy's broadcast for NRAS, tune in to BBC Radio 4 on Sunday, 16th October at 7:55am and 9:26pm and Thursday, 20th October at 3:27pm.

To see more about our Appeal (and donate too!) visit: www.nras.org.uk/radio4appeal



Policy and Public Affairs

Engaging with a new government

An opportunity to make the case for people living with RA or JIA



Ailsa, Conn and Phil meeting Teresa May and Stephen Crabb

Most of our interaction with government is with the Dept. of Health and the Dept. of Work & Pensions

A fresh cabinet and newly appointed ministers, irrespective of party, is always a welcome opportunity for renewed engagement and a chance to make the case for people living with RA or JIA. The new government, headed by Theresa May, provides this opportunity.

Most of our interaction with government is with the Department for Health and the Department for Work and Pensions. At Health, Jeremy Hunt continues as the longest serving Health Secretary in recent times whereas at the DWP, Damian Green becomes the third Secretary of State this year! Both departments have seen significant shake-ups in their junior ministerial teams. We hope in due course to work with all the relevant ministers and ensure they are well informed on the issues that matter to people with RA/JIA.

We've had strong and productive working relationships with ministers and officials through the Blair, Brown, Cameron/Clegg and Cameron

governments since NRAS was founded in 2001. In the aftermath of the vote to leave the European Union in June, there was uncertainty and upheaval so having a government of any form to work with formed so swiftly was a welcome development and we look forward to engaging with the May administration.

As constituency MP for Maidenhead, Theresa was very supportive of our founder and Chief Executive, Ailsa Bosworth, (who lives in Maidenhead and where our offices are still based) in the formative years of the charity. As you may know Theresa has been our patron since 2003 and in this capacity she has supported several parliamentary events as well as attending local events in Maidenhead. As a charity, we are apolitical and it is important to state that we are likely to disagree at times with decisions made by governments of whichever political hue, but this should not prevent us from being a critical friend in order to engage effectively. Whilst grateful for the patronage of the Prime Minister, we will continue to review issues on a case-by-case, evidence-led basis and there will



There is much in the pipeline that could benefit people living with long-term conditions.

be times we exercise our independently formed opinion in contrast to that of her government.

There is much in the pipeline that could benefit people living with long-term conditions. Some things are likely to be postponed or redesigned to fit in with the direction of the new government. There is an already overdue "green paper" on disability and work expected in the autumn and a "seven day NHS" is very much still on the agenda with Jeremy Hunt having stayed on as Health Secretary.

Followers of our Facebook and Twitter feeds will already be aware that after the particularly disappointing decision by the then Secretary of State for Work and Pensions, Iain Duncan-Smith to cut the Employment and Support Allowance for people in the Work Related Activity Group by £30 a week, we wrote to Theresa to express our disappointment at the government's decision. Theresa facilitated a productive meeting with Duncan-Smith's successor, Stephen Crabb, and as a consequence, Ailsa has now been appointed to a government Expert Advisory Group for the Work and Health Unit. These opportunities for productive engagement are invaluable in influencing positive change for people with RA/JIA.

Alongside working productively with the government of the day, we seek to work also with the main opposition parties who traditionally form the "government in waiting". NRAS will also be making your views known to and getting commitments from parties when in opposition which can pay dividends. At the moment, it is difficult to make headway with the Labour party who are in the middle of a leadership contest. We will continue our efforts in this area and hope to have more success once they are on an even keel again! As Policy & Public Affairs Officer, I will be attending both the Labour and Conservative party conferences this autumn.

Politics can be a difficult business and yet I think we have successfully influenced change over the years. Politics is about constant renewal, picking up the pieces and fighting the next battle; we have to work in the circumstances as they present themselves to us in order to advance our cause.

...of course in the current political landscape, it could all be different in the morning!

Policy and Public Affairs

Descending on Westminster

MPs take the opportunity to learn more about the impact of RA



On the Monday of RA Awareness Week, dozens of key NRAS Volunteers and Lifetime NRAS Members from across the country descended on parliament for the launch of a new report produced in partnership with pharmaceutical company, Lilly.

Sir David Amess, MP for Southend-on-Sea launched proceedings and stayed with us for the evening of networking and enjoying the sun on the terrace of the House of Commons. Members of Parliament dropped in to the event and took the opportunity to learn more about the impact of RA.

Contributors to the report took the opportunity to speak to the gathered audience. NRAS Chief Medical Advisor, Professor Peter Taylor, updated us on the rapid developments in RA care in recent years: "As a rheumatologist, I have seen a dramatic improvement in the outlook for people newly presenting with RA over the last 15 years. It is noteworthy that the survey findings launched today

highlight the importance of a positive relationship between people living with RA and the healthcare professionals that provide their care.



Yet there is still room for improvement. Swift diagnosis and early treatment are key components to achieving the best possible care. This can be achieved by adequate provision of healthcare professionals who are equipped with the right tools and training to be able to talk to, assess and provide support for the physical and emotional well-being of people with RA."



The true star of the evening was Katy Pieris who spoke about the particular difficulties she had faced since her diagnosis five years ago at the age of twenty-eight. Katy spoke about the impact of the disease on planning a family and about the variance in levels of care and compassion when you are moved between consultants. Katy conveyed the full impact of a progressive and fluctuating condition with great eloquence and I hope you will read her full contribution to the report.

Having heard from the speakers and read the report, the patients, family members, health care professionals and parliamentarians gathered acknowledged the progress that has been made in treating and supporting people living with rheumatoid arthritis while recognising that not everyone receives consistent levels of care and support. We found that 26% of patients waited a year or more for diagnosis and that even after diagnosis many patients can wait a further six months to find a treatment which starts working for them.



Challenges at every step: current management of Rheumatoid Arthritis (RA)

Early diagnosis is key for people living with RA. NICE states that **potentially devastating effects to late diagnosis.**

NICE guidelines recommend any patient who seeks medical help after more than three months with symptoms should receive an **urgent specialist referral.**

Only **38%** of patients report being referred immediately by their GP to specialist care for suspected RA.

Currently **49%** of patients get a diagnosis after four months or more of symptoms. **26%** wait over a year for a firm diagnosis.

Even after diagnosis, many patients can wait a **further six months** to find a treatment which starts working for them.

26%	of patients wait less than 3 months to find a treatment which starts working for them
19%	wait 3 months or more but less than 6 months
12%	wait 6 months or more but less than 1 year
10%	wait 1 year or more but less than 2 years
12%	wait 2 years or more
16%	feel their condition hasn't improved as a result of their treatment
6%	Other

When patients do receive a diagnosis, only **30%** receive advice from a specialist on where to find additional information and support.

Less than half of people diagnosed over the last five years feel comfortable discussing their treatment with their healthcare professional. **64%** of patients agree that their friends and family are not equipped to help them manage their condition.

People with rheumatoid arthritis deserve **fast diagnosis, effective treatments, and support** to lead a full and healthy life.

Policy and Public Affairs

Greater Manchester needs you

Could you be an NRAS Ambassador for Greater Manchester?



If you are living in the Greater Manchester area, you have likely heard the new buzzword in town – DevoManc. DevoManc is the informal name for a serious project in Greater Manchester, a big shakeup in the governance of health and social care.

The devolution (passing down) of power and responsibility to a directly elected mayor and local government officials is a radical realignment of how decisions will be made. The devolution of responsibility for healthcare, coupled with rapid integration of health and social care means there is a vital need for the voices of people living with long-term conditions like RA or JIA to be heard.

We would like to set up a network of NRAS Ambassadors (drawn from members and volunteers living with RA or JIA) to strengthen the organisation's campaigning voice and increase our level of interaction with policy-makers across the Greater Manchester area. This is a model that has

worked to great effect in Scotland and Wales and we have high hopes for implementation in this region.

The involvement of local people with lived experience ensures NRAS campaigns best represent everyone in the area. We will organise training for those appointed as NRAS Ambassadors. The training will encompass an introduction to the new political set up in Greater Manchester followed by sessions on lobbying/influencing and a review of developments in health and social care policy.

To find out more and see the full role description, visit www.nras.org.uk/DevoManc or email campaigns@nras.org.uk. We'd love to have you on board.



Policy and Public Affairs

Working Towards 2017 NRAS Work Survey



By Sam Boyle

Sam Boyle has worked for NRAS throughout the summer as a Policy & Public Affairs Intern. During his internship, Sam's primary focus has been researching the important topic of employment and RA/JIA. The 2007 (UK wide) and 2010 (Scotland) NRAS reports on work and RA continue to be very influential and we intend to investigate this topic and publish a

new report, ten years on from the original, in 2017.

NRAS is very grateful to Sam for his valuable contribution to this important research project and we wish him all the very best for the future. First with an exciting holiday to Russia and then for his Master's degree at the University of York where we are sure he will do very well.

As my time with NRAS comes to an end, I would like to reflect on the time I have spent working on preparations for the 2017 NRAS work survey and report.

Firstly, I would like to thank the NRAS team for making me feel welcomed and valued during the last 8 weeks. It has been an enormous privilege to work here. In a short time, I have got to grips with a wealth of information on RA and JIA, written a literature review and helped lay the groundwork for the upcoming 2017 Work Survey.

It is an exciting time for our new report to be published, one decade on from the 2007 work survey. In just 10 years, the estimated number of people diagnosed with RA in the UK has been quite drastically revised. In 2007 we estimated that there were around 387,000 people diagnosed with RA in the UK, in 2016 it is thought that there are 690,000. In light of this, a new piece of thorough research and a fresh survey of our members and supporters could not be more relevant.

We have been finding out about what matters to people with RA who work full time, part time, who are self-employed, currently not working or retired. Since 2007 there have been reforms implemented by the Labour, Coalition and Conservative governments, many of the reforms have been in the context of a global recession and the age of austerity. It will be illuminating to see these changes for good and bad through the eyes of respondents.

There have been various changes to the welfare system such as the introduction of Personal Independence Payment (PIP), changes to Employment and Support Allowance (ESA) and the gradual phasing in of Universal Credit. It will be interesting to see what impact this has on working people.

Moreover, our analysis has brought up new areas of interest, which were previously under-explored. In 2007, we included broad occupational categories that our participants worked in. In 2017, we are expanding on this by planning a detailed analysis of how a diagnosis of RA affects individuals in different employment roles looking at physical demands and work patterns.

Initial research suggests that the degree to which roles include manual work, the size of the organisation people work for and the pattern of work schedules may have a substantial impact on the working lives of people with RA/JIA. Accessibility of work is also important and we will look at the logistics of working in urban and rural areas. It will also be revealing to look at the working lives of those who are self-employed and their contrasting personal experience if they previously worked for someone else. Of particular interest will be to look at the differing working hours and how financial planning was affected as a result of the change. In addition, being able to review the number of people who are aware of work programmes and indeed the number who go on to access them will be advantageous to us.

This has been a great organisation to work with and I must thank Conn, our Policy and Public Affairs Officer for his support, our Chief Executive Ailsa Bosworth and all the great NRAS staff and volunteers who work tirelessly to promote our cause. Finally, I would like to thank the NRAS Members who shared with me their experiences, I will take away with me an understanding of how RA can affect all facets of life and how courageous and resilient so many people are in work and in daily life.

I would like to thank the Members of NRAS who shared their experiences with me. I will take away with me an understanding of how RA can affect all facets of life.



By Rebecca Stancombe

My Story

2016 UK Edgar Stene Essay Prize entry

Living with a rheumatic or musculoskeletal disease (RMD): How I take action to enjoy life to the full.

Standing next to a cairn last summer on the top of Scafell Pike, at 978 metres the highest peak in England, I could barely contain my joy as I hugged my husband. I had finally achieved one of my most challenging goals, a feat I never thought I would, or even could, achieve when I was first diagnosed with rheumatoid arthritis at the tender age of 24.

Looking back on the initial diagnosis in the doctor's surgery in April 1992, I remember that my first feeling had been one of relief as I finally had a name for this disease which was beginning to deform my joints and making my usual striding gait a painful and self-conscious hobble. Little did I know then that the first couple of years after my diagnosis would be bleak ones, with my daily activities restricted by stiff and painful joints, fatigue and wasting muscles, not filled with optimism or excited anticipation as you would expect of someone in their twenties. These were the difficult days before the advent of biologic drugs and the talk of disease remission. The thought of enjoying life to the full then seemed like a cruel joke or a distant memory.

I perhaps was not initially aware that I was suffering from depression due to the profound and unwelcome changes in my lifestyle brought on by this debilitating disease and this, in turn, was preventing me from enjoying or living life to the full. I became introverted and lost confidence, unable to pursue my usual activities but unwilling to push myself to try new ones. The terrible fatigue was the greatest issue. Walking even a few metres felt like walking in a sea of treacle over sharp rocks. However, as I slowly started to come to terms with my 'new life', I began to realise that I had to adapt and learn to appreciate any small achievement, even if it was just being able to button up my cardigan without any help. I slowly and surely began to push myself to try new experiences which I could do without any pain, such as learning to speak Spanish and Italian. My confidence began

to return which was given a major boost by the arrival of anti-TNF therapy at the end of the twentieth century, radically transforming my life, and thousands of others peoples' lives. Before the advent of these biologic drugs, walking a mere few hundred metres would have been a challenge. Once on anti-TNF therapy, I began to walk to work for one day per week, which gradually increased until, as my confidence and fitness grew, I was able to walk to work every day. A simple activity, which had seemed impossible to me during the previous few years, was now an achievable goal. Who would have thought that I would have been so delighted to be wearing out a new pair of shoes every few months?

The continual walks to work then increased my desire to attempt fell-walking again in the Lake District. I had just begun to enjoy fell-walking in my early twenties, hoping that one day I would be able to climb Scafell Pike, when the rheumatoid arthritis had struck. Now, with a sense of renewed optimism and determination to appreciate my new-found fitness, I felt that I could take on a challenge which I may even have found tough in my younger days.

So, having invested in a sturdy pair of walking shoes last summer, my husband and I drove to the Lake District, armed with Ordnance Survey maps, a compass, waterproof clothes and plenty of blister plasters. Basing ourselves in the picturesque village of Great Langdale in the heart of the Lake District, we set out one day from the Old Dungeon Ghyll pub on a 14-mile round trip to Scafell Pike, a steep and challenging ascent of 1042 metres. We started out on a route which, at first was misleadingly gentle, until we got to Rossett Gill, where I really began to appreciate the scale of the task I had embarked upon: a seemingly never-ending steep climb on sharp, occasionally slippery and unforgiving granite... and the worst was yet to come!

We wound our way slowly to the next peak, Esk Hause, before continuing past the aptly named Broad and Ill Crag. From Ill Crag, the summit of

Walking even a few metres felt like walking in a sea of treacle over sharp rocks.



However, all the pain and fear melted away when I scrambled over the last boulder of granite and saw the final cairn marking the summit.

Scafell Pike suddenly came into view. Believing we had not too far to go, I started to celebrate before it slowly dawned on me that, according to our ordnance survey maps, there were two more considerable descents and a huge boulder field to cross before the final steep ascent to the summit. Reminding myself of the difficult early years of the disease made me determined to plough on. The boulder field, however, really tested my new mantra of 'living life to the full' as it seemed to be a relentless and unwieldy block of volcanic rock, punctuated by dangerous and leg-breaking crevasses. At this point, my joints and muscles were aching and my heart was thumping with fear and adrenaline. My fear of heights was also being sorely tested, particularly when I embarked upon the final steep scramble to the summit: with no sense of shame, I used my hands, feet and any part of my body which would keep me attached to those huge boulders!

However, all the pain and fear melted away when I scrambled over the last boulder of granite and saw the final cairn marking the summit. The views of the surrounding Lake District, the Isle of Man, the Irish Sea and the Scottish hills on such a beautiful and clear day were stunning and truly complemented my sense of elation. However, after a few minutes of celebrating my achievement and the breath-taking views, I realised that I would have to attempt the same route back down to the start: living life to the full can have its downsides too! Fortunately, the descent went smoothly, although somewhat painfully and very slowly, and, after 10 continuous hours of walking and scrambling, we reached our starting point at the Old Dungeon Ghyll pub where we celebrated my achievement (and the accompanying bruises and scratches) with a huge piece of Cartmel sticky toffee pudding and a pint of ale!

Having accomplished this particular goal, I have truly begun to embrace all the challenges in my life. I have just increased my hours at work, I am attending talks and lectures, enjoying an active social life of cinema, theatre and travelling...and, of course, continuing to walk and hike. The road to the top of the fell was a long and painful one, both literally and metaphorically. It was a result of a conscious and determined decision to enjoy my life to the full, and I continue to this day to appreciate and cherish my abilities and achievements, no matter how great or small.



My Story

Liverpool Night Rider Challenge

Charlotte Taylor tells us why she took to two wheels in memory of her dad



My dad, Paul Anthony Taylor was diagnosed with RA when he was just 28 years old.

He never complained and always tried to live as normal a life as possible. The difference was that each day he knew he was getting worse and every week he was subject to relentless pain.

After a few years it was clear the condition was affecting virtually every joint in his body. Dad had two hip replacements, numerous stays in hospital and eventually the dreaded RA attacked his lungs.

Despite his difficult day to day life, Dad managed to work full time, support his daughters through university and be a loving husband for 25 years. Dad had to stop playing football and squash but maintained a keen love for all sport – he'd have loved watching the recent Olympics! As his disease progressed he was only seeing a few key members of the family and was no longer able to leave the house. Knowing one day that he would have to leave "his girls" behind must have been a huge worry.

When I told Dad that I was going to do a 60 mile bike ride to raise money for a charity of his choice he was hugely supportive, that is when he'd eventually stopped laughing! We chose to raise money for rheumatoid arthritis in the hope that extra funds will give support and provide solutions for many sufferers of RA. Dad passed away before I completed the Liverpool Night Rider Challenge but I hope he would have been proud of myself and my fiancé Katie Martin. We also raised funds for the Carers Link Lancashire as my mum, sister and I had cared for dad for a long time and Carers Link offers support to all carers.

NRAS would like to say a huge thank you to Charlotte and Katie for supporting NRAS and if you would like to add your support you can still donate on their Just Giving page www.justgiving.com/fundraising/charlotte-taylor-cycle

JIA & Me

'JOGLE' for JIA!

(John O'Groats to Land's End)



Dr Vineet Joshi

On 4th July this year a local GP from Oxford, Dr Vineet Joshi, his good friend Rob Patterson and their back up team mate Trevor Amos set off on a long distance cycle challenge, raising money for JIA-at-NRAS along the way, with over 920 miles to cycle in 10 days from John O'Groats to Lands End, or as they aptly named it a 'JOGLE for JIA'!

Vineet was diagnosed with psoriatic arthritis last year and so cycling the length of the country is not something you might consider lightly. What made this cycle even more inspiring was that he was motivated to pursue this JOGLE for JIA ride after seeing a painting which had been entered into the JIA&ME art competition, held in the paediatric rheumatology unit at the Nuffield Orthopaedic Centre in Oxford by 9 year old Alec Perry. Vineet read what Alec had said about living with JIA and after meeting Alec was determined to help raise awareness and support the growing JIA service at NRAS. Vineet jumped in with both feet, getting Alec to design a special logo for JOGLE for JIA; Facebook and Just Giving pages were set up and the special cycle jerseys with the unique logo were made up for the cycling duo.

Vineet and Rob started training in earnest in early February 2016 and notched up numerous miles in the rainy winter months. The community of



Alec Perry

Wantage in Oxfordshire, really got behind their local GP, Vineet. Local ladies organised a bake sale, the Wantage Rotary Club donated to Vineet's challenge and Sainsbury's Wantage set up static bikes and a few members of staff rode nonstop for 3 hours and collected sponsorship from passing customers; Alec even joined Vineet for this one! Vineet, Rob and Trevor were delighted that as the miles went up so did the money on their Just Giving page.

So on 2nd July Vineet, Rob and their support team headed up to Perth in Scotland for preparations to start the cycle on 4th July. The first couple of days the Scottish weather was none too kind, but by 8th July the guys had crossed the border into England. On 12th July Vineet finally crossed into Cornwall for the final push to Lands End. 13th July arrived and Vineet, Rob and Trevor completed their 920 mile trip, eagerly greeted by family who had made the journey to be the welcoming party and to be there to give moral support and huge cheers and hugs on their arrival at Lands End! Vineet reached the target of £5000 that he set himself to raise for JIA-at-NRAS and has helped to raise awareness along with Alec about what JIA means when you are just 9 years old. If you would like to read more about the adventures of this couple of courageous cyclists or even donate you can still do so by visiting Vineet's Facebook page or his Just Giving page:

www.facebook.com/jogleforjia

www.justgiving.com/fundraising/gp-on-a-bike



A 9 year old's view of JIA

By Alec Perry

"I was 7 when I was told I had arthritis, I didn't know what arthritis was but I knew my joints hurt and were aching. My worst joints were my knees. I went to see Dr Joel at Oxford and he looked at my knees and was in shock at how big my knees were. On that same day I had a blood test, a joint injection, my eyes tested and I went to the physio room. The worst part of that day was the joint injection as it felt like a volcano had erupted in my knee. The best part was the physio room as it had fun stuff to do and a bike to ride on.

My arthritis doesn't stop me going on my bike, and Dr Joel said that cycling was good for my knees, which is good as I go on my bike all the time.

I don't like my injections, who would like injections?! But if I didn't have my injections I can't ride my bike. I entered an art competition for children who have arthritis and I drew me on my bike and some mountains and a volcano. I drew the volcano because of the joint injection and also because my arthritis is like a volcano, I don't know when it will erupt in my body and hurt my joints again."



By Anne Gilbert

NRAS Youth and Family
Services Manager



It was fantastic to see everyone mingling and chatting with each other like old friends.

JIA & Me

JIA-at-NRAS Family Fun Day

Saturday 23rd July



For the last two years, the NRAS Family Fun Day has been held in Coventry; this year we moved further north to Ilkley in West Yorkshire, with its spectacular scenery and fortunately on the day, warm, intense sunshine.

Nell Bank is a purpose built activity centre, with inclusive and accessible activities for all abilities and ages and it provided us with the opportunity to meet a whole host of families we hadn't met before as well as health care professionals. The children and the teenagers took part in supervised activities and at lunchtime they sat together, making new friends and enjoying the banter. It was fantastic to see everyone mingling and chatting with each other like old friends and it was a humbling experience for us to chat with parents and hear their stories, some very positive while others quite shocking and emotive.

Pond dipping for mythical water monsters and tracking down friendly brown cuddly bears provided hours of fun in the morning and in the afternoon

the children relished in den building and more water play. At one point in the afternoon the water sprinkler was turned on much to the delight of all the little ones who enjoyed jumping in and out of the cold spray. Their parents on the other hand, then spent some time trying to dry socks and trainers under the rest rooms hand-dryers!

The day is just as much about the parents as it is about the young people with JIA, so whilst the children were having a thoroughly wonderful fun time the parents were able to listen to and interact with a number of JIA specialist health care professionals, who spoke on specific topics and were available to answer questions after their presentations and throughout the day.

As always the health care professionals who came along and supported the day were wonderful. Dr Janet McDonagh, Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology at Manchester University spoke on transition (making the move from paediatric to adult care) and Vanessa Van Rooyen, Children's Rheumatology Team



Leader at Leeds Children's Hospital talked in general about JIA, flares and well-being. For the first time we heard from young people living with JIA. Jordy who is 12 was inspirational and despite his JIA which has meant he has had to make some significant life changes he has got on with living life to the full and everyone at the event was moved by his achievements. Jazmin, aged 25 years who has also had JIA since she was 2 years old, shared her story of completing a PHD and travelling the world. She is a shining example for parents who worry for

their children's futures. Jazmin showed them that despite JIA you can achieve your dreams.

Eventually the fun had to come to an end and all the families gradually made their way home, with exhausted but happy children, and we made our way to Leeds station. On the train back to Maidenhead we chatted and re-lived the day, still on a high and all very much thinking that we will definitely do that again next year, when we have fully recovered!





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JIA & Me

Juvenile Idiopathic Arthritis in Adulthood

What is Juvenile Idiopathic Arthritis?



Juvenile Idiopathic Arthritis (JIA) is an inflammatory arthritis of unknown cause that begins before a patient's sixteenth birthday and persists for at least 6 weeks.

"Juvenile", in this case, means that symptoms appear before 16 years of age, and "Idiopathic" means that we don't yet know the cause of the disease. JIA is not the same as other types of arthritis such as Rheumatoid Arthritis (RA). RA is a disease of adults (or occasionally older teenagers). JIA does not "turn into" Rheumatoid Arthritis when a child reaches a certain age.

Like other inflammatory arthritides, such as RA,

JIA is characterised by joint stiffness, swelling and pain. There are several different forms of JIA, distinguished mainly by the number of joints involved, and by the presence or absence of symptoms in other parts of the body. (Table 1) Oligoarticular JIA is the most common subtype, commonly beginning in early childhood. Uveitis (inflammation of the eye) is a relatively common and potentially very serious complication of JIA and children diagnosed with JIA have regular eye screening until around 12 years of age.

JIA is one of the most common chronic illnesses of childhood, affecting about 1 in 1,000 children (a similar prevalence to diabetes and epilepsy).

Table 1:
ILAR classification of JIA

* Rheumatoid factor (RF) is an antibody that is detectable in the blood of approximately 70% of adults with rheumatoid arthritis. RF positive JIA is rare in children, affecting <5% of all children with JIA and typically presenting during the teenage years.

Type of JIA		
Systemic		Systemic Features
Oligoarticular	Persistent	1-4 joints involved
	Extended	>4 joints become involved
Polyarticular	Seropositive	>4 joints involved at onset (RF* positive)
	Seronegative	>4 joints involved at onset (RF negative)
Psoriatic		Associated with psoriasis
Enthesitis (irritability of soft tissues where they enter into the bones e.g. tendons, muscles, ligaments)		Associated with enthesitis
Undifferentiated		

Can adults have JIA?

Yes.

JIA is a disease which begins in childhood but can persist into adult life. It is estimated that around 50-60% of children with JIA will continue to have active episodes of arthritis during adulthood, frequently requiring regular medications. In addition, a proportion of children with JIA will develop complications of the disease or treatments which can persist into adult life. Examples include joint damage, eye inflammation or damage, secondary osteoarthritis, osteoporosis, micrognathia (an underdeveloped jaw) or growth restriction. With the advent of new medications and earlier more aggressive treatment regimes, in particular biologic therapies, many of these complications can be prevented.

Are there any clinical differences between JIA and RA?

Yes.

JIA is an umbrella term for a number of different chronic arthritides presenting in childhood, the majority of which are very different diseases to RA. Differences between JIA and RA include:

- The autoantibody profile: An autoantibody is an antibody (a type of protein) produced by the immune system that is present in many autoimmune disorders and is directed against one or more of the individual's own proteins. Autoantibodies are seen in many autoimmune disorders including both JIA and RA. Patients with JIA may have antinuclear antibodies (ANA) but RF (rheumatoid factor) is uncommon. Patients with RA may have RF and anti-CCP antibodies.
- Uveitis: JIA, unlike RA, is associated with uveitis (inflammation of the eye), particularly in those patients who are ANA positive and have oligoarticular disease. Therefore children with JIA are screened for this complication by eye specialists, ophthalmologists, (uveitis may not have any symptoms at presentation) and may be followed-up by such specialists into adulthood.
- Long term remission rates: more common in JIA
- Damage: Appears to occur later in JIA

Although there are clinical similarities between JIA and other inflammatory condition such as RA or ankylosing spondylitis (AS), it is important to realise that JIA is a distinct clinical entity and remains so throughout its clinical course into adulthood.

What Is Transition?

Transition refers to the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from a child-centred to an adult-oriented health care system. Transition is a process and not an

event and in recent years, there has been more interest in transitional care services for young adults. The National Institute for Health and Care Excellence (NICE) has recently published guidelines on developing transitional care services and other guidelines have also been published by the British Society for Paediatric and Adolescent Rheumatology (BSPAR), Care Quality Commission (CQC), Department of Health (DoH) and Royal College of Physicians (RCP). These guidelines aim to improve the experience of transitioning from child-centred to adult-centred services through involving young people in service design, delivery and evaluation and improving communication between teams. Transition planning should begin during early adolescence and young people should be supported to build independence through provision of developmentally appropriate services. Medical teams caring for adolescents and young adults with JIA should be aware of transitional care issues and confident to discuss important physical, psychological and social aspects of adolescence. Young people should be made aware of about the full range of care and support available, including primary care, mental health services, sexual health services and pharmacy services.

Are there differences in how JIA and RA are managed?

Yes.

The management of RA and JIA (both in childhood and adulthood) bear many similarities but there are some key differences. NHS England has recently published a statement on the use of biologic therapies for the treatment of JIA. This statement critically and deliberately does not differentiate JIA in childhood and JIA in adulthood and is disease (not age) specific. Methotrexate (MTX) is the first line Disease Modifying Anti Rheumatic Drug (DMARD) for the treatment for JIA and those patients with JIA whose arthritis remains active despite MTX or who are intolerant of MTX should be considered for treatment with a biologic therapy. A number of biologic therapies are currently licenced and NICE approved for different sub-types of JIA in childhood (including abatacept, adalimumab, etanercept and tocilizumab) and other biologics are licenced and NICE approved in adults with inflammatory arthritis (including rituximab, infliximab, certolizumab and golimumab). There are no validated disease outcome measures for adults with JIA and NICE guidance for biologic eligibility for adults with RA (ie having a DAS28 >5.1 and having not responded to a combination of conventional DMARDs) does not apply to adults with JIA.

"Patients with JIA that remains active despite optimal dosing, or who are intolerant of methotrexate need to be treated with a biologic" according to the NHS England clinical commissioning policy statement 2016.

Key Points

- JIA is an umbrella term for any inflammatory arthritis of unknown cause that begins before a patient's sixteenth birthday and persists for at least 6 weeks.
- JIA commonly persists into adult life.
- JIA in adulthood is a very different disease to rheumatoid arthritis.
- Patients with JIA that cannot be controlled by an adequate dose of methotrexate (or who are intolerant of methotrexate) require biologic therapy.
- Transition is the purposeful and planned process of moving adolescents and young adults with chronic physical and/or mental conditions from a child-centred to an adult-oriented health care system.

JIA & Me

Wear Purple for JIA

Purple People Populating the Planet for JIA!



The idea for #Wearpurpleforjia came from the resourceful imaginings of Lynette and Sarah, two mums from Northampton. Lynette knows only too well the impact juvenile idiopathic arthritis (JIA) has on a young child; her daughter Farah, now 4 years old, was diagnosed just after her 2nd birthday.

Prior to Farah being diagnosed Lynette, like many people, never realised that children could get arthritis and subsequently the huge impact this can have not only on the young person diagnosed but also the family; and so #Wearpurpleforjia was conceived on the back of first-hand experience and a passion for helping to change lives.

Early on in 2016 Lynette contacted us to tell us that she had chosen JIA-at-NRAS as the charity they wish to support and any funds raised by #Wearpurpleforjia would be passed directly to JIA-at-NRAS to support the work we do for children and families. It came as a great surprise to us and naturally NRAS was delighted to work with Lynette on this innovative project.

Lynette said "We wanted to do something fun that everyone can get involved in whilst raising much needed funds for JIA." The purple theme is a simple

idea and easy to implement but has great impact, whether you don a purple wig for the day, make purple cakes or wear purple clothing.

6th May 2016, the chosen "Wear Purple Day", was a huge success with lots of publicity around the UK and over £5,000 was raised. #Wearpurpleforjia really took off with a number of schools and nurseries getting involved, Lynette and Rachel, her friend, had posters and T shirts produced and set up a dedicated Facebook page and along with the help of NRAS spread the word about the day. After a fantastically successful enterprise NRAS is very excited at the prospect of continuing on with this initiative and working with Lynette, Sarah and Rachel in 2017.

Proposals are already afoot for 2017 and we hope for bigger and better ideas and with all of us collaborating we can see even more events taking place in schools, toddler groups, NRAS groups and businesses around the UK donning their best purple outfits to really put the day on the map.

If you would like to register your interest and find out more about how to get involved, please either visit the JIA website www.jia.org.uk/wearpurpleforjia or keep updated with Lynette's Facebook page www.facebook.com/Wearpurpleforjia.

A Co-production Model

Five values and seven steps to make this happen in reality

What is co-production?

Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective.

Co-production is part of a range of approaches that includes citizen involvement, participation, engagement and consultation. It is a cornerstone of self-care, of person-centred care and of health-coaching approaches.

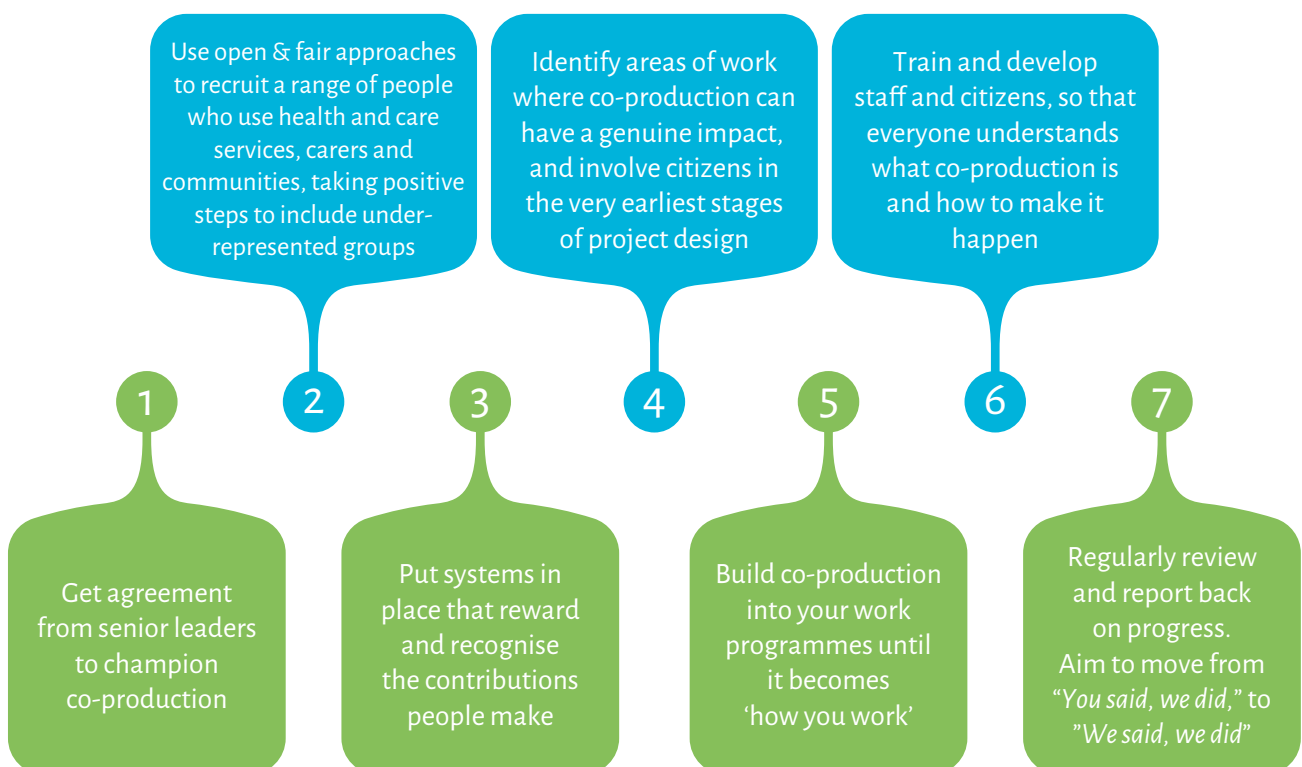
Values and behaviours

For co-production to become part of the way we work, we will create a culture where the following values and behaviours are the norm:



How to do it?

Seven practical steps to make co-production happen in reality:



WIN



Competition

EULAR Edgar Stene Prize

Open for Entries!



The Edgar Stene Prize 2017 competition is open to people 16 years and over who are living with a Rheumatic and Musculoskeletal (RMD) disease. The 2017 prize will be awarded to the winning essay on the topic:

"Time is joint - Joints over time"

"Early diagnosis and access to care in rheumatic and musculoskeletal diseases (RMDs) – the ideal world and the reality – my personal story"

For many people with RMDs it can be a long journey to receive the right diagnosis and appropriate treatment for their condition. The competition invites entrants to write about their personal experience: How long did you wait until your diagnosis was confirmed and how did you cope with the uncertainty, pain and fear during that period? Would an early diagnosis have made a difference from how you are feeling now? Do you have access to care and optimal treatment and management of your disease? What would an ideal situation look like and what is your reality?

Please submit all completed essays to Emma at emma@nras.org.uk or by post by midday on Wednesday 21st December 2016. Each entry should not exceed two A4 pages. Full competition rules and further details can be found on the EULAR website: www.eular.org

Each national jury will nominate the best entry from their country and a EULAR jury will select the 2017 overall Stene Prize winner by 15th March 2017.

The Stene Prize winner will be awarded a prize of **€1,000 and will be invited to attend the Opening Plenary Session of the EULAR Congress in Madrid** (14th June 2017) with travel and accommodation covered. The runner up will be awarded €700 and third place awarded €300.

GOOD LUCK!

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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