



nras
National Rheumatoid
Arthritis Society

WINTER 2013
Magazine

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Improving access to
musculoskeletal health
care in Kenya



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Please read and feel free to share

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Dear members...

May I wish you all a peaceful New Year on behalf of the whole team here at NRAS. Hopefully you have enjoyed the Christmas break and are perhaps, like me, now on the new year diet, full of good intentions! Speaking of diet, we hope to be able to run an interesting paper recently published in scientific journal on diet and RA in the next issue, so watch out for that!



2014 is a major year of growth and new beginnings for NRAS. We are now installed in a larger office with room for growth (still in Maidenhead, about 4 miles from the old office) and I hope that if you are coming anywhere near Maidenhead in 2014 that you will pop in and see us for a cup of tea!

One of our new beginnings is the launch of our new service for children, young people and families living with and affected by Juvenile Idiopathic Arthritis (JIA). JIA-at-NRAS will launch early in 2014 with a major media event so do watch out for coverage in the press. We have a new JIA Services Manager, Maria-Benedicta Edwards, who started with the charity on 9th December. We welcome Maria to the team and look forward to working with other charities in the sector, as well as the whole rheumatology community involved in the care of children with JIA to help support families living with the disease. Our report 'A focus on JIA' which describes many of the different models of care around the UK for children with JIA and gives feedback from families and young people about the problems they face, will be published at the launch and will be available on our website

to download soon afterwards. We would be interested to talk to any young people with JIA, families, health professionals or others who would like to support our work in this field. There is a lot of confusion around JIA as young people transition into adulthood and adult care. For many the disease can go into remission during teen years, however, for those who progress with it into adulthood, it doesn't somehow morph into RA, it remains JIA for the rest of life. We will be ensuring that these distinctions are clear on a new JIA web area which we will be starting work on in December. The new web area will be the first step in providing support to this community. We are also going to be working on ensuring that the needs of families and young people living with JIA are properly communicated to those responsible for specialised commissioning and policy makers in the coming year as services take shape in the new NHS landscape.

Another new direction for NRAS will be the provision of consultancy and directly commissioned patient support services. As a partner in the Rheumatology Commissioning Support Alliance (RCSA) with the British Society for Rheumatology

and Arthritis Care, we have already provided consultancy services to both Wiltshire and Bath & North East Somerset Clinical Commissioning Groups (CCGs) during 2013 and this work will continue into 2014. We believe that the clinicians (including nurses and allied health professionals) and the patient voice are a powerful combination and we have a lot to offer to CCGs. We are also starting to see a recognition from CCGs that properly structured patient self management support services are a vital part of delivering cost effective long term care that can provide more rounded, holistic support to people with musculoskeletal conditions, such as RA, and we are partnering with Arthritis Care to provide innovative, commissioned services in a locality which will start to come on stream during 2014.

So, another challenging and busy year ahead for the team here! With all best wishes to you for 2014, do let us know how we can help you and thank you to all our members, volunteers and supporters for everything you did in 2013 to support NRAS.

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A tribute to Helen Eadie MSP

The musculoskeletal community is mourning the death of Labour MSP Helen Eadie, at the relatively young age of 66. Helen was diagnosed with cancer in October and passed away on 9 November after a period of care at the Queen Margaret Hospice in Dunfermline.

Helen had a distinguished background in Labour politics and became an MSP in the newly established Scottish Parliament in 1999, first for Dunfermline East, and later for Cowdenbeath, following boundary changes.

Not only was Helen one of the longest serving MSPs, but she was also widely regarded as the leading voice for the advancement of arthritis and musculoskeletal policy in the Scottish Parliament, co-founding the Cross Party Group on Arthritis and Musculoskeletal Conditions on 29th February 2012.

The Group remains the principal platform for political dialogue about musculoskeletal policy and NRAS has been providing the secretariat through Scottish Ambassador, Sheila MacLeod, who much valued working with Helen. Commenting on Helen's passing, Sheila said: "I feel, as will so many, immensely sad at the loss of such a gracious and self giving lady. She combined a politician's determination and pursuit of principle with deep humanity and warmth. It is tragic that, after so many years of generous public service, she will not have the retirement with her family to which she was much looking forward. This is a huge loss."

The charity's links with Helen go back to its earliest days and she had been a particularly passionate campaigner for improvements to rheumatoid arthritis services in Scotland. In 2007 Helen sponsored a roundtable on RA in the Scottish Parliament, which gave



NRAS volunteers a rare opportunity to speak directly to Scottish politicians about the impact of the disease. In 2010, Helen was also one of several high profile MSPs to accompany NRAS on a site visit to the Fife Rheumatic Diseases Unit to showcase good quality care. On another memorable occasion Helen tabled forty parliamentary questions about RA in the Scottish Parliament during a feverishly busy two days.

NRAS will remember Helen with great fondness, as a person that remained a dedicated supporter to the end. One of her final actions, at the request of the charity, was to co-sponsor a motion about our Breaking Down Barriers report on public awareness of rheumatoid arthritis, which was published in June 2013 to coincide with the launch of the first national RA Awareness Week.

Helen was a wonderful spokesperson for the cause of arthritis and musculoskeletal conditions who will be sorely missed by all who knew her in the sector. We are grateful for her huge contribution through the years and would like to extend our deepest sympathies to Helen's family for their terrible loss.

NRAS's chief executive, Ailsa said: "I have known Helen for many years and worked closely with her on many occasions in the Scottish Parliament. I thought of Helen very much as a friend rather than purely an MSP we had strong links with. She was an immensely warm, human and empathic individual with a drive and integrity that are all too rare today. We shall miss her presence and contribution to our community greatly."



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Meet the Team...

Nicky about Gill

Gill works on setting up NRAS groups and developing new volunteer activities. Like many others in the NRAS office, Gill is an avid 'Strictly' fan. Last autumn Gill and Clare had an unprecedented experience visiting the 'It Takes Two' recording studio and meeting many well known celebrities! This did not deflect from her enthusiasm and commitment to working with the new and established NRAS groups around the country as well as encouraging and supporting volunteers so that they feel highly valued and appreciated.

Gill seems to have unlimited energy and happily travels many miles at all times of the day or evening to be in the right place at the right time. Happily for NRAS, Gill is in the right job at the right time.



Jilly about Tammy

Tammy, our office administrator, has worked for NRAS for 15 months. She enters with enthusiasm into every activity NRAS is involved with. She is conscientious and always concerned with using our funds as economically as possible, for instance, in the post room, when sending out many large parcels of publications. She is also receptionist, publications and stationery 'monitor', queen of the franking machine and keeper of our holiday records.

When I came to write about Tammy, I realised to my shame that I wasn't even sure about her country of origin (her English is so good), so I 'interviewed' her briefly. My goodness, I was impressed! She came to England from Croatia at 19, on her own and knowing only 10 words of English! She kept her mouth shut for 3 months until she felt she knew enough of the language to open it – when she had started to dream in English! Coincidentally, her first job here was in Maidenhead – in the neighbourhood of the offices we're moving into! She has travelled a lot, has lived in Windsor for 15 years and should write a book – I'd buy it so long as she autographs it!



Get involved...

We depend on the community to support our work. Here are some ways to get involved.



Membership

By joining NRAS you are helping us to support you by ensuring our voice becomes louder and awareness of this often misunderstood disease is more widely raised. Please go to www.nras.org.uk to see the full benefits of NRAS membership!



Fundraising

We depend on the community to support our work. Whatever you do to raise funds, it will help people living with RA achieve a better future. Find out more by emailing fundraising@nras.org.uk or by going on our website!



Volunteers

Our volunteer network is made up of volunteers throughout the UK, all of whom have rheumatoid arthritis so they really do understand what it is like to have the disease. If you are interested in volunteering for NRAS, from distributing leaflets to your local hospital, or training to become a telephone support volunteer and help others who have RA, then please go to the volunteer section on www.nras.org.uk for more information.

T: 01628 501547 WWW.NRAS.ORG.UK INFO@NRAS.ORG.UK

Thank you so much for all your hard work. NRAS appreciate all that you do.

My story... by Laura E James

I was eighteen when I developed RA. My mother had been diagnosed with the same condition five years before, so when my knuckles discoloured and 'puffed up', it was immediately investigated. It took five years before I was given my diagnosis. I lived in Bedfordshire at the time.

Now in Dorset, married for seventeen years to Garry, and with two children, Eleanor, thirteen, and Alex, nine, I have lived with RA for nearly thirty years.

It was during the summer holidays of 2007, having undergone surgery to partially fuse my wrist, my mum passed me a book by Jill Mansell. I enjoyed it so much, I literally read it from cover to cover, and at the back was information on the Romantic Novelists Association and their New Writers' Scheme, set up to help develop romance writers.

I'd always enjoyed reading, and had written poetry since a young age and song lyrics for a local band in which I sang in my twenties. Prompted by my discovery of the New Writers' Scheme, and sporting a rather hefty back-slab cast on my left arm, limiting what I could do, I decided to write 'that novel' I'd sworn was inside. I'm right handed. It was the perfect time.

Over the next six years, whilst raising a young family and caring for my disabled mother, I practised my art, attended romance festivals, conferences, and writing workshops, and built my online presence and writing profile. I threw in the odd singing competition too!

The RA affects many of my joints, but my hands have suffered the most. I was referred to a hand surgeon at Dorset County Hospital, Mr Sean Walsh FRCS (Tr and Orth), who, with his wonderful team, have taken care of my hand function. I've had synovectomies, a knuckle replacement, joint rotations, fusions, and tendon repairs and grafts.

During one operation, as I chatted with the theatre staff, I thanked them for keeping my hands in good working order. I explained I was an aspiring author, hoping to one day become published. I recall a member of the team joking about being acknowledged in the book.

There and then, prostrate on the theatre table, one arm dead to the world, having its ruptured tendons repaired, I smiled, and said it would be an honour to acknowledge them.

That day arrived. My debut novel, *Truth or Dare?* was released by Choc Lit UK in October 2013.

Without the constant care of Mr Walsh and his amazing team, I might not have achieved my dream of publication. I use my hands to type, and although I've been advised to use voice recognition software to save my fingers and save the pain, I love to write. I love to hold a pen and make it glide across the page.

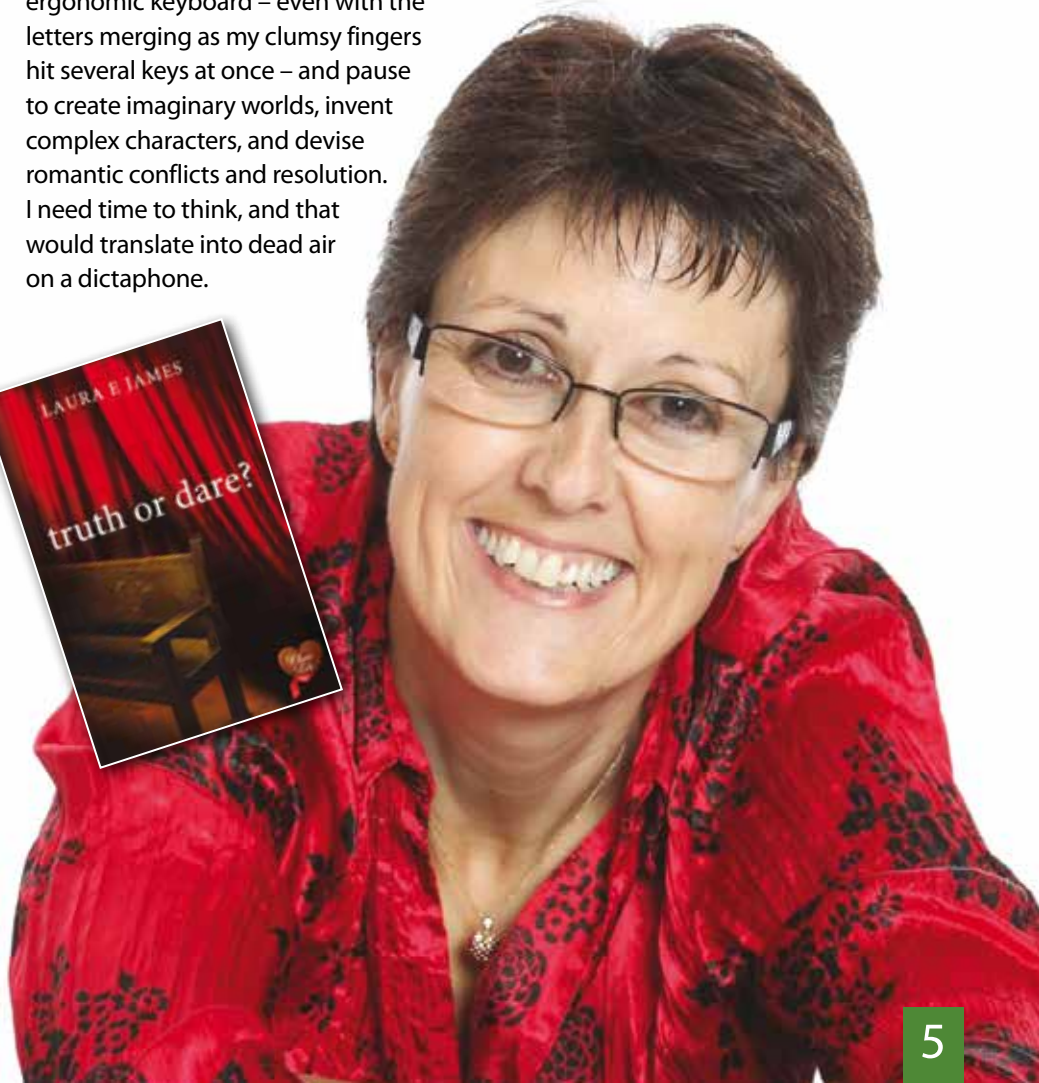
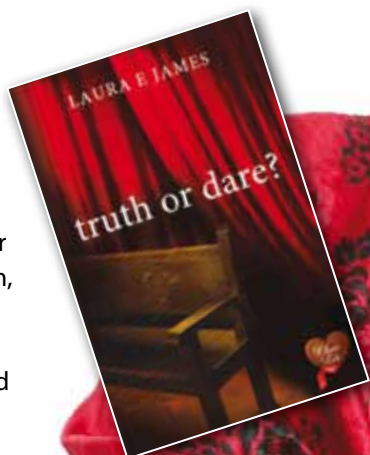
I like to sit at my desk, tap away at my ergonomic keyboard – even with the letters merging as my clumsy fingers hit several keys at once – and pause to create imaginary worlds, invent complex characters, and devise romantic conflicts and resolution. I need time to think, and that would translate into dead air on a dictaphone.

Yes. I have rheumatoid arthritis – I get fatigued and I live with pain. Yes. I inject 50 mg of Enbrel into my thigh every week, and yes, I have surgery on a regular basis, but I have achieved my dream.

I am both thankful and grateful to the team that keeps the tools of my trade in working condition. They are miracle workers, and they deserve the acknowledgement.

Thank you.

You can follow Laura at www.lauraejames.co.uk or on Twitter @Laura_E_James



Eileen's Festival Tips

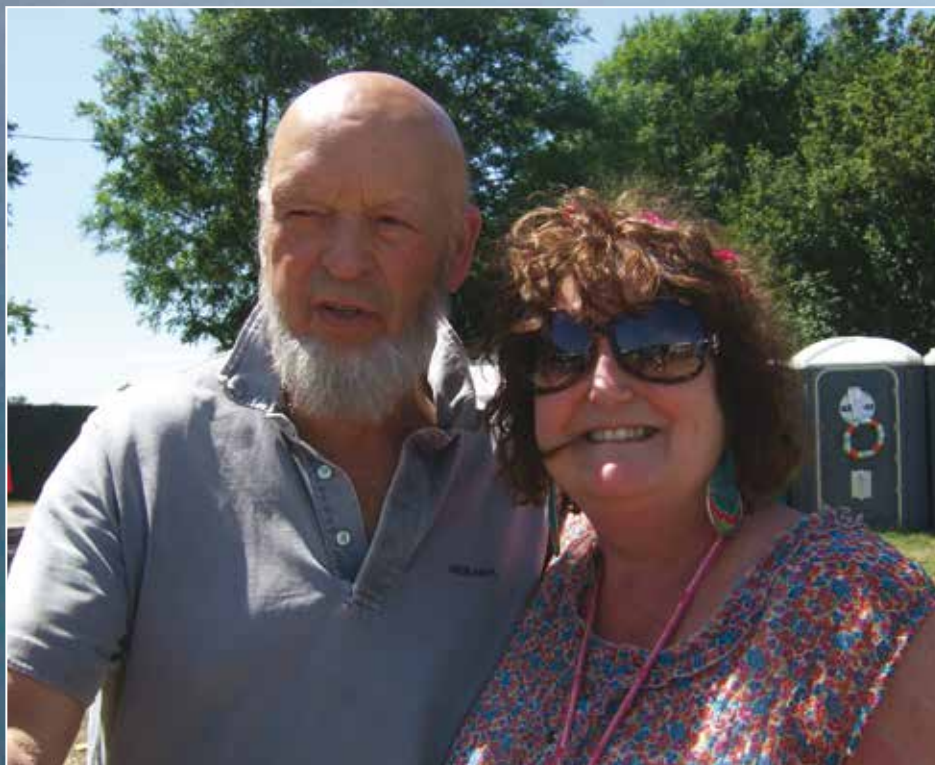
Ok, so I'm 53, ok, so I'm fat, ok, so I'm disabled, but I have been going to music festivals since I was a teenager! So if you think, a) I am past it or b) I won't manage it, well I have just had one of the best summers ever at Glastonbury and Leeds/Reading festival.

Preparation is the key, of course. First, get tickets! Some venues do have a disabled hotline where you can apply away from the main ticket sale. But most sites are equal. If you get your tickets then you can apply for camping/caravanning on the disabled site.

This is where the wonderful "Attitude is Everything" www.attitudeiseverything.org.uk charity comes into its own. It has mystery shoppers and volunteers to check out music events and "Attitude is Everything" gives them advice on their facilities for disabled people with mobility, hearing or seeing problems. They are a great bunch of people.

Tip: If you have any problems at all or need help in any way the Attitude volunteers are friendly, and as they are also disabled in some way, they have a good idea of any problems you may encounter.

Tip: For Glastonbury, get the "Green Coach"; saving fuel in the Glastonbury spirit, and a lot easier than driving. We chatted and talked about musicians and our previous Glastonbury festivals all the way there but I must admit we slept a lot on the way back! When we got to the amazingly huge site the sign-in tent for the festival was right beside the coach park and there was also a disabled car park.



Eileen with Michael Eavis



Tip: I was allowed a personal assistant too, who got a free place on their marvellous 2 for 1 scheme!

Then we got on the bus to the disabled site on the lovely festi bus.

Tip: The drivers love sweets, and put your gear on the bus for you! We got to our site – wow the volunteers put our tent up for us!! How easy is that!

Members Top Tips...

There are disabled toilets, wheelchair friendly showers, a tent with a little cooker, kettle and electric air bed pump, and it's a great place to meet and 'chillax'! We spent many an early hour around the campsite with my little hot water bottle, a couple of drinks and amazing company!

There were also mobility scooters to hire for the weekend or day on the site and we had access to the disabled platforms. These are a wonderful idea as you can sit with your PA above the crowd and see the stage. We do have a party on the platforms and you get to know everyone so well over the weekend on the site and on the platforms. You can also use shortcuts through the stages.

Will we go back again? I hope so, but we didn't get tickets for 2014. Oh well, I will always have memories of a wonderful time in 2013.



Eileen in festival mood

In each magazine we will publish other members helpful tips, in the hope that you will find them useful. If you have any great ideas, please do send them in.

Travel case

This cool bag to hold medicine is made by a Company called Frio.

I bought the large one at about £17. We used it on our big holiday in Australia, which was wonderful.

The cool bag appeared to work really well, it just needed to be re-wetted a couple of times. I had my last injection from the cool bag on 30th November and it still hasn't dried out fully yet. I took 3 pens with me and all seemed to work fine

www.friouk.com/shop/medical/new-vitesse-travel-case.aspx

Daphne Lucas



Memory foam mattress topper

I recommend a memory foam mattress topper. Mine is 3" thick and lies on top of my normal mattress. It has made a huge difference to me and allows me a much better night's sleep. You can buy one from around £29.99 online

Dawn McColl

Sabichi Pug shopping trolley

I adore the Sabichi Pug shopping trolley. It really takes the weight out of shopping and is available to buy at:

www.sabichi.co.uk/shopping-trolley-pug.html

I also use a hinged clip for when my RA is too bad to attempt a decent job at styling my hair. Lastly, comfort insoles for sore feet are really helpful. I buy mine from –

www.scholl.com/en-GB/Scholl-Airpillo-Comfort-Insoles

Helen Moody



Boiling vegetables

For boiling potatoes or vegetables, fill your pot with water out of a plastic measuring jug to save lifting a heavy pot of water and you can also boil your vegetables or potatoes whilst sitting them in a sieve. Also, when my fingers were really sore and stiff in the mornings I used to open shampoo bottles the evening before.

Lisa McBurnie



Silk nightwear

Nightwear made of a slippery fabric like satin makes it a lot easier to turn over in bed, alternatively satin sheets for added luxury.

Julie Dickins



Share your ideas...

If you have a helpful tip that you want to share, please email us at media@nras.org.uk

Dear Helpline...

I was recently diagnosed with rheumatoid arthritis (RA). At the appointment I was given a steroid injection, and within a couple of days I was feeling amazing. They have said they want me to start disease modifying anti-rheumatic drugs (DMARDs) but as I am doing so well now, why can't I just be treated with steroids?

It is quite common for steroids to be administered in the early stages of this condition and for a lot of patients they can have an amazing effect on the symptoms of RA, making a difference within forty-eight hours that can last for weeks or even months.

When steroids were first prescribed, they were given much more regularly and in higher doses than they are today. This is because the potential long-term effects of using high dose steroids were not known at this time, and there were less alternatives to this treatment.

Steroids play an important role in the treatment of rheumatoid arthritis. By injection they can work quickly to get inflamed joints under control and can either be administered generally by an injection into the buttocks or directly into a joint if a specific joint is very inflamed.

They can also be given in the form of tablets.

Although they can be very effective and possess some disease modifying qualities, steroids would not normally be the main means of controlling rheumatoid arthritis, as they can cause harmful side effects over time. These side effects include osteoporosis (weakening of the bones), heart disease and increased blood pressure. The DMARDs are also more likely to prevent joint damage than steroids

Though these side effects are alarming, they are most likely to occur when the steroids are administered over long periods of time and in high doses. In rheumatoid arthritis patients, DMARDs such as methotrexate and sulfasalazine (and at a later stage, biologic DMARDs) are usually used as long-term treatment for the condition and can generally control

the condition very well, so that steroids will be given only when needed.

Steroids are a valuable tool to consultants. They work much quicker than DMARDs, so can do a lot of good in controlling flare-ups, helping to prevent inflammation from sitting in a joint for too long and causing damage. They are also very useful when people are just starting on DMARDs or have to change medication and need something to control their RA before the other drugs have a chance to work, and are sometimes needed (usually in low doses) alongside DMARDs.

One of our medical advisors told us how she usually describes steroids, "I often refer to steroids as a "fire extinguisher" – they are excellent for putting fires out but they can cause a lot of damage and don't prevent the next fire"

For more information on steroids and their use in RA, please see the article on the NRAS website

I was recently given a diagnosis of rheumatoid arthritis by a rheumatologist, but in his letter to my GP he said that I have seronegative inflammatory arthritis. What does this mean? Is this the same condition?

There are many different types of inflammatory arthritis, one of which is rheumatoid arthritis. Unfortunately, because there is no single, definitive test for these conditions, some patients might not get a firm diagnosis, particularly in the early stages of the disease. You may therefore be told that you have some form of inflammatory arthritis, but not told what type, though they may say that it is likely to be rheumatoid arthritis. It is always worth asking them for their opinion on the most likely diagnosis, but be aware that this may be subject to change if it is not an easy diagnosis.

The term 'seronegative' refers to being negative for some of the antibodies commonly found in the blood for people with conditions like rheumatoid arthritis. Most commonly in rheumatoid arthritis this term refers to the 'rheumatoid factor' test, though it can also refer to the 'anti-CCP' blood test. It is possible that when you first present with symptoms of RA, rheumatoid factor might not show up in your blood tests, but that you might be positive for it at a later stage. About a quarter of RA patients will always be negative for it, and their disease might therefore be referred to as 'seronegative' rheumatoid arthritis.

So, if you are negative for rheumatoid factor, how can you still have a diagnosis of RA? The diagnosis is not based on any one individual blood test, so the consultant is likely to take into account other blood tests, such as ESR and CRP (which look for signs of inflammation in your blood) and may run the test for the aforementioned anti-CCP antibodies. In addition to these blood tests, they will also examine the joints, talk to you about your symptoms and may run other investigations, such as x-ray or ultrasound. A diagnosis would take each of these investigations into account.

For more information on the differences between seropositive and seronegative RA, please see the article on the NRAS website

Guidance on the new shingles vaccine

Following a number of telephone calls to our helpline about the shingles vaccine, NRAS has asked one of our medical advisors whether or not this vaccine is safe for people with rheumatoid arthritis.

There are two types of vaccine, 'live' and 'inactivated' vaccines. A live vaccine contains an element of the virus itself, which has been weakened, so that it cannot cause the infection associated with the virus. The general guidance to people on disease modifying anti-rheumatic drugs for rheumatoid arthritis is to avoid these 'live' vaccines. However, based on information from the British Society for Rheumatology (BSR), the guidance is slightly different for the shingles vaccine.



Peter Taylor, NRAS medical advisor

The following is written by Professor Peter Taylor, NRAS medical advisor

"The Department of Health encourages injection of a vaccine against shingles (caused by Herpes Zoster virus) in adults over the age of 70. The vaccine is called Zostavax. It should be noted that this vaccine works by encouraging the body to raise an immune response to injected virus which has been treated so that it is not as harmful as the naturally occurring Herpes Zoster virus. Instead, Zostavax directs the body's immune system to become programmed to respond to naturally occurring Herpes Zoster. Nonetheless, the virus used in the vaccine still has potential to cause infection in individuals whose immune system does not function normally or which is dampened down by other drugs they are taking.

For patients with rheumatoid arthritis, it is safe to have the vaccine if you are on prednisolone at doses of 10mg a day or less. It is also safe if you are taking any of the following: methotrexate, sulphasalazine, hydroxychloroquine, azathioprine or leflunomide. However, if you are on a biologic drug taken by self administered injection or at the hospital by infusion, you should not receive Zostavax immunisation."

This information is based in part on the following guidelines produced by the British Society for Rheumatology (BSR):

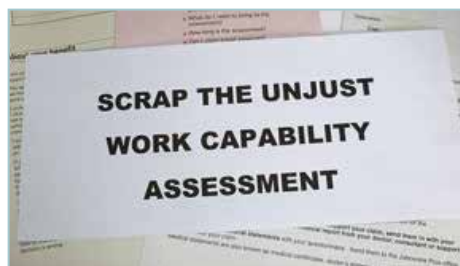
www.rheumatology.org.uk/includes/documents/cm_docs/2013/i/immunisation_with_zostavax_for_people_with_inflammatory_rheumatic_disease.pdf

If you are unsure of whether or not this vaccine is safe for you to take, please check with your rheumatology team

Government Affairs

During August the government affairs team continued to campaign around the welfare reforms. First off, the team responded to a Department for Work and Pensions (DWP) consultation relating to the mobility component of the new Personal Independence Payment (see article in this magazine).

Secondly, we provided a submission to the DWP's Independent Review on the Work Capability Assessment, chaired by Paul Lichfield, on how the test can be further reformed to better meet the needs of RA patients which included a number of Member case studies.



The Work Capability Assessment

In September, NRAS also blogged for the National Voices coalition of patient organisations about the unfair imposition of the 20 metre rule for PIP claimants. Finally, we also submitted detailed comments to Atos in relation to training materials it intends to provide to its assessors about fluctuating conditions.

NRAS remains committed to strengthening the public voice in discussions about configuration of health services and we met with Olivia Butterworth and Emma Easton from the Public Voice, Patients and Information Directorate at NHS England to raise the charity's concerns. Following the meeting the NHS England team announced it would be taking forward an NRAS recommendation for NHS England to hold a series of taster sessions to educate patients about the skills required to help to redesign local NHS services.

Commissioning continues to be a major focus for NRAS in England. During September under the auspices of the Rheumatology Commissioning Support

Alliance (RCSA) - a partnership between ourselves, the British Society for Rheumatology (BSR) and Arthritis Care – we progressed a consultancy project with Bath and North East Somerset Clinical Commissioning Group and Wiltshire Clinical Commissioning Group looking at the quality of their local rheumatology services. We undertook several telephone interviews with GPs, delivered a major workshop to discuss the quality of services with patients, service providers and other bodies with an interest in health services across the two localities, and submitted a report summarising our findings.

Elsewhere, NRAS contributed to further government consultations relating to drug driving, vulnerable older people and the refreshed NHS Mandate. Responding to the government's



Olivia Butterworth



Rheumatology Commissioning Support Alliance (RCSA)

consultation on drug driving, NRAS argued for the introduction of some form of dispensation for patients with chronic long term conditions who need to take high doses of pain medication so they are not accidentally prosecuted. In respect of the vulnerable older people's consultation, NRAS argued for the comprehensive implementation of shared care protocols between primary and secondary care for RA patients. We also argued that patients should have a key say over any proposals to appoint a 'named clinician' responsible for looking after their care to instil confidence.

In September, we started preparation for our second annual RA Summit in Parliament on the theme of public awareness, in the House of Lords, with the kind support of Baroness Brinton. The occasion is an opportunity to launch a new political briefing paper based around the Breaking Down Barriers report that was published for RA Awareness Week. The RA Summit will feature keynote speeches from the National Clinical Director for Musculoskeletal Conditions, Professor Peter Kay, and Professor Karim Raza - a renowned expert on public awareness issues relating to RA. During September, the government affairs team also presented about the welfare reforms at our annual Members Day



Baroness Brinton

and presented on the same theme to the NRAS Swansea Group.

We are trying to engage local authorities in discussions about how to improve local RA services and NRAS gave oral evidence to Calderdale Council's overview and scrutiny committee in October about the findings of an earlier summit meeting on local RA services hosted by Linda Riordan MP, which took place in November 2012. The NRAS evidence was well received and the Committee agreed to write to local stakeholders about the state of services and kept the door open to conducting a possible further detailed review of local RA service performance in the future.

Following unsuccessful attempts to secure a live web chat and a ministerial site visit to an early arthritis clinic for World Arthritis Day in October, Health Minister Norman Lamb MP subsequently accepted a proposal for a joint site visit

to the RA Clinic at Guy's hospital with the BSR. This took place in late November and was a rare opportunity for NRAS and BSR to discuss the importance of incentivising early diagnosis.



Meanwhile, in Scotland, NRAS held an away day during October with our Scottish Ambassadors. A number of prospective new Ambassadors attended the day long training session, which included a presentation on a draft of NRAS's first Scottish public affairs strategy by Government Affairs Officer, Leo Watson.



Health Minister Norman Lamb MP

Attendees also heard a further presentation about health priorities in Scotland by Shelley Gray, Director of Policy and Communication for The Alliance Scotland, a coalition of 400 health and social organisations. Subsequent to the event, NRAS also held a follow up conference call with Ambassadors to discuss the Scottish public affairs strategy in more detail.

IMID 2013

In September I attended the IMID (Immune Mediated Inflammatory Disease) Summit in Vienna. This is an annual event, hosted by AbbVie, which brings together patient organisations representing immune mediated diseases such as RA, Psoriatic Arthritis, Ankylosing Spondylitis, Chrons Disease and Colitis, to share good practice, experiences and knowledge for the benefit of all our service users.

A wide range of countries were represented, from the UK and Ireland to South America and Korea, and we spent two days hearing about developments in the treatment of immune mediated diseases and working in small groups on particular topics of interest to learn from each other.

There were sessions on biosimilars, social media, and clinical trials and how to engage with patients to name but a few, all of which were very interesting and stimulated much food for thought!

Tracey Hancock



Healthcare Champions

On 8th November, NRAS held its biennial Healthcare Champion awards ceremony in Portcullis House, Westminster with the kind permission of Linda Riordan MP. The event was a resounding success with over 80 NRAS Members, health professionals, MPs and special guests attending.

The awards, taking place for the fourth time, provide the opportunity to celebrate the dedication, professionalism and excellent care given by those healthcare professionals that go 'the extra mile' to provide the best possible outcomes for the many people coping with RA, while also working in a challenging environment of NHS reforms and financial cuts.

This year we asked our Members to nominate their choices for the awards and from a wide variety of nominations a special panel of judges which included our Chief

Medical Advisor, Professor David Scott, ten winning entries were selected on the basis of those who best demonstrated a commitment to meeting the needs of their patients, who treated patients holistically and involved them in decisions about their care and who really listened and educated their patients about their disease, their treatment options and next steps in their care pathway.

During the evening guests heard keynote speeches from Professor Stephen Bevan, Director for Workforce Effectiveness at the

Work Foundation, and Professor Peter Kay, National Clinical Director for MSK at NHS England. Professor Bevan gave a preview of key findings from a report which was launched in mid November, entitled 'Life and employment opportunities of young people with chronic conditions', detailing the devastating impact of diseases like RA on the career prospects and emotional self confidence of young people. Prizes were then awarded by the Home Secretary and NRAS Founding Patron, Rt Hon Theresa May and NRAS CEO, Ailsa.

The winners of the 2013 NRAS Healthcare Champion Awards were:

1. **Dr Deborah Lane**, Medical Director, Ruardean Surgery, Gloucestershire – recognised by Liz Buckley
2. **The Rheumatology Team at Glasgow Royal Infirmary** – recognised by Amanda Payne
3. **Theresa Jewell**, Rheumatology Nurse Specialist, Musgrove Park Hospital, Taunton – recognised by Sue Pargeter, Margaret Johnston, Elizabeth Spence and Janet Wagstaff
4. **Dr Elizabeth MacPhie**, Consultant Rheumatologist, and the rheumatology team at Minerva Health Centre, Preston – recognised by John Paton and Katie McKeever
5. **Hannah Duggins, Linda Longmore and Angela Lawrence**, Rheumatology Specialist Nurses at Chesterfield Royal Hospital – recognised by Wendy Hardwick
6. **Sheelagh Baldry**, Occupational Therapist and Kay West, Physiotherapist at James Cook University Hospital - recognised by Eileen Hutchinson
7. **The Rheumatology Teams at North Hants, Winchester and Basingstoke Hospitals** – nominated by Marion Woods
8. **Jean McMillan**, Rheumatology Nurse Specialist at Wrexham Maelor Hospital – nominated by Anne Williams
9. **Dr Chris Deighton**, Consultant Rheumatologist, and the rheumatology team at Royal Derby Hospital – nominated by Geoff Griffiths
10. **JOINT AWARD**
Dr Alistair Hepburn, Consultant Rheumatologist and **Pam Davies**, Physiotherapist at Worthing Hospital
Dr Claire Farrer, General Practitioner, and **Sheree Hepburn**, Phlebotomist at The Barn Surgery, Ferring – recognised by Liz Mines



1. Ailsa, Dr Deborah Lane (Ruardean Surgery), Liz Buckley, Theresa May MP
2. Sheelagh Baldry and Kay West (James Cook University Hospital)
3. Ailsa, Moira McDonald (Glasgow Royal Infirmary), Theresa May MP
4. Cathy Boys (North Hants, Winchester and Basingstoke Hospitals), Theresa May MP, Marion Woods
5. Elizabeth Spence, Janet Wagstaff, Theresa Jewell and Lorraine Cook (Musgrove Park Hospital), Margaret Johnston, Sue Pargeter
6. Anne Williams, Jean Mcmillan (Wrexham Maelor Hospital), Theresa May MP
7. John Paton, Ailsa, Dr Elizabeth MacPhie and Leslie Ashcroft (Minerva Health Centre), Theresa May MP
8. Pam Davies and Dr Alistair Hepburn (Worthing Hospital), Dr Claire Farrer and Sheree Hepburn (The Barn Surgery, Ferring), Geoff and Liz Mines
9. Ailsa, Hannah Duggins, Linda Longmore and Angela Lawrence (Chesterfield Royal Hospital), Theresa May MP
10. Ailsa, Marion Orme and Kate Gadsby (Royal Derby Hospital), Theresa May MP



If you would like copies of any of the photos taken on the night, please contact the membership team at membership@nras.org.uk



My Story... by Jo Connors

There are some things you wouldn't initially associate with having RA, abseiling and riding a motorcycle for example. Both activities are things I loved doing and 21 years after my RA diagnosis and 14 years of not riding, thinking it was lost to me forever, October 9th 2013 became the day I got back on a motorcycle.

I originally purchased a bike when it was decided that Birmingham didn't need a night service bus, so with the silly shift start times I had with my job, it meant getting to work was going to be more difficult. So I treated myself to a 125cc bike to get to work for those 2.50 am starts and that is when it all started.

There is a motorcycling documentary called, 'Why we Ride', and one of the people interviewed beautifully sums biking up with the following, *"...some people have it inside, it's a seed and if you ever put the water on it and feel the sensation, the seed is sprouted and it doesn't die till the day you take your last breath."* So, what started out as just a cheap way to get to work, meant that seed sprouted, grew and enriched my life. The joy, freedom and the wonderful people who ride motorcycles made it something special.

After I was diagnosed with RA, I was struggling to get on the bike. I had incredible difficulty at work as my RA was really aggressive at the start, to the point where Professor Emery (my then rheumatologist) told me I was either mad or had a really high pain threshold to still be working. We agreed that it might be a combination of the two!

As the RA continued I was forced to give up the job I loved and the company doctor retired me on ill health grounds. So, in 1999, my biking days came to an end. Wanting the best for my family, and having a hip replacement at the age of 29, I was forced to sell my bike, only receiving a fraction of its true value. Watching it disappear into the back of a van was heartbreaking, taking a part of me with it that has been missing ever since. I've never strayed far from bikes. As I wrote earlier, once biking is in your blood, it stays there. It was always so close, but seemed out of reach due to the RA.

Also being a bit of a geek, I get my 'bike fix' via various websites and social media. It was on Twitter that I learnt of a charity called The Bike Experience. I looked them up and was amazed at what I saw - they were getting people with all sorts of disabilities back on to a bike and for free! Watch the video on their site, even if you're not a fan of motorcycles you can't help but appreciate what this charity is doing. It's also quite moving and they certainly deserve support.

I got in touch with them explaining my circumstances and they got back saying they could help, but both of the last two events of 2013 were full. Pleased that I had something to look forward to in 2014, I added The Bike Experience (TBE) as a charity I was supporting in my abseil at Walsall Art Gallery on 5th October, also in aid of NRAS. A few days after booking my abseil I got a message from one of the founders saying a place had come available for the last event of the year on 9th October at Silverstone. I signed up to attend despite my abseil a few days before (I usually need a few days to recover).

The 9th arrived and I headed over to the training area at Silverstone, and was greeted by a wonderfully friendly group of volunteers and three other disabled riders. After being helped into some leathers, helmet and gloves, we went through the safety procedures and how wheelchair users get on the bike with the help of the crew. Watching the two guys who were in wheelchairs climb aboard, being held front and rear until the clutch bit and then heading off to the other end of the straight, where two catchers helped them stop and stay upright, was amazing.

My turn came - with a bit of help from the team I got on the bike. It was a Suzuki SV650, which I got in gear via the handlebar mounted gear changer. I felt the bite of the clutch, got the revs up and headed down towards the catchers. It was wonderful, all those memories and the great feeling you get from biking came rushing back. With the help of the catchers, they turned me round and I headed back to the other end. I came to a stop and got some great encouragement from the team at that end. It all became a bit much, and I started crying,

as I never thought I'd feel this again - the TBE volunteers were really supportive and kept saying it's something they often see!

I spent the rest of the day improving my skills on an Aprilia 850 - they soon came back. I was worried about problems with my joints whilst riding, especially my shoulders as they're shot and there's nothing they can do for them due to the ruptured tendons. But after around 3.5 hours on the bike, there were no problems at all with hips, knees or shoulders. It was as if the bike had been made for me. At the end of the day we all had smiles across our faces, mine is still with me almost two weeks later. I'm hoping to go back to TBE in the New Year and am considering volunteering for them myself, even if it's only making the tea. It's such an amazing charity, with such wonderful people.

Having any long term condition or disability can seem to stop life in its tracks. You can't do the things you love because of the pain and the stiffness, having to fight the effects on a daily basis and the negative effect that it can have on your emotions. I certainly know it did in my case, but in time you shift and become able to help others, and decide that RA is just a part of you, it doesn't define you as a person. You might have to do things slightly different or get help to do things, but don't let that stop you.

Bono sang that he still hadn't found what he was looking for, but with advances in treatments, support from the rheumatology team, orthopaedic surgeons, family, friends and the wonderful work of some fantastic charities, I have and you can too!

www.tbex.co.uk and on Facebook at <https://www.facebook.com/pages/The-Bike-Experience/101810996578296>.



Jo Connors with The Bike Experience team

Alison takes on the Docklands Swim in aid of NRAS

In 2008, Alison was diagnosed with both rheumatoid arthritis and hypermobility syndrome. The diagnosis took 4 years throughout which she endured joint problems, numerous tests and chronic fatigue.

To some people swimming one mile doesn't seem very far, but for Alison this was a massive challenge, particularly with the lack of mobility in her shoulders and constant fatigue. She had never swum in open water before and the thought of it filled her with fear!

Alison completed her swim, although the last 200m were very difficult, with cramp in her calf becoming almost unbearable and her left shoulder almost gave up on her. She was determined to prove people wrong and finished the swim unaided! Alison raised over £400 for NRAS.

Alison is now looking for her next challenge – she is thinking of taking on the London to Paris cycle ride in 2015! Thank you for supporting NRAS.



Alison Hales

School children take on fundraising in aid of NRAS

Four young friends, Emily, Molly, Luke and Dani, have been busy fundraising for NRAS.

Molly and Emily, both aged 10, launched their fundraising mission as Emily's mum, Nicki, has RA. Emily said *'We don't like to see anyone in pain, especially my mum. No-one should suffer with the pain caused by this disease and we wanted to raise money to help people with RA.'*

They organised a tea party, table top sale then and completed their mission by taking on the challenge of walking a staggering 21 miles in one day by completing 250 laps around Exmouth Road in Sale. They were joined by Emily's cousin, Dani Heywood, 12 and neighbour, Luke Weader, 10, to become a determined team of four. Cheered on by neighbours and friends they completed their challenge despite some minor injuries. Emily said, *'People suffer pain every day they just can't walk away from it. I finished this walk for Mum and others like her.'*

Nicki said, *'I am so proud of all four of them. It's great that the children are*

raising money and awareness. It can affect anyone, young and old.'

The fantastic four fundraisers plan to continue finding innovative ways to raise funds. What an inspirational group of young people!



Luke, Emily, Molly, and Dani

NRAS Tea Parties

The NRAS Tea Party will be launched again in January at our new offices, and we hope that as many of you as possible will hold a party during the year to help us raise awareness of RA. If you would like a Tea Party Fundraising Pack, which has lots of helpful information and ideas for your party contact Bronwen in the Fundraising department at Bronwen@nras.org.uk or call 01628 823524 or download the information from the website.

Bouncing for NRAS

A team of 9 took part in a very unusual challenge in August - to attempt to break the record for the world's longest bouncing marathon on a bouncy castle! The record was 30 hours and the aim was to break this by bouncing for 36 hours non-stop.

Sian, the daughter of one of the Weston Super Mare NRAS Group coordinators, who took part said *'Not everyone realises how life changing RA can be and having a close member of the family suffering from it I have seen it first hand. That's why I have chosen to support NRAS.'*

The team were successful in breaking the record and Sian raised £254 for NRAS.



Sian on the bouncy castle

What a great challenge! Thank you all so much

Joanne abseils yet again for NRAS!

Joanne Connors (or RoboJo/Spider Jo) has had to live with RA since she was 26. It changed her life completely, she had to give up work after her diagnosis and has had 2 major joint replacements and 4 other surgeries as a result of her disease.

Joanne is lucky enough to have a great rheumatology team and orthopaedic surgeons who keep her going. NRAS is also a very important part of Joanne's life. She has been a member and has volunteered for us for several years and it has made such a difference to her quality of life. Helping others has made her feel as though she is no longer 'on the scrapheap'.

Joanne has taken on many different challenges for NRAS and most recently abseiled down the New Art Gallery in

Walsall (having already abseiled for NRAS in the past). Of the most recent abseil Joanne said 'it was a good abseil, a bit windy at the top, making climbing over and standing on the little suspended plant a bit hairy. Once I got back into the swing it was great, a real buzz and by far the best RA medicine there is!'

Joanne continues to support NRAS and we look forward to hearing what her next exciting challenge will be!

Around the Clocking Sailing Challenge for NRAS

Earlier this year, I combined raising money for NRAS and learning to sail – both on my to-do list. I have RA but I am determined not to let it prevent me from being active. My friend Gail and I signed up for the Around the Clock Sailing Challenge to the Channel Islands.

We met the crew and saw our home for the next four days, Musketeer. Our first attempt to sail to Guernsey was scuppered by the weather. It was foggy and by the time we passed Old Harry Rocks, it still hadn't cleared so we headed back to Poole for the night.

Next day, with glorious sunshine we headed for Guernsey. We used the skills we'd learnt the day before to hoist the sails and helm. Making tea for everyone was a challenge in itself!

At nightfall we split watches, our main task being to look out for traffic and lights to guide us to our destination. I was at the helm when the heavens opened, luckily I was well prepared! We arrived at St Peter Port just as the rain stopped and had a celebratory drink.

The team organising the challenge were great, they were very patient teachers and adept sailors, we were in safe hands. We sailed 210 miles over 42 hours,

including 12 hours night sailing in winds up to force 6+ with gusts of force 7. A good sense of humour and some waterproofs are what is needed for this challenge!

(Written by Jill Crosbie)



Jill Crosbie on her sailing challenge for NRAS

Join the



We launched the new NRAS Lottery in September and a huge thank you to all those who have signed up already. We now have over 230 players, and are seeing a regular stream of winners each week.



But we need more

players... if you haven't joined and would like to please sign up at www.nras.org.uk/lottery or visit the Unity Lottery website at www.unitylottery.co.uk and select NRAS. You can also help us by telling friends, family, work colleagues, neighbours and anyone else you know about the NRAS Lottery. It's a great way to help us establish a regular income stream, gives you the chance to win up to £25,000 for just £1 per week and helps raise awareness of NRAS and the work we do.

So, in 2014, make it a New Year's resolution to help us grow the NRAS Lottery and raise funds to help us continue to help you. Thank you!

Climbing the heights of Kilimanjaro

A group of 7 rheumatology nurses, along with 2 occupational therapists, made the decision last December to climb Mount Kilimanjaro for their chosen charities. NRAS was lucky enough to be nominated by 6 of the group. By January the trip was booked!

The majority of the team were novice walkers but all agreed it was an amazing way to raise money for NRAS. They knew very little of what was required of them to climb such a mountain. Full of expectation, they arrived at Heathrow Airport and met other members of the team. The first sighting they had of Mount Kilimanjaro was as they descended on to the runway in Nairobi – it looked so high!

The next day was an early start at 6.30 am. Backpacks were packed and repacked, to ensure that they had less than 15 kg in them, a cause for concern for a group of mostly women! Finally, the trek began, going through lush rainforest, spotting Colobus monkeys and many different birds soaring high above. It seemed like no time at all and it was time for lunch. The group turned a corner and were very surprised to see a table full of sandwiches and drinks – they were the envy of all other hikers who were snatching a few minutes to grab something to eat!

Once refuelled, the trek continued with the group's guides making sure they drank plenty (sippy, sippy) and slowly (pole, pole) – this became their mantra 'sippy, sippy, pole, pole', eventually even the guides joined in! When they arrived at Machame Camp they were greeted by porters, guides and cooks all singing and dancing to welcome them – a wonderful greeting and much needed.

The trek progressed well, with spirits very high and all managing the trip without too much difficulty. By the end of day three, Pamela, the group's doctor, said, 'up until this point the trek has been a walk in the park – it is going to get much tougher from here on in'. Day 4 started with their usual cup of tea at 6.30 am, they were on their way to Barranco Camp – a trek of 6-7 hours. This part of the journey took them through vast areas of rocky plains and enormous open spaces where they walked in the shadow of the mountain which commanded their respect.

The altitude was beginning to take effect, with quite a few of the group suffering from headaches and nausea.

The group's spirits were high, having shared stories with each other about their inspiration for taking on such a climb and there were a few tears shed along the way. With the summit now in sight the team knew the hardest trekking was to come. The landscape had once again changed and was far more barren. Biting winds and snow meant when they arrived in camp their tents were covered in snow!

By 11.30 pm that night the group was ready to start the final ascent to the summit. It was a magical sight with snow on the ground and stars shining brightly in the sky. Finally they made it to the summit. Having climbed 5,895 metres, the feeling was impossible to put into words – they had done it! It was very emotional for everyone.

The trek back down began which was quite difficult as it was very slippery in places and quite often they would end up sliding down rather than walking!

The overriding memory of climbing Kilimanjaro is one of it being an amazing experience, tough but so worth it, with lifetime memories gained by all. The group were like a family, it was a truly unique experience.

So far the ladies have raised over £7,000 with more money still coming in. A huge thank you to Roz, Heather, Corrine, Erica, Charlene and Sammy for taking on this challenge for NRAS. If you would like to climb Kilimanjaro in 2014 please visit our website at www.nras.org.uk/events or give Val a call on 01628 501547 who will be happy to give you more information.



Erica and Heather at summit

Tony cycles a mile for each year of his life

Tony Hubbard's wife Jane has had RA for the last 5 years and it has taken most of this time to get her disease under control. Whilst RA may not be life threatening, it can take away your life and Jane has earned the praise of her medical team and peers alike for her determination to beat RA.

Unfortunately, Tony suffered a stroke 18 months ago; however he worked incredibly hard to regain his fitness and decided to take on the challenge of cycling 100k (62.5 miles – near enough one mile for each year of his life).

Tony wanted to raise funds for NRAS as Jane has found us to be of great support, by understanding her condition and what she is going through. He completed his ride in 5 hours and raised almost £800 for NRAS.



Tony Hubbard

Well done Tony, a fantastic achievement!

Our Runners do it for Rheumatoid!

September and October are busy months for our runners, with supporters taking part in the Great North Run, Great South Run and Royal Parks Half Marathon, all of which we have charity places for each year.

Great North Run

This year 22 runners travelled to Newcastle to take part in the Great North Run, in rain and wind, but all ably battled the elements and completed the 13 miles. Chris Deighton, president of the BSR, along with Liz and Diane once again pushed member, Helly Berger, in her wheelchair, this year dressed as superheroes!

Great South Run

4 runners took part in Southsea in October, including Grace from Marketforce, that is supporting us as Charity of the Year in 2013.

Royal Parks Half Marathon

6 runners ran this race through London's parks, including Hanna, also from Marketforce, our nominator for Charity of the Year.



Caroline, Michele and Amy

A total of almost £13,000 was raised from the three races – a huge thank you to you all!

Places can now be reserved for 2014. Email val@nras.org.uk to find out more or to reserve your place.

Tiggy's Story

Tiggy Goodwin was diagnosed with RA three years ago at the age of 21. Determined not to be beaten by it, she has recently run the Clapham Common Series 10K. This is her story.

"Rheumatoid Arthritis effects are not well publicised, awareness of the condition tends to be restricted to those who are directly affected and their relatives and friends. Although most of you reading this probably fall into one of those categories, I hoped to raise further understanding and awareness of RA by attempting to run 10km.

"I was diagnosed at 21, whilst in my final year at university, and if I had a pound for every time someone has said 'oh, but you're too young' I would not have to be fundraising! But here I am, and I am so grateful for everyone's support.

"I have come across many challenges in my diagnosis and treatment, however recently I have found myself fighting against NHS budgets. The limited awareness and relatively low profile of

RA means that the funding is limited for the best medicine (biologics) I can have. Despite dealing with pain, swelling and exhaustion regularly I was not considered severe enough to receive biologics for a few years. My constant frustration with my consultant (who is brilliant!) is, do I have to wait for my hands to disfigure or to have a hip replacement before I am allowed this potential life changing drug... why not halt the disease before it gets worse? Although I am now at the stage where I am being referred to receive biologics, I do not want anyone else who is newly diagnosed with RA to have to fight for the option to receive the drugs they need and should have.

"Having thought that sports were out of the question 2 years ago, here I am having completed a run... a 10km run to be precise... my own little marathon, yikes!

"Thank you all so much for your support!"

Tiggy has raised an incredible £3,763 with more sponsorship still coming in. Thank you Tiggy and what an amazing challenge to have completed.



Tiggy Goodwin

Unusual ways to raise funds!

An unusual challenge recently undertaken was by a group of dancers who held a BellyFunk Tribal Fusion Dance Show in aid of NRAS. It was an evening of lively and colourful dance organised by NRAS Member, Donna Curtis, which raised £500 for NRAS.

Thank you to all those involved in making these two events such a great success.



What will you do in 2014?

Our events calendar for 2014 is included with your Magazine and we hope that there will be something there for everyone who wants to challenge themselves this year. We have charity places in a variety of runs around the country, including for the first time, the Brighton Marathon which is the second largest marathon in the UK. There are also swims, cycles, walks and overseas events so if you want to make 2014 the year you do something special, Val in the Fundraising department would love to hear from you.

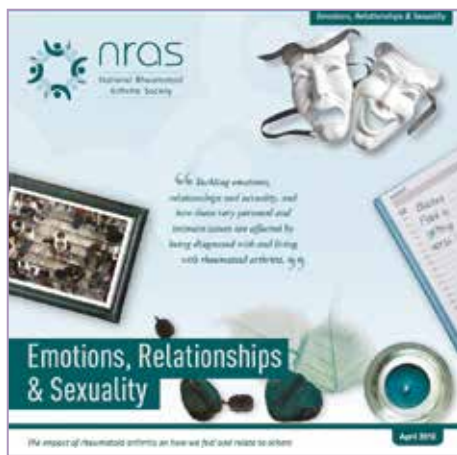
E: val@nras.org.uk

T: 01628 501547

Why are we so reluctant to talk about relationships?

Clare Webb, Senior Clinical Educator Rheumatology/Occupational Therapist
– Medical Specialities Clinic, Royal Derby Hospital

Whilst at the British Society of Rheumatology (BSR) conference 2013, I was handed a booklet to read written by NRAS, '50 shades of RA' (!), or as it is officially titled, 'Emotions, Relationships and Sexuality'.



Emotions, Relationships and Sexuality

This is an in-depth booklet which discusses "...emotions, relationships and sexuality, and how these very personal and intimate issues are affected by being diagnosed with, and living with, rheumatoid arthritis."

The booklet was produced following the NRAS 2013 survey that looked into the topic. The whole time I was reading the booklet I was thinking, why as healthcare professionals do we not discuss this topic? I teach medical students as part of my role as a Clinical Educator/Occupational Therapist about the effects having RA can have on relationships, and so thought that I was very open to the subject. However, in reality, I can only think of a couple of patients I have discussed this topic with.

Having spoken to a group of occupational therapists, physiotherapists and nurses within Derby, it became apparent that very few of us would discuss the subject of intimacy unless the patient brought up the subject. Comments included...

"This is a private matter which I would not wish to discuss myself with anyone."

"Should we really talk to all our patients about sex, what if they are in their 60s?"

As a patient, would you think that a healthcare professional would be happy to talk to you about these sorts of problems? I think as healthcare professionals we are happy to discuss these issues but assume that people will open up if they have a problem. We keep a lot of our thoughts in our heads and don't allow them to flow into our clinical assessments.

What I have found in my clinical practice is that sex can be a difficult issue to discuss, and many people are frightened of upsetting or embarrassing the patient. There is also fear from staff that they are not experts in intimate relationships, and would not know how to advise a person should there be a problem. I do not think that as healthcare professionals we are supposed to be experts in this field but I do think we have a right to offer patients the time to discuss the problem and signpost them to the appropriate help.

Should we maybe introduce the subject to people with a general opening question such as...

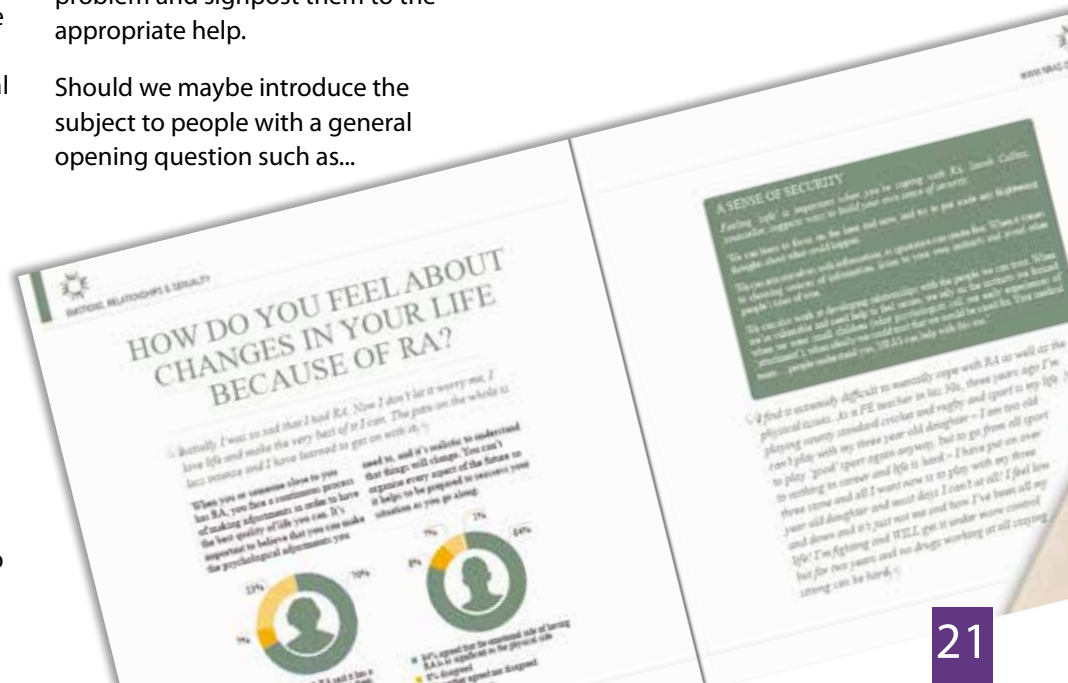
"How does your disease affect your life and relationships?"

"Being in such pain must have an impact on your relationship."

If our patients do not want to talk about the subject they can decline just as they may do so if we ask about any other private issues such as financial situations.

As a rheumatology department we have decided that within our introductory packs that new patients receive, we would like to feature the NRAS booklet on Emotions, Relationships and Sexuality. This is a large booklet which will be on display in the clinic rooms and waiting areas for people to look at. This may then develop a culture within our rheumatology community that we are professionals who are happy to talk about the subject of sexual relationships if required.

If we do not give everyone the opportunity to discuss a natural human desire then are we doing our patients a disservice and not fulfilling our duty as healthcare professionals within the area of rheumatology?



Gum disease linked to rheumatoid arthritis

Researchers from the University of Louisville School of Dentistry Oral Health and Systemic Diseases, as well as scientists from the European Union's Gums and Joints project, worked together to assess exactly how the bacteria that cause periodontal disease (gingivitis) work to trigger earlier onset of rheumatoid arthritis, speeding its progression and increasing the damage caused by the disease such as the breakdown of bone and cartilage.

What they found was that *Porphyromonas gingivalis*, the bacteria involved in gum disease, also produces a specific type of enzyme and it's this enzyme that promotes the progression of an animal model of an arthritis like rheumatoid arthritis. The enzyme triggers changes in the body's proteins, which then causes the body mistakenly to attack those proteins. The result is chronic inflammation. Other bacteria linked to oral health were not found to have the same effect on collagen-induced arthritis.

The researchers hope that with further research it might be possible to reduce the severity and symptoms of rheumatoid arthritis by targeting this bacterium and maybe even work to prevent it.



For those with RA, it's important to remember that maintaining good oral health keeps gingivitis at bay before it evolves into periodontal disease. Proper dental care, it seems, might help to prevent rheumatoid arthritis or to reduce the damage it causes.

Combination DMARDs More Cost-Effective with Comparable Lifetime Results than Anti-TNF Therapy in Treating Rheumatoid Arthritis

New research findings presented at the American College of Rheumatology Annual Meeting in San Diego in October 2013 concluded that starting with a combination of three traditional disease-modifying anti-rheumatic drugs (DMARDs) for treating early rheumatoid arthritis is more cost-effective long term, with comparable benefits, than using either an immediate or step-up approach with anti-tumour necrosis factor (called Anti-TNFs) drugs and methotrexate.

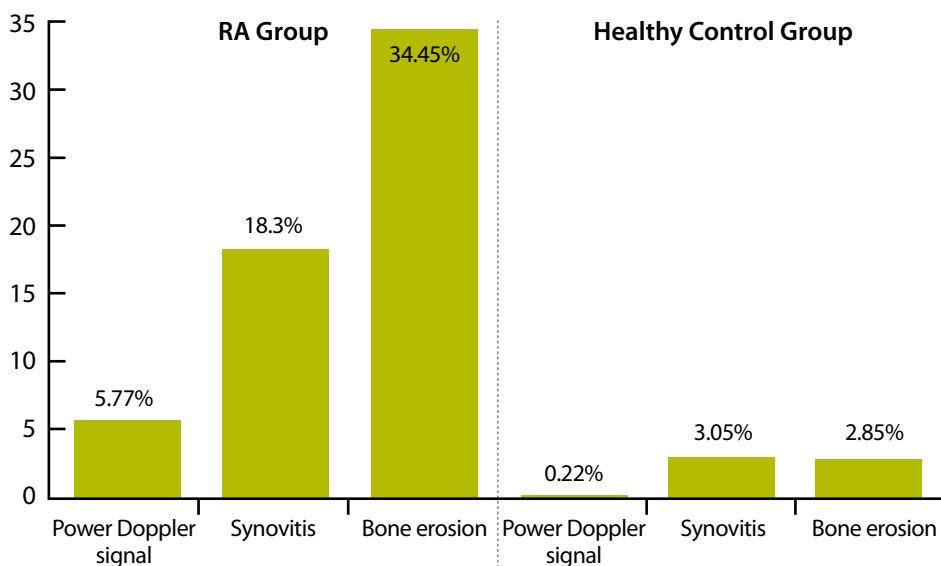
The researchers looked at four strategies: immediate triple (IT), immediate etanercept (IE), step-up triple (ST), and step-up etanercept (SE). The step-up strategies involved switching those with persistent disease activity (DAS28 \geq 3.2) from MTX monotherapy to MTX plus either etanercept or triple therapy at 6 months.

The authors concluded that the benefits from all strategies were comparable, but biologics strategies were almost twice more expensive than triple strategies making the increased cost of biologic therapies possibly unacceptable to healthcare providers in these straightened times.

Ultrasound detected joint alterations in asymptomatic feet of RA patients

In Sao Paulo, Brazil, fifty patients with RA and fifty healthy people all with no symptoms in their feet, were compared across both feet. Twenty two joints were examined in each person by ultrasound (2200 joints in all).

Higher values were found in each category of investigation for those with RA



Ultrasound for investigation of RA in feet, even without symptoms, has demonstrated a significantly greater number of inflammatory changes and erosion in comparison to control healthy people. Joints in the midfoot, in particular the talonavicular joint, have the greatest number of ultrasound findings.

Do patients prefer nurse specialists to manage their DMARD treatment?

This Norwegian study of 68 people taking disease modifying anti-rheumatic drugs for three months, aimed to establish whether the patients were more or less satisfied with their follow up appointments if these were undertaken by a nurse specialist or a doctor.

Previous research evidence on only four studies was inconclusive. The 68 people were randomly divided into two groups to have regular thirty minute appointments with a nurse specialist or a rheumatologist. Satisfaction with care questionnaires were completed at the start, at nine months and again at twenty one months.

People who saw nurse specialists were more satisfied with their care than those who saw doctors and this increased over the study period. The results showed that this was the case in all aspects of care that had been measured:

- Information provided
- Access to care and continuity
- Empathy, technical skill and attitude towards them

The researchers report that there were no notable differences between the two groups in the symptoms people experienced or how they coped.

However, it is reported that there were six rheumatologists involved in the study and only two nurse specialists and this fact may have influenced the patients' reduced satisfaction with their continuity of care.

The conclusions suggest that patients may be more satisfied to have follow-up care with a specialist nurse who is well placed to provide this in their role of providing patient education and helping people to understand and manage their condition. The advice given to people with inflammatory arthritis is to consider discussing with your doctor whether ongoing management of treatment with DMARDs could be undertaken by a specialist nurse in rheumatology.

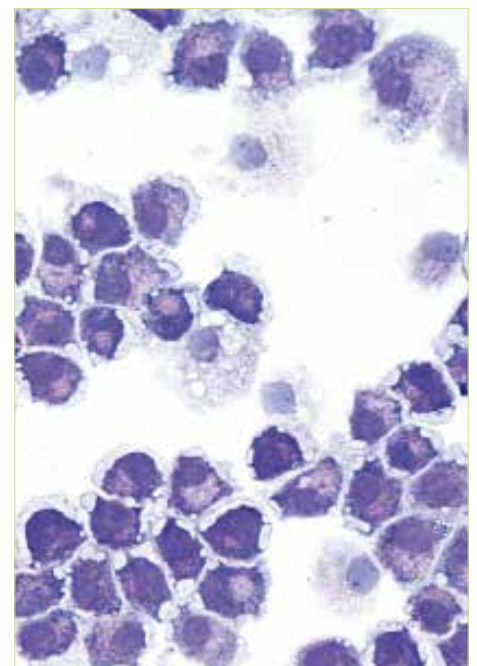
These conclusions were also shown in the work carried out in Leeds in that patients seen by nurses in UK clinics had as good outcomes when seen by nurses as by rheumatologists and that it was cost-effective.

Promising early results for new rheumatoid arthritis treatment- Mavrilimumab

This new drug has been reported in an early trial in combination with methotrexate as a potential treatment for moderate to severe RA. Mavrilimumab works on macrophages* by controlling their numbers. Macrophages are involved in the swelling (synovitis) of the joints in RA.

Two hundred and forty patients were divided into five groups with each group taking different doses and one group a placebo, for twelve weeks. The early results are encouraging but further research is needed to establish confidence in relief of symptoms or possible side effects. This will take some time.

* **Macrophage:** A type of white blood cell that ingests foreign material. Macrophages are key players in the immune response to foreign invaders of the body, such as infectious microorganisms. They are normally found in the liver, spleen, and connective tissues of the body.



Biologic and oral disease-modifying anti-rheumatic drug monotherapy in rheumatoid arthritis – Emery et al

Clinical evidence shows that giving patients with RA a combination of an anti-TNF agent together with methotrexate is more effective than just taking the anti-TNF agent alone, which leads one to believe that prescribing MTX together with all biologic agents and other oral disease-modifying anti-rheumatic drugs (eg sulfasalazine, hydroxychloriquine) is necessary to get the best outcomes for patients. A review of peer reviewed literature and abstracts shows, however, that almost one third of patients who are prescribed a biologic agent do not take this combination but just the anti-TNF agent or oral DMARD alone. Other data also shows that 58% of patients who are prescribed MTX alongside their biologic/oral DMARD therapy did not even collect their MTX prescriptions. Analysis of the data suggests that tocilizumab is the only biologic drug which when given alone is as effective as a combination therapy with MTX.

A week in a life of...

...a Rheumatology Advanced Practice Physiotherapist

by Will Gregory, Salford Royal Hospital



Physio team (from left to right: Carol, Steve, Will, Katie) team at Royal Derby Hospital

I have been a physiotherapist for 12 years, spending the past 9 years leading the rheumatology physiotherapy service at Salford Royal Hospital, formerly Hope Hospital. I live in a suburb of Greater Manchester with my wife and two small children. I commute to work on my bicycle in an attempt to keep fit enough to justify telling all my patients to keep fit themselves and also to prove it doesn't always rain in Manchester!

I am fortunate to work as part of a large and well developed team looking after rheumatology patients from the local area and further afield. The clinical team in rheumatology consists of 6 consultants, 3 registrars, 6 specialist nurses, 2 occupational therapists, a podiatrist, a pharmacist, a dietician, and 3 physiotherapists. Over the 9 years in post, I have seen dramatic changes to the services provided and in my job role. Working as an advanced practitioner means doing some of the jobs that were previously traditionally done by doctors, but now with appropriate training and supervision can be performed by an advanced practitioner. My advanced training has included joint and soft tissue injection skills, non-medical prescribing and the ordering and analysis of blood tests, scans and x-rays. I also maintain my traditional physiotherapy skills to ensure that the patients I assess and treat hopefully get the best of both worlds.

1. Monday

The week always starts with a 30 minute physiotherapist team meeting. The 3 of us sit down, reviewing the computer notes of what has been happening on the ward. We discuss any challenging cases we have seen since we last met and look ahead to which patients are due in over the next day or so. Our ward has 5 allocated beds for rheumatology patients – today we are using just one of them and from reading the notes this patient does not have physiotherapy needs on this admission.

I have a role as hydrotherapy clinical lead, so I pop into the pool area to check that our new poolside assistant is settling in well. Then, back to department for a list of outpatients. I have a mix of new and follow-up patients. The follow-up patients are doing well with their agreed home exercise programmes. I get them to show me what and how they are doing them and encourage them that their scores are improving. I use the grip strength meter for one patient and reassure him that the power numbers are at a good level.

Next, it's off to clinic for our multi-disciplinary-team session. We try and keep to NICE clinical guidance and see all our new inflammatory arthritis patients within 4 weeks of their diagnosis. We have 2 newly diagnosed RAs today, both men in their early 40s. The first patient has a slightly swollen knee and I do wonder if I should drain it, but he is getting towards the time when his DMARD will be working maximally so I decide to just monitor this and tell him to call me if the swelling hasn't settled in the next week or two.

In the afternoon, I have a hydrotherapy session. It's a 90-minute session for me in the water, divided into 3 appointments, with 4-5 patients booked into each slot. It can be frantic, but I do overhear some nice conversations between people with similar medical conditions, discussing their tips for managing the issues they've each experienced.

2. Tuesday

I've quite recently started working in the MSK pain clinic, where the remit is to see all the non-inflammatory patients we have in our rheumatology department. This fits in quite well with my physiotherapy background as the answers for this patient group are not usually drugs, but rather specific exercise programmes, talking therapies, and possibly a few drugs to allow this all to happen. I have a 9 o'clock new patient who thinks that they have fibromyalgia, so this makes my assessment a bit easier, but we still have to rule out all the other possible causes for their symptoms. A physical exam is followed by bloods and we then book a 6 week review to discuss the outcomes. I have 3 phone call follow-ups to discuss with patients their progress on the plans they put together during their face-to-face appointment with our consultant lead 6 weeks prior.

Lunchtime is followed by a patient education session. We have 12 patients attending this afternoon. There are 2 talks and then a gym exercise session. The specialist nurse talks about diagnosis and best management, I talk about which exercises are best to do and why and then after a warm up and stretch we do the exercises as a circuit. I finish by handing out the home exercise booklets.

3. Wednesday

Wednesday morning is our physiotherapy new patient clinic. Between the 3 of us, we have 18 patients booked in each Wednesday morning. So, the first half hour of my day is spent reading through these 18 referrals. Then as Carol and Steve from the team arrive, we have 30 minutes to discuss these patients. There are a few whom I know and get the team up to speed on what to expect and how to best work with these people. Most, however, are brand new to physiotherapy so we spend time discussing their diagnoses, guessing how they might present and how we can best help them.

Five of my 6 patients attend. I'm pleased to have managed to get them all on board for the treatment plans we had agreed based on the issues I found on assessment. Two of them start hydrotherapy with me next Monday, one is coming to an exercise class next week, another to an education session and the fifth was happy to be discharged with advice and exercises.

Wednesday afternoon is my favourite part of the week – a full list of 10-11 patients coming for joint and soft tissue injections. The clinic runs until 6.30 pm and I am glad I am able to offer people after work appointments. But the main reason for me particularly liking this clinic is that I know people will have much less pain and better movement once they have had their injections. Patients are referred in by a variety of our doctors and specialist nurses and can also self refer.

Wednesday is my long day, working a double shift to allow me to see patients at more convenient times, but also giving me the bonus of a day off later in the week. So, after leaving injection clinic at 6.30 pm I quickly pop to the shop for their discounted dinner options. I then have a couple of hours to check blood test results and x-rays. This evening, I have to call a patient to screen them for an MRI scan, as their x-ray has come back showing a need for further scanning.

4. Thursday

First thing is our Ankylosing Spondylitis exercise group. This starts at 7.45 am to allow the patients to perform their gym and hydrotherapy pool exercises and still be at work before 10am. The early start also allows us to have free reign of the gym and pool. These are a group who I have been working with for the past 9 years I have been in post, so it's good to hear how they are all getting on. We have one member of the group considering starting biologics medications and so he is keen to ask the rest of the group about their experiences with this.

I leave early as I have a clinic list starting at 9am and like to arrive 15 minutes early to set up and read through the patients' notes (I think there is a theme to my diary here! My Boy Scout years have obviously made a lasting impression – be prepared!)

5. Friday

Working a full week's worth of hours in 4 days allows me to have Fridays off work. I do however possibly work hardest on this day "off". My wife is off to work at 7.20, so it's the school run for my 4 year old and then quality time with my 2 year old for the day!



My Friday off

So what's your excuse for not exercising?

An introduction to the new exercise section www.nras.org.uk/exercise by Clare Jacklin

"My joints have been too damaged due to living with RA for so long"

"I haven't time to go to the gym or swimming pool"

"I'm too embarrassed to exercise in a group"

"I can't manage to exercise for an hour at class"

...all these are very valid and understandable reasons for not participating in "organised" exercise. It was to address some of these issues that we have developed a new section on the NRAS website showing how some simple exercises that you can do at home, even when watching the telly or waiting for the kettle to boil, can make a difference.

We all know from being bombarded with messages in the media that exercise is good for our physical and emotional health. Exercise is not just about donning the lycra and pounding the treadmill (oh, how I shudder), it can be all sorts of "activities" that may just get you a little breathless by raising your heartbeat – walking, dancing, swimming, tai chi, Pilates or even gardening. However, for many with long established rheumatoid arthritis all these may seem daunting so why not start on a smaller scale? Even 5 to 10 minutes a day will start to help!

We recruited some willing volunteers (yes, they were willing honestly) with varying levels of disease progression to join Ailsa and physiotherapist, Jessica Wilson, from the Nuffield Orthopaedic Centre in Oxford, to be filmed demonstrating some simple exercises. Stretching, strengthening, aerobic and balance are the key areas we focussed on. We had good fun with cameras and cables trailing all over Ailsa's home much to the bemusement of Ailsa's cats Isla and Conti! Conti even tried to join in by catching his very first pigeon and presenting it to us in the kitchen (still alive) and to cries of, "Clare, catch the pigeon"

from Ailsa I had my own exercise for the day, capturing and repatriating to a safe space one disgruntled pigeon! Laughter is, of course, a great exercise in itself!

But back to the topic in hand, over the coming months this new exercise section will be developed and we are keen to hear your stories of how exercise has helped you in better managing your RA. If you would like to share your personal "keeping fit and active" tip or story please let us know by emailing clare@nras.org.uk

Thanks to Richard, Helly, Kelly and Bob for being our "models" on the day.



Jessica Wilson, from the Nuffield Orthopaedic Centre in Oxford, demonstrating various exercises with Ailsa, Richard, Helly, Kelly and Bob

Autumn 2013 – New NRAS Groups are born!

September saw the launch of two new NRAS groups, one in Surrey and one in the Medway area.

Firstly Gill, Kim and Leo launched the Surrey NRAS group with the support of Frimley Park Hospital and two dedicated NRAS Members, Helen and Barbara. There were over 60 attendees on the night who heard all about the hopes of Helen and Barbara for a new group in the area. There were five healthcare professionals from Frimley Park Hospital who formed a panel for a grilling from the audience. This brought forward many interesting questions (for those that were there you will know which particular one caused much amusement!).

Regular meetings are planned for 2014. Please see the NRAS website for details.



Surrey Group

The second September launch saw Gill, Kim and Clare head to Medway where there was an overwhelming

attendance on the night. More than 100 people came along with five healthcare professionals from Medway Maritime Hospital. Our thanks to NRAS Members Jan, Cheryl and Chris for helping us organise the evening and being a strong team to take the group forward.

Their first group meeting took place on the 18th November with regular meetings planned for 2014.

Good luck to both of these fledgling groups, we have high hopes for their success. Find full details for both groups at www.nras.org.uk/groups.



Medway Group

NRAS was also in North Wales in October following on from a well attended information evening in April. Wrexham Maelor Hospital supported this meeting with guest speaker, Consultant

Rheumatologist Dr Vun Lim talking about how ultrasound is used to detect active inflammation in RA.

It was a very successful evening with 8 people coming forward to help coordinate regular group meetings. Keep a look out on the NRAS website for details of these, hopefully coming soon.



By the time you are reading this an information evening will have been hosted in Margate to launch the Thanet NRAS group. This has been organised with the full support of the rheumatology team at Queen Elizabeth the Queen Mother Hospital.

All NRAS group meeting details are updated regularly on the NRAS website www.nras.org.uk/groups.

Other ways to raise awareness of NRAS

Ann Montgomery, Leicestershire Group Coordinator, wanted to let other group coordinators know that, even if your local hospital won't display conventional posters, there are other ways to raise awareness of NRAS and your group in the community!

Anne says:

"We have 3 hospitals in Leicester and while they are very supportive of our local group, they are reluctant to have our paper posters on the walls because of infection control.

I have managed to source A1 silver spring-loaded poster frames, with the display covered by a clear matt plastic cover so the display can be wiped clean. They are very light and are fixed to the wall with 4 screws. The frames are around £20 each and to raise the funds for these, we applied to the Asda Community Life green token scheme. Our group was chosen for support and we received £200 from them. I have purchased 3 frames to date and one will be put up in

each hospital. The supplier is RAL Display. Their website is www.ral-display.co.uk. The product reference number is GFA1S.

The sisters in charge were very happy to have them on the walls once they saw them.

You can see from the photograph that I have copied the front cover of some NRAS booklets and put these into a frame to show what information is available from NRAS. Other information about the local group was also included and I bought A1 thin card to attach the photocopies to. I also put an acknowledgement to the Asda Community Life fund on each poster. The posters can be brought up to date quickly and easily when

there are updated versions of the booklets available, or new information is available."

If you need help making an application to local funding sources, please contact Oli at oli@nras.org.uk who will be happy to help.



A1 spring-loaded poster frame

The UWEZO Project...

Improving access to musculoskeletal health care in Kenya

According to the recent Global Burden of Disease study, musculoskeletal conditions are among the leading causes of disability worldwide. There are now effective ways to treat many of these conditions but this is dependent on access to appropriate care.

Despite musculoskeletal conditions being extremely prevalent in Africa, due to the fierce competition for scarce health resources, they are largely ignored. In Europe there are approximately 18.9 health workers per 1000 population; in Africa there are only 2.3. In rheumatology the situation is even more extreme. The World Health Organization recommends that there should be at least one rheumatologist per 100 000 people; in sub-Saharan Africa (excluding South Africa), there are less than 20 rheumatologists for over 800 million people. In the UK access to early diagnosis, effective treatments and rehabilitation means that many people with musculoskeletal problems maintain their mobility and have a good quality of life. In sub-Saharan Africa the situation is very different - musculoskeletal conditions have a major impact on people's health, their quality of life and their ability to work and be financially secure. There is a huge amount of suffering and disability that could be averted though improved care.

"It's really difficult for me to do my daily chores. I have to find help to do everything – to fetch water, get firewood. If I had a water tank next to my house that would make a big difference" Patient with RA aged 35, Western Kenya

Kenya has only 2 full time rheumatologists to serve a population of 41 million and the training of primary care physicians in musculoskeletal conditions is minimal. Health professionals say that a lack of awareness of the prevention, treatment and management of MSCs amongst the general public and health professionals leads to delayed or inappropriate treatment which can have devastating effects on the lives of people with conditions such as rheumatoid arthritis. The disfigurement of joints and physical disabilities due to rheumatoid arthritis are becoming rare in the UK but are

commonly seen in Kenya. Research shows that arthritis is one of the most common diseases treated by traditional herbal medicine practitioners in Kenya. Long delays in seeking conventional medical care can result in irreversible damage to joints, leading to complete loss of mobility.

"It's a problem because the people don't know what can be done. They don't come until the damage has been done, sometimes not till they are bed bound with bed sores and then there is very little we can do – we need people to be more aware" Clinical Officer from Eastern Kenya

In a response to these challenges, a team of clinicians, researchers and patients from the UK, Sweden and Kenya are working together to try and improve access to timely and appropriate health care for musculoskeletal conditions in Kenya through the development of a training programme called the UWEZO Project (UWEZO means Capability in Swahili). This is an innovative project where physicians and patients from across Kenya are being taught to become trainers so they can teach health providers who work at the community level, such as nurses and clinical officers, the basic skills needed

for the prevention, diagnosis, treatment and management of musculoskeletal conditions. An important aspect of the project is the use of patients as trainers, an approach used successfully by the team in the UK and Sweden. When teaching health providers, the patient trainers bring the conditions to life. They talk about the impact of these conditions on their lives, they highlight the importance of taking a good medical history and they provide the opportunity for medics to see and feel what the conditions' symptoms are. The project also aims to raise the advocacy skills of patients and to raise national awareness of these conditions.

The first round of training began in April 2012 and to date over 500 health professionals from 11 different locations across Kenya have received training. Measuring the long term impact of the training on musculoskeletal health is a challenge, but evaluation of the project shows that the training has led to a raised awareness of MSCs and to changes in the working practices of health professionals across the country. In response to the needs identified in the first phase of the project the team are also developing a



UWEZO Nairobi 2012 Patient Trainers

patient self-management programme for people with long term MSCs in Kenya. The trainer course for this programme was piloted in August 2013 and it will be trialled across Kenya. The team would also like to see the project expanded to include occupational therapists and physiotherapists so that multi-disciplinary teams could be established in locations across Kenya. There has been interest in the UWEZO Project from neighbouring countries and ultimately the project aims to develop a training package for health

providers and patients that could be used to improve access to effective care for musculoskeletal conditions across the region and in other low resource countries.

The project is a joint initiative between the Royal Cornwall Hospital Trust, the Swedish Rheumatology Association, the Kenyan Rheumatology Association and The African League of Associations in Rheumatology. Funding has come from the International League of Associations for Rheumatologists (ILAR), Cornwall Arthritis

Trust and The Rotary Club in Falmouth, Truro. The Bristol based company, Limbs & Things, donated 12 model limbs which were used for joint injection training and now are an important resource for ongoing rheumatology training in Kenya. However, for the project to move forward next year, the team will need to find new funding sources. If anyone would like more information, please contact Dr Jo Erwin on 01872 256431 or email josephine.erwin@rcht.cornwall.nhs.uk.



UWEZO Nairobi training a 2012



UWEZO Physician trainees – Garissa 2012



UWEZO Training Nairobi 2012

Global Inflammation Advocacy Summit

In November NRAS was asked to take part in the first Global Inflammation Advocacy Summit, hosted by Pfizer. The Summit's theme was 'Stronger Together Against RA' and was attended by 34 patient and advocacy organisations from around the world.

Delegates had the opportunity to attend presentations on RA and developments in its treatment, discuss ways in which awareness could be raised and ways to effectively communicate with patients as advocates, and work in smaller groups to discuss issues each country faces in making RA understood.



Pfizer Global Inflammation Summit attendees

Personal Independence Payment and the Motability Scheme

Lord Sterling, Chairman of Motability, made the following statement in September 2013.

“Following a period of consultation, we have finalised a package of transitional support for Motability customers who may lose their eligibility for the Scheme due to the introduction of PIP.

The Motability Scheme Transitional Package

For those customers who leave the Scheme as a result of being reassessed for PIP, Motability will provide a package of transitional support including information and practical help, along with a one off cash element. This package is designed to help customers source a used car or manage an alternative mobility solution. Motability will formally review the support package in 2015, to take account of economic circumstances and consider possible changes the Government may make to PIP at that time.

In summary, the Motability Scheme transitional package includes:

- For customers returning their car within agreed timescales, a cash element is provided as follows

- First joined the Scheme before 2013: £2,000

- First joined the Scheme during 2013: £1,000

- New customers, that is, those who first join the Scheme after 2013, will not receive transitional support, but will be eligible for a standard return-to-dealer payment of £250

The package will be provided to customers who return the car within 21 days of their allowance ending

- Customers can buy their current vehicle from us at a fair market price
- A ‘claims history’ letter from RSA will be sent to each customer
- Customers will also receive a ‘Staying mobile after Motability’ information pack with insurance information and broker details, suppliers of breakdown cover and guidance on sourcing used cars

Support for Specialised Mobility Customers

- Customers who have a Wheelchair Accessible Vehicle (WAV) will have six months to return their vehicle. Motability will work with these

customers on a case-by-case basis with a view to enabling them to retain their current vehicle

- For Powered Wheelchair and Scooter Scheme (PWSS) customers, we will provide a package of support and advice, to enable customers to retain their current product wherever possible. However, for customers who decide to not retain their product, Motability will pay a one-off transition payment of £125
- Motability customers with adaptations on their vehicles will be eligible for a full refund for privately purchased adaptations. For customers with Motability managed or grant funded adaptations, help will be provided towards the cost of fitting the same adaptations to a non-Scheme vehicle.

If anyone has any questions, they should call the Customer Services helpline number or look on the Motability website.



Scan the QR code below for more information



Customer Services:
0300 456 4566

www.motability.co.uk

PIP and Changes to Rules for Qualification

Over the last two and a half years, NRAS has been campaigning extremely hard to make the Personal Independence Payment a relevant, fair and workable benefit for people with rheumatoid arthritis (RA).

However, this October the Government said 'no' to changing the PIP mobility criteria from 20 metres to 50 metres, as it was under the Disability Living Allowance. In 2012, out of the blue, the Department of Work and Pensions (DWP) announced that they were introducing plans to change the qualifying walking distance that a disabled person would be required to meet in order to receive the highest rate of mobility payment, from 50 metres to 20 metres.



DWP
Department for
Work and Pensions

Under this policy, if disabled people can walk more than just 20 metres – even using aids such as sticks – they will no longer qualify for the highest rate of mobility under PIP. To put the 20 metres distance into context, it translates to roughly the same length as two buses or less than a single tennis court. In fact, when in full flow, 100m legend Usain Bolt could cover it in approximately 1.6 seconds.

Why is this shortening of the walking criteria a problem? This one change in the law will instantly remove 428,000 people from the higher rate of the benefit according to the Government's own projections, meaning that many people with RA will lose money, their access to a Motability vehicle and their independence.

Following outrage from NRAS and the charity sector at what has become known as the '20 metre rule', this

summer the DWP opened a public consultation asking whether the rules should be changed.

NRAS responded robustly to this consultation, utilising four in-depth case studies and 200 survey responses from our Members, demanding a return to the 50 metre criteria. Our concerns about the changes and the likely impacts on people with RA fell into six broad categories: a reduction in independence due to loss of access to Mobility vehicles; enhanced barriers to staying in work; increased problems associated with deficiencies with public transport and the Access to Work scheme; negative impacts on mental health; and increased burden on informal caring.

And we were not alone. Working alongside the Disability Benefits Consortium, a national coalition of over 50 different charities and other organisations committed to working towards a fair benefits system, we compiled the signatures of 11,000 people and 80 organisations as part of a letter sent to David Cameron and Nick Clegg urging them to reinstate the 50 metre distance.

Despite this pressure and the DWP receiving over 900 responses opposing the new PIP mobility test, the Government is pressing ahead with plans that will mean that many disabled people unable to walk less than 50 metres, but more than the current 20 metre limit, will lose their support.

Ailsa Bosworth, CEO of NRAS, said: *"This decision is a huge blow to people with rheumatoid arthritis and the disabled community. NRAS put in an enormous amount of work to try and get this new rule amended. Despite 914 out of 1142 respondents to the public consultation indicating a clear preference for changing these mobility criteria, the Government has stuck to their 20m rule.*

This decision is a huge blow to people with rheumatoid arthritis and the disabled community.

This rejection of change will cause many people with RA to fear losing their jobs and being isolated from society.

While the announcement of some transitional help for those who will lose their Motability car is welcome, as is the introduction of a requirement for the health assessors to confirm they have considered the reliability criteria when formulating their advice on a person's claim for PIP, this still falls desperately short of what is required."

NRAS' work will not be stopping though. We will continue to engage with the DWP and the private providers of the PIP health assessments (Atos and Capita) to ensure that the process works as much as it possibly can for people with RA and takes into account the issues associated with the disease.

By Leo Watson

Transport for All

Disabled and older people in London have come a long way in the last 20 years. Due to the tireless work of accessibility campaigners, more and more of London's transport system had been unlocked.

There are now more step free Tube stations than ever before – 66 of them to be exact! Every London bus now has wheelchair access and audio visual information. We've come a long way since the days when disabled activists chained themselves to Routemaster buses in protest at not being able to board a bus!

Yet still, there's a long way to go until older and disabled people are able to use transport with the same freedom and independence as everyone else.

Transport for All is the organisation representing London's disabled and older transport users. We work for an accessible transport network in London, providing advice and information to older and disabled people about getting from A to B.

We offer:

- Get Moving: a free 60 page booklet on transport access we can post to disabled and older Londoners
- A 'one – stop shop' website on accessible transport in London www.transportforall.org.uk
- A telephone information hotline which specialises in free advice and information about accessible transport in London for disabled and older transport users and takes up complaints. Phone 020 7737 2339: we're open 10 – 5 pm
- Outreach on accessible transport issues. If your group or social club would like a speaker, get in touch with Transport for All
- Five Transport Action Groups, in Lambeth, Ealing, Newham, Redbridge and Brent
- A regular e-newsletter roundup of the latest accessible transport news. Sign up by emailing contactus@transportforall.org.uk



Transport Advice Line

If you would like information about travelling in London, Transport for All can help you. We cover all aspects of accessible transport, from Blue Badge queries; to advice on planning accessible bus, Tube and train journeys. From checking whether you can take your mobility scooter on the bus; to finding out which stations have accessible toilets to replacing a lost Freedom Pass, we can help you stay mobile and independent.

There are many maps and guides which make it easier for those with RA to plan accessible journeys. But all too often the information is hidden away on a website! Our phone line aims to remedy that. We can post you maps that show the size of the gap or step between platform and train at different Tube stations and maps that show where toilets are on the Underground.

The biggest secret in rail!

Few people know that if you can't use your local rail station for access reasons, you are entitled to a free taxi from the inaccessible station to the nearest step free station! The same applies if you want to travel to a rail station which has no lift, but can't manage stairs. Rail companies are obliged to pay for your taxi, if you notify them in advance, but they hide this information in the small print of their Disabled Person's Protection Policy.

The same applies if a lift or escalator on London Underground is broken and there's no alternative bus route – you're entitled to a free taxi under the Taxi Policy.

Campaigning for truly public transport

One in five rail stations have no step free access and remain inaccessible to those who have limited mobility, including those with RA.

We are currently campaigning for a step free Crossrail. Despite the fact that £14.5 billion of public money is being spent on this new railway spanning London, 7 of the stations are not planned to have step free access. Installing lifts would cost only 0.2% of the Crossrail budget.

Over the summer, our members came together for a stunning protest by the Crossrail offices. The Government is now beginning to listen to disabled people and carrying out a feasibility study on making the whole line step free. If you agree that the lack of planned access is disgraceful, please write to your MP and ask them to sign EDM 336 for an accessible Crossrail.

Transport for All is free to join. If you'd like to join with the UK's only charity dedicated to transport accessibility, phone us. Accessible transport is our right.

NRAS Members try out Infrared Cabins

Five NRAS Members were recently invited to trial Health Mate UK's Infrared Cabins. Some research carried out in Austria has shown that Infrared Cabins can provide some improvement to pain and mobility levels in degenerative osteoarthritis, low back pain and RA but there has been no such research done in the UK.

Here is what the NRAS Members thought of the experience. These comments are the individual's own personal views and not those of NRAS.

"The session was very relaxing. However I have not noticed any benefit from my session yesterday. My pain level and stiffness is just as bad. The cabin was not padded enough for my joints either. I did feel slightly less fatigued though." (Angela)

"Wow I feel amazing this evening. My knees have never felt so good since I've had RA.

They don't feel tight or stiff like normal. I'm so thrilled and I wasn't expecting it!" (Jane)

"Bit stiff to sit on but I do feel really relaxed. The next day I felt good in myself and I slept very well. I can't say my joints feel any better, but perhaps it would take a sustained period of sessions to make a real difference. I am very glad I tried it out though and I would want to explore having a course of sessions." (Sarah)

More information on Infrared Cabins can be found at: www.health-mate.co.uk



Pictured 'in the cabins' are Angela and Sarah (above), Jane (top right) and Maggie (bottom right)

RA Awareness Week

Last year NRAS held the UK's first ever RA Awareness Week. We were overwhelmed with



the support we received from our Members and with your help we had 399 people sign our e-petitions, 34 information stands manned across the UK, including Luton & Dunstable Hospital, over 20 features in the media, (including features in the Sunday Post and Daily Express) and 14 tea parties raising vital funds to support those with RA in the UK. Undoubtedly we increased public awareness of RA and that the disease 'can strike at any age'.

Encouraged by the success of the week, we decided it needed to be a permanent fixture for our calendar, and so, 16th – 22nd of June 2014, will again be RA Awareness Week. We recently put the question to you of what you felt the message for the week should be and we were inundated with requests for NRAS to raise awareness that RA is an 'Invisible Illness'. So there is the theme for 2014!

On the agenda this year is a brand new walk, suitable for all to get involved, social media content to raise awareness on a larger scale and your favourite awareness raising activities – tea parties, awareness stands and many media, campaigning and press opportunities! We will have an update in our Spring Magazine, which will also include this year's poster.

If you have any ideas of how you would like to get involved please contact us on media@nras.org.uk. We can't do it without you so please do get involved.



Raising awareness at Luton & Dunstable Hospital



There is still time to apply for a 2014 flying scholarship

Anyone wishing to apply for a 2014 flying scholarship with Flying Scholarships for Disabled People should submit their full application form to them by not later than Tuesday 31 December 2014.

Details of the scheme are available on the Charity's website www.fsfdp.org.uk where a preliminary application form is also available.

To obtain a full application form please contact Julie Bull, FSDP General Manager, Douglas Bader House, Horcott Hill, Fairford, Gloucestershire GL7 4RB.

Telephone: 0844 578 4 578
 Email: info@fsfdp.org.uk
 Website: www.fsfdp.org.uk

All enquiries to Julie Bull (contact details as above)

THANK YOU SO MUCH

"Many thanks to the 539 people who completed the online survey in relation to foot health education and RA. This is a fantastic result and I now have to get down to the job of collating all the data and analysing the results. This will take some time, but I will share the findings with NRAS in due course. The aim of this survey was to find out your views, as people with RA, about the current provision of foot health education and what you feel is most important to you. I am sure that the results of this survey will illuminate your views and help us to further develop effective and accessible foot health education. Once again, thank you"

Kindest Regards, Andrea Graham – Lecturer in Podiatry, Clinical Podiatrist, Directorate of Prosthetics, Orthotics and Podiatry, University of Salford.

Company/Corporate Fundraising

With the start of the New Year maybe your company is looking for a new charity partner? NRAS could be that partner! We have experience of working with organisations of all sizes, ranging from a one-off day of support to a full year's charity partnership and we can help you with tea parties, dress down days, seasonal events and awareness stands. Also, we can offer you a range of charity places in half marathons, marathons, cycling and walking events, some of which you can sponsor if you wish! If you would like to discuss how you and your company can help support those living with rheumatoid arthritis in 2014, give Oli a call on 01628 823 524 or email oliver@nras.org.uk.

PREVENT RA!

"The University of Manchester now have over 100 participants in the PREVENT RA study, which is establishing a national register of first degree relatives (parents, siblings and children) of rheumatoid arthritis patients.

Participants simply need to complete a questionnaire and give a blood sample at their GP or one of a number of clinics throughout England. They are seeking more people to take part nationally - if sufferers have relatives who are aged over 30 and do not have rheumatoid arthritis themselves, please contact 0161 275 5504, preventra@manchester.ac.uk or go to www.preventra.net"

PREVENT RA

Date for your Conference

Rheumatoid A

This 1 day CPD... some of the n... in the field of... medicine wit

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EVENTS

NRAS HAS MOVED!

We have outgrown our previous office space and moved to larger premises in Maidenhead. This will not affect anything we do but it has given us the space to continue to grow over the coming years to meet the demand on our services we anticipate. Look out for some pictures in the spring issue when we will hopefully be more settled!

Our new address is:
Ground Floor
4 The Switchback
Gardner Road
Maidenhead
SL6 7RJ

Our Diary: Hallam Centre, London

Arthritis 2014, Friday 14th March 2014

A 2 day certified conference will assemble most highly respected professionals in rheumatology and musculoskeletal medicine within the UK.

It will be an excellent arena for rheumatologists, GPs and specialist nurses to discuss the latest developments in service delivery, diagnosis, treatment and research in rheumatoid arthritis.

The programme will be released soon, but the topics will include:

• Improving good links between primary and secondary care services: Dr Louise Warburton, Hampshire

• Using novel imaging technologies to aid diagnosis and disease monitoring: Professor Peter Taylor, Oxford

• A new view of current biological therapies and when should these be used? Dr Andrew Östör, Cambridge

• Interactive case studies – systemic vasculitis: Dr Richard Watts, Ipswich

• Interactive case studies – cardiovascular complications: Dr Nicola Goodson, Liverpool

• Interactive case studies – periodontitis: Dr Paola de Pablo, Birmingham

For more information about the conference visit:
www.mahealthcarevents.co.uk/RA2014

WANTED – volunteers to offer help and support to others

Your society needs NRAS Telephone Support Volunteers in the following categories

- People with young families
- People in full time work or education
- Men
- People under the age of 35

If you have a positive outlook and are willing to share your RA experience with others it could really help someone else living with RA.

Someone who has "been there, done that" ... Is that you?

It is now possible to complete the training from the comfort of your own home with our new online tuition.

If you can offer a small amount of your time to be a telephone support volunteer or want to find out more please email volunteers@nras.org.uk or call 0845 458 3971 and speak to Gill or Kim.



FOLLOW US TODAY ON OUR SOCIAL NETWORK

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nationalrheumatoidarthritisociety](http://www.facebook.com/nationalrheumatoidarthritisociety)

[Twitter@NRAS_UK](https://twitter.com/NRAS_UK)

To see what is happening
on Helpline follow them

[Twitter@helpline_NRAS](https://twitter.com/helpline_NRAS)

For up to date membership
information follow

[Twitter@members_NRAS](https://twitter.com/members_NRAS)

Please Gift Aid your Donations

If you are a UK tax payer you can gift aid any donation made to NRAS (including your membership subscription) by simply ticking the box on the form or by completing a separate form if you are already donating. You only need to sign the declaration once and then all donations made are eligible for gift aid.

If you would like a Gift Aid declaration form to be sent to you please let either Fundraising or Membership know or when you next fill out a donation form or membership subscription to NRAS remember to tick the Gift Aid box.

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nras
National Rheumatoid
Arthritis Society

Email: enquiries@nras.org.uk

Web: www.nras.org.uk

Telephone: 01628 823 524

0845 458 3969

Freephone Helpline: 0800 298 7650

Fax: 0845 458 3971

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www.theinformationstandard.org

Tweets



NRAS @NRAS_UK

13 Nov

Just had a surprise fiesta as @Oliver_NRAS is getting married on Friday! His honeymoon is in Mexico hence the outfit!
pic.twitter.com/Vp30ifjKvG



Expand



Charity Ecosystem @CharityEco

28 Oct

Great support coming from @NRAS_UK. Another donation has come in today which will help provide much needed information packs!

Retweeted by NRAS

Expand



leigh walmsley @auberginearcher

23 Oct

Thank you for everything you do to help us @NRAS_UK @Helpline_NRAS @members_NRAS @Volunteers_NRAS @traceynras @Jamie_NRAS @Oliver_NRAS

Retweeted by NRAS

Collapse

Please Remember NRAS in your Will

A gift to NRAS in your Will is a way of continuing to support a cause which mattered to you during your lifetime. This year we have been very fortunate to receive gifts in Wills which have enabled us to hold a series of member involvement days across the country; commission a training programme for volunteers and design and print our new 'Emotions, Relationships and Sexuality' publication.

A Gift in Your Will Supports Our Future



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.

Our thanks go to AbbVie for the distribution of this magazine.