



nras

National Rheumatoid  
Arthritis Society

NRAS Magazine

Spring 2013

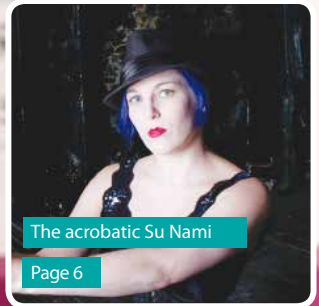
## Launch of the Comorbidities Report and our first RA Summit in Parliament

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National  
Arthritis



The acrobatic Su Nami

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Dreaming of playing  
for England

Page 23

A better life for  
people living  
rheumatoid

ritis



## 2 Dear Members

*As I write this, signs of spring are few and far between, but I hope that by the time you read it we shall be awash with blossom and enjoying the lighter, longer evenings! It is my favourite time of year and always fills me with positive hope and expectation.*

I'd like to take this opportunity to thank all our members who have kindly taken the time to complete our recent surveys for which we have had some truly fantastic responses, which has given us a sizeable amount of very insightful and robust data. These surveys include the one that will inform our new booklet on Relationships, Emotions and Sexuality which we are very excited to be launching at the British Society for Rheumatology (BSR) conference in April. The booklet will be available to order or to download from the website from the 23rd April. There was also the survey on what 'remission' means to you, and we will be providing feedback on this in due course.

As I'm sure you are all aware, big changes are currently taking place in the NHS in England. From the 1st April health services are to be commissioned by GPs via clinical commissioning groups (CCGs). These CCGs replace the Primary Care Trusts and Strategic Health Authorities and will be responsible to the National Commissioning Board rather than the Department of Health. This, and other changes to the NHS, are part of the biggest reorganisation the NHS has ever seen since its inception so it is important to keep updated as you might find that services you normally access may change over time. For more information on how changes in the NHS are affecting the treatment of long term conditions including RA, please visit our website and read Jamie's update on page 30 and 33.

Many of you have contacted our helpline in recent months over changes to benefits such as Disability Living Allowance. This includes the way in which assessments are being carried out, and you have also been asking about the introduction of the proposed new Personal Independence Payment (PIP). Our Government Affairs Team has been working hard on your behalf in these areas and again you can find out more about what is happening within the campaigns section of our website and Jamie's update later in this magazine.

It will be a busy spring and summer for many of us with a trip to Birmingham in April for the annual BSR conference, followed by a longer trip to Madrid for the EULAR conference in May. Also in April we are hosting four regional volunteer training days, designed to replace the annual coordinators' conference. These will be followed by what is an exciting new event for us – the first ever Rheumatoid Arthritis Awareness Week to be held in the UK, taking place between 24th and 30th June. Keep an eye on the website to find out what is happening and how you can get involved. Another important date for your diary is the Members' Day on 19th September in Birmingham. Find out more about the these events on pages 21 and 35 of the magazine.

*In the meantime, my very best wishes to you all and thank you so much for all you do. Your continued support helps us to help others.*



*Alison*

### Key dates and events in 2013



International Convention Centre (ICC) in Birmingham hosts the BSR conference from 23rd to 25th April



In April we are hosting the first of four regional volunteer training days



The next EULAR Annual European Congress of Rheumatology will take place from 12th to 15th June in Madrid, Spain



The first ever Rheumatoid Arthritis Awareness Week to be held in the UK will take place between 24th and 30th June



Members' Day on the 19th September in Solihull

**Are you about to start treatment or have just started treatment with a biologic drug within the past few months?**

**Have you been registered with the British Society for Rheumatology Biologic Registers?**

These registers are monitoring the long term safety and effectiveness of biologic therapies in rheumatoid arthritis and ankylosing spondylitis across the UK.

Ask your consultant or rheumatology nurse specialist today if you would qualify to join this study.

**More information at**

[www.medicine.manchester.ac.uk/arc/BSRBR/](http://www.medicine.manchester.ac.uk/arc/BSRBR/)  
[www.abdn.ac.uk/bsrbr-as](http://www.abdn.ac.uk/bsrbr-as)



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## Meet the team...*by the team* *Emma Seymour on Ruth Grosart*

Ruth is a breath of fresh air in the office, full of ideas and enthusiastic about her fundraising work. You can see this by all the activities she's thrown herself into; NRAS 10k run dressed as a Red Indian, a run round the Olympic park, dressing up as Buttons for the NRAS pantomime, ...and that was just last year! When not involved in fundraising herself, Ruth is our queen of social media and is also working on our new website (exciting!), all ways that enable us to reach out to even more people living with RA.



## *Lorraine Tanner on Clare Jacklin*



I think it can truly be said about Clare, NRAS Director of External Affairs, that once seen, never forgotten! She is an incredibly engaging and charismatic individual who enlivens all around her. She leads a very busy life both at work and in her private life but seems to have boundless enthusiasm and energy for both and she can always be relied upon to make us smile if not guffaw with laughter. Her very direct and practical approach to her job, combined with great insight and a keen intelligence make her a very valued and popular member of the team.



# JIA review project

Following funding received early in 2012, in May we began our planned survey of the JIA services currently being delivered in the UK, with the aim of being able to identify how NRAS can best develop a service to support any gaps identified and then move forward with providing a service to meet those needs. From its inception in 2001, NRAS has envisaged providing a service for children, young people and families living with JIA, but until now has not had the funding, time or resource to take the project forward.

Nicky Kennedy, a retired rheumatology nurse specialist with experience of treating JIA over many years, has been working on this evaluation on a part time basis, visiting centres around the country to gather data to enable us to map local services in different areas. Nicky has been spending time with the consultant/s, members of the multidisciplinary team, some managers and, in some centres, with parents and young people with the disease. She has been recording both quantitative and qualitative data, capturing the referral patterns from surrounding hospitals to both tertiary and non tertiary centres, outreach and inreach team composition and the ongoing management patterns for continuing care.



So far Nicky has visited 16 centres across the country, with visits to a further 14 centres planned. The North/South divide in terms of equitable and timely access to a full multidisciplinary team is significant. In many areas of the country families are facing lengthy journeys, not only for routine care but also urgent review. What is becoming evident is that there are huge variations in the size and scope of the centres in staff to patient ratio, the ability to

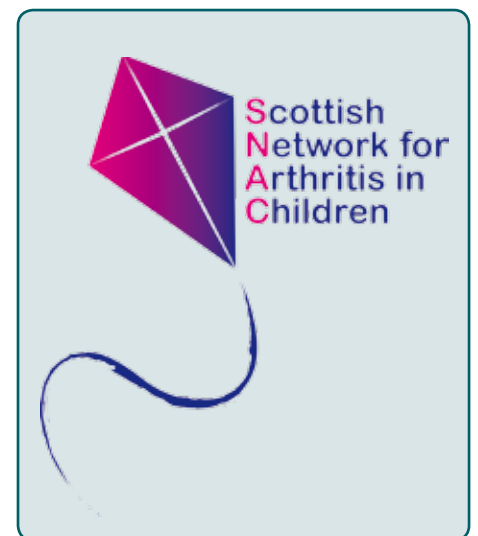


follow up patients in a timely way or to cater for urgent flares and disparity between centres for easy access to joint injections and protected theatre time. Initial referral to a centre well equipped to diagnose all forms of JIA and to treat and support the child and families as a full multidisciplinary team is also very variable. The opportunity to maximise and improve outcomes for the children and young people is at risk of being compromised.

Nicky has been welcomed warmly at all the centres and the support for the project's aims universally acknowledged. There has been huge cooperation from the clinical teams, parents and young people with JIA! The message coming from the families is that JIA is little known, understood or acknowledged. Our aim (over time) would be to raise the profile in the general population so that JIA becomes as well recognised as diabetes in childhood for instance.

Families have expressed an interest in a comprehensive web portal, where clear information could be accessed as well

as signposting to other sites for more specific information such as Scottish Network for Arthritis in Children (SNAC), Children's Chronic Arthritis Association (CCAA) and Arthritis Care, who all offer support in different ways for families and young people with JIA. To this end we have secured funding to create a microsite, which will be accessed via the NRAS website.



We plan to have completed our evaluation by mid-year and our report together with recommendations for a future programme will then go to our Board of Trustees for approval.

We will also share the report with the British Society for Paediatric and Adolescent Rheumatology as we feel that the data will be of value to all those working with children and young people with JIA.

We have already made it clear that we do not wish to reinvent wheels but to work collaboratively with the other charities in the sector to support families and young people living with JIA. Needless to say we are all very excited by the potential for this new service and look forward to being able to support this section of the musculoskeletal community in the future.

Juvenile Idiopathic Arthritis (JIA) is usually considered to be a rare disease of children and sometimes goes unrecognised for many weeks or even months. Even after diagnosis, many JIA patients and families feel isolated and alone. However, it is one of the most common causes of physical disability that begins during childhood. In the UK, between 10,000 and 15,000 children under the age of 16 years are affected by the disease.

**There are seven relatively unique patterns of JIA, some of which carry an increased risk of poor outcome and justify more aggressive treatment approaches.**

### **Persistent oligoarthritis**

only ever affects four joints or less, and has the best outlook of all of the varieties.

### **Polyarthritis, rheumatoid factor negative**

begins with many inflamed joints and testing for rheumatoid factor is negative.

### **Polyarthritis, rheumatoid factor positive**

is more often seen in teenage girls and testing for rheumatoid factor is positive. This subtype is one of the more aggressive patterns of JIA and can therefore require more aggressive treatment.

### **Systemic arthritis**

this subtype often has prominent clinical features such as fever, enlarged glands, and occasionally inflammation of the heart and other internal organs. Arthritis of many joints may be a major long term problem.

### **Extended oligoarthritis**

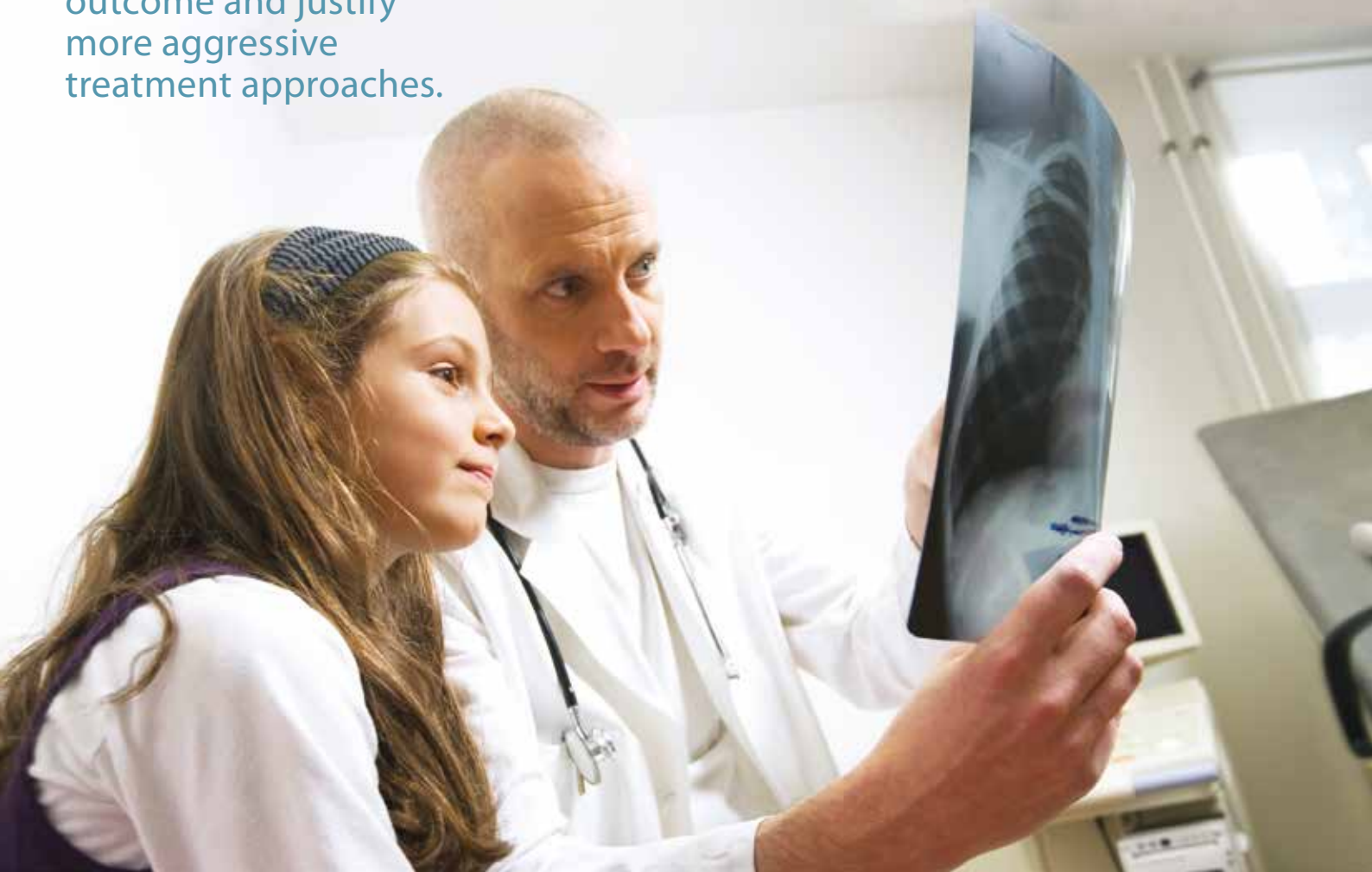
begins just like persistent oligoarthritis but then spreads to involve many joints.

### **Psoriatic arthritis**

this may be difficult to diagnose in children as the typical rash of psoriasis may be relatively hidden (in the scalp, the belly button, behind the ears or in the groin) and may not occur until many years after the onset of arthritis.

### **Enthesitis Related Arthritis (ERA)**

this form of arthritis affects mainly older boys and teenagers. As well as arthritis, there may be inflammation and pain in the soles of the feet, behind the heels and around the hips. This subtype of JIA may evolve to ankylosing spondylitis during the adult years.



# What rheumatoid arthritis has taught me

By Su Nami

In January 2011 I received a grant to do a three month circus course in Sheffield in which I could specialise in acrobatics which consists of learning cartwheels, handstands and other gymnastic style moves, and aerial which is performed on static trapeze/silks by climbing the equipment and performing acrobatic moves on them. I was very excited.

When I arrived at the course everything seemed normal, but the early morning warm ups were tiring. I was really not used to this kind of physical activity first thing in the morning so I put it down to that. In the second week my collar bone/breast plate joint started to swell.

I went to a physio who told me I had pulled a muscle. I had my doubts but he was the professional so I deferred to him. A month later I became convinced it was not muscular as I had pulled muscles before and did not feel like this. He insisted it was and continued to treat it as such, encouraging me to go back to the physical activity.

I continued trying to learn handstands through gritted teeth before I realised I had to give up completely. I had already given up aerial as it was just too painful. Soon I could no longer do acro because the pain and exhaustion were too much. When I couldn't use my arm anymore, let alone juggle, I decided the best thing to do was go home and get treated.

My doctor initially thought it was a partially dislocated clavicle so sent me to another physio for diagnosis and again the physio told me it was muscular. This back and forth between different professionals would continue for months as I got worse and worse.

I was unable to work, money was scarce and I was exhausted and stressed. I had bilateral frozen shoulder as tendons in my other arm were swelling. It was difficult at this stage to look after myself, I was struggling to do basic things such as cook and even on some mornings, dress myself. My walk became more of a

shuffle and I felt incredibly weak and ill. My quality of life reduced dramatically. I went from juggling, dancing and running around to being housebound and unable to stand for more than ten minutes. I took anti inflammatories but they weren't working as they used to and the pain became unbearable.



I got the diagnosis of RA in May and as I started treatment my health went downhill again. Some days I got a little relief and did my best to get outside and meet people so I didn't become a complete recluse, but talking took energy. I started to lock myself away more and more to retain what little

energy I had left. It was a hard year. I was terrified of what might happen to me. All my knowledge about the illness was outdated. I thought that even with treatment my future was grim beyond words and I was too afraid at this stage to do the research. It terrified me.

I bought a cane. It came in handy to get me around the house and when I could stand for more than ten minutes I played with it. My hands were getting back to normal and my wrist would hold out for a while too. That winter was very hard. I never knew if I was going to be able to walk from one day to the next and waves of depression descended upon me keeping me from being as positive as I would have liked. I found it difficult to talk to people, the pain made me snappy which just made me want to spend more time alone.

Months passed and although I was in pain every day, some days the pain was more manageable. I started performing at local cabarets to keep myself focused. I couldn't train for it the way I wanted to but when I was on stage for a few minutes the adrenaline made me able to walk again. I could feel human for three minutes at a time. I put down my crutch just before I got on stage and picked it up afterwards. I was free from the disease while I was up there. The relief was profound and the energy I got from that got me through. As I got a little better I wanted to perform better so whatever time I had on my feet was used as efficiently as possible, I stopped spending time with people that used up my energy and started juggling more.



Knowing that the days I could move might not last taught me to budget my energy. If a person or task took up too much energy I had to weigh up whether it was worth it. This may sound cold but from the perspective of a person who doesn't know how long they have to get the basics in their life done, it becomes necessary. Too much time in a conversation may mean I don't have the energy reserves to do my shopping that day. I learned to prioritise, I had to start putting myself and my health first.

I do believe that you have to push yourself beyond your limits to see where they are. Some days I push too far, incurring serious punishments from my body in the form of days of exhaustion and/or pain. I became so sensitive to my body that I could feel the RA coming on, understand what it was telling me and know when to rest. It can be hard to explain to people you need to rest as a pre-emptive measure, especially when you don't look tired yet. Nobody understood and some even accused me of playing it up.

Finally, in February 2012, I came off the crutch for the last time (I hope) and was juggling a lot more. Now that the pain in my feet has gone, mostly, the only pain I experience regularly is in my shoulder and neck. It's inconvenient but the pain gets less over time thanks to my medication. I get occasional pain in my feet and hands but the flare ups are few and far less intense. I am so grateful for modern medicine and the scientific breakthroughs that have allowed me to work at regaining some normality of life and I know this was not the case for everyone before me. I have nothing but the utmost respect for those people for what they have had to endure.

I treat myself better now than I ever have before, I give myself one day a week to relax and do nothing even when not flared up, as a day with a flare up is not a day off. I juggle as much as I can, pushing myself harder than ever but getting there, albeit a lot slower! I have no idea how long my good days will last before fatigue or pain sets in so I grab them with both hands. I spend time during my flare ups doing physically undemanding things like drawing,

writing or learning the ukulele. I bought a red one recently and am in love with it, it causes me no physical discomfort at all and is so easy to learn. RA has changed my priorities for the better. I am still afraid of the complications this disease may bring and I don't know how long I will be able to do what I love, but I also know I may be able to achieve drug-induced remission with medication. I am afraid of RA but am more afraid of leaving a life unlived. Right now I am working on a hat and cane routine with the very same cane I bought when I was first diagnosed. It makes a beautiful toy that begs to be juggled. Hopefully I will never have to use it as anything other than a juggling prop again.

**You can see Su's videos and other information about her performances by visiting**

**[www.facebook.com/Su2Po](http://www.facebook.com/Su2Po)**

**or**

**[www.youtube.com/user/Su2po](http://www.youtube.com/user/Su2po)**



## Dear Helpline

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

### Packing

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

### Sun/heat

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

### Flying/airports

- Travelling around some airports can require walking very long distances. If you do struggle with mobility it would be worth contacting the airline you're travelling with in advance to see if they can offer help with transportation around the airport. Your airline may also have a desk within the airport where you can request assistance.
- Once on board the plane remember to do the range of motion exercises with your legs that are usually recommended on board and try to get up and move around from time to time to prevent joints from stiffening up.
- Perhaps think about taking an extra pillow for your neck if you're on a long haul flight and tend to find the airline pillows uncomfortable. This can usually be purchased at the airport

### Insurance

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

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

### Travelling with medications

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





## Dear Helpline

# If my rheumatoid arthritis goes into remission, would I automatically come off of my medication?

There is no definitive answer to this, as it will generally be decided on a case by case basis between you and your rheumatologist. However, there are recommendations to help guide this decision. The first thing to determine with your rheumatologist is why they believe your disease is in remission.

There is currently no cure for rheumatoid arthritis, but patients can go through periods of remission, where their disease is at a very low level of activity and they may be experiencing little or no symptoms. Remission can be measured in different ways, though a common measure is a disease activity score (DAS) of below 2.6 (DAS is assessed by examining 28 joints in your body, and combining this information with other factors, such as blood test results). The National Institute for Health and Clinical Excellence (NICE) guidelines recommend that DAS is used regularly to monitor your condition, but we know from speaking to people on our helpline that this is not happening consistently. However, if you are being told that your disease is likely to be in remission it is worth asking if your DAS can be assessed.

NICE guidelines recommend that for patients with established disease that has gone into remission, their rheumatology team should cautiously reduce the dose of their disease modifying drugs, but act promptly to increase the dose again at the first sign of a flare. Within the guidelines, NICE refers to periods of 'sustained disease control' and define this as 'a minimum



period of six months of remission or minimal disease activity'. Therefore, if your disease has only been in remission for a short period, you may not be advised to make any changes to your medication until a greater period of stability has been established. Similarly, in Scotland the Scottish Intercollegiate Guidelines Network (SIGN) guidelines suggest that disease modifying drugs should be "carefully and slowly withdrawn in patients who are in remission."

So, if your rheumatologist suggests that you may be in remission, you should ask how this has been determined and if possible find out what your current DAS is. Once remission has been determined, the guidelines suggest that your treatment be withdrawn gradually. Remission can last for weeks, months or even years, so if your medication is lowered or removed and your symptoms worsen, you should seek advice from your rheumatology team as soon as possible.



## Dear Helpline

### *I have just received a letter telling me that my DLA benefit is going to be stopped and giving me the option to apply for PIP – what does this all mean?*

The personal independence payment (PIP) is the benefit that is going to replace disability living allowance (DLA) from April 2013. Like DLA, PIP is a non means-tested and non taxable benefit which is paid regardless of work status. It is designed to help cover the extra costs that can occur as a result of living with a disability and can be spent in any way you wish.

There is no automatic transfer from DLA to PIP and so letters will be sent to current DLA claimants inviting them to apply for PIP. PIP will have different entitlement criteria to DLA and so being eligible for DLA will not necessarily mean you are now entitled to PIP. Everyone will be individually assessed against the new entitlement criteria. If you decide to apply for PIP your DLA payments would normally continue until a decision on your PIP claim is made (so there should be no gap in benefit payments). If you are assessed as not entitled to PIP, or choose not to claim it, you will not be able to retain your DLA as an alternative.

PIP will have a daily living component and a mobility component as DLA does now, but each component will only have two rates – standard (for limited ability) and enhanced (to reflect severe limitation). From the Department for Work and Pensions (DWP) website, the proposed PIP rates for 2013/14 are:

Daily Living	Mobility
Enhanced Rate	£79.15/week
Standard Rate	£53.00/week
Enhanced Rate	£55.25/week
Standard Rate	£21.00/week

To receive PIP you will need to score points in relation to 11 test activities. These activities consider your ability to move around, prepare food and drink, take nutrition, manage your therapy or monitor your health condition, bathe and groom, access the toilet, and dress and undress. The activities will also consider your ability to communicate, make financial decisions, or plan and go on a journey.

Each activity has a set of descriptors and points are awarded according to your limitations for each activity. To allow for fluctuating conditions if a descriptor applies to you for six months within a twelve month period you will score points, so the form should reflect how you feel at least 50% of the time.

The introduction of PIP is happening in stages:

**April 2013** – In the North East new claimants will apply for PIP (with the rest of the country's new claimants still applying for DLA).

**June 2013** – PIP will be rolled out to the rest of the country for all new claimants.

**October 2013** – The DWP will begin reassessing all existing DLA claimants.

**March 2016** – By this time the DWP aim to have contacted all existing DLA claimants about reassessment for PIP.

They will also decide the length of your award and the date when it will be reviewed.

It is very hard to know more about the impact of these changes until PIP is introduced and the assessment processes are actually being carried out. If you are concerned and would like further information about how PIP may affect you it would be worth contacting your local Citizens Advice Bureau, or the Disability Information and Advice Line

The screenshot shows the Department for Work & Pensions website. The main navigation bar includes 'About DWP', 'Newsroom', 'Consultations', 'Policy', and 'Publications'. The 'Policy' section is active, showing a breadcrumb trail: 'Home | Policy | Disability | Personal Independence Payment'. The page title is 'Personal Independence Payment'. The main content area states: 'From 8 April 2013 the Government is introducing a new benefit called Personal Independence Payment (PIP) to replace Disability Living Allowance (DLA) for eligible working age people aged 16 to 64.' A sidebar on the left contains links for 'Home', 'Policy', 'Disability', 'Personal Independence Payment', 'PIP FAQs and myth buster', and 'Toolkit for support organisations and advisers'.

If you chose to apply for PIP, the DWP will send you a 'how your disability affects you' claim form which you will be required to complete and send back to the DWP along with any supporting evidence. Most people will be asked to attend a face to face interview with an independent health professional assessor (similar to the Work Capability Assessment for Employment and Support Allowance (ESA)). A DWP Case Manager or 'decision maker' will use all the information in your claim form, along with any supporting documents and information provided by the health professional assessor to come to a decision about your PIP claim.

(DIAL). Some DIAL offices are able to supply details on benefits and help with claim forms but not all of them offer this service. To find your nearest DIAL office call: **01302 310123**.

NRAS is also looking to bring out a 'Guide to Claiming PIP' to replace our 'Guide to Claiming DLA booklet' so this will hopefully be available soon.

For more information, visit the DWP website at [www.dwp.gov.uk](http://www.dwp.gov.uk) and search for PIP, or read 'the new Personal Independence Payment' article on the NRAS website at [www.nras.org.uk](http://www.nras.org.uk)

## Dear Helpline

### *My RA is generally quite well controlled but I still really struggle with fatigue. Why am I experiencing this, and do you have any tips for coping with this debilitating tiredness?*

People will often say to us on the helpline that fatigue is one of the most difficult RA symptoms to deal with. The chronic fatigue experienced by those with RA is completely different from the regular tiredness felt after a long, busy day and often cannot be resolved by simply getting a good night's sleep.

Many people also speak to us about the mental exhaustion which can accompany the extreme physical tiredness, and even an emotional fatigue which can leave them feeling tearful and irritable. Along with this there is often a lack of understanding from those around you to contend with because fatigue is an important but invisible symptom of RA. There are a number of reasons why you may feel fatigued which can include the active disease process within your body, living with chronic pain and a loss of muscle tone. Fatigue is also a very common symptom of conditions like depression and anaemia which those with RA can be more prone to.

In active RA the lining of the joints becomes inflamed and these inflamed tissues release chemicals called cytokines. Similar chemicals are released in viral illnesses such as colds and flu and cause the profound fatigue often seen in these conditions. Active RA can therefore leave you feeling wiped out in a similar way as you would with a bout of flu. Living with pain can be a major contributor to fatigue as dealing with long term pain can be very debilitating and wear you down. It can also disturb

your sleep, and there is evidence that poor non restorative sleep contributes to daytime symptoms of RA, including pain, stiffness and fatigue, a vicious cycle.

Loss of muscle tone is often experienced by those with RA due to periods of forced inactivity because of joint pain and potential difficulties exercising. If muscles become weak more effort is needed to make joints and muscles work and carry out day to day tasks so you will feel tired more quickly.

Other conditions such as diabetes and thyroid problems can contribute to fatigue, and having one autoimmune condition like RA can make you more prone to developing another. Eight out of ten people with RA also have anaemia (a condition where the blood is unable to carry oxygen efficiently due to a reduced number of red blood cells) and tiredness and lethargy are the two most common symptoms of anaemia. In addition things like having a poor diet, low mood, prolonged stress and simply pushing yourself too far or 'overdoing it' can also contribute to fatigue.

### So what can be done?

Firstly it's important to try to identify the main cause of your fatigue. If the fatigue is caused by uncontrolled active disease, getting the RA under good control with the use of DMARDs should lead to an improvement in fatigue as inflammation and disease activity levels decrease. Painkillers and NSAIDs (non-steroidal anti-inflammatories) may also be helpful, as they would be when suffering with cold or flu symptoms. These medications should also help manage the pain of RA, and hopefully would therefore allow you to get a more restorative night's sleep.

If you are able to manage some gentle exercise this can have widespread benefits, including helping to maintain muscle tone and joint flexibility. There is also a lot of evidence for the positive effects of exercise on mood, sleep quality and energy levels. If you are worried about starting a new exercise regime it is best to start off slowly, with perhaps just a five to ten minute walk, or some gentle stretching exercises and gradually build up. Alongside this, eating a healthy balanced diet will help to ensure you're getting all the essential

[continued on page 12](#)





# 12 Dear Helpline

vitamins and minerals, fibres, proteins and fats to keep your body running efficiently. Your GP, a dietician and a physiotherapist would be able to advise further if you plan to make changes to your diet or exercise regime.

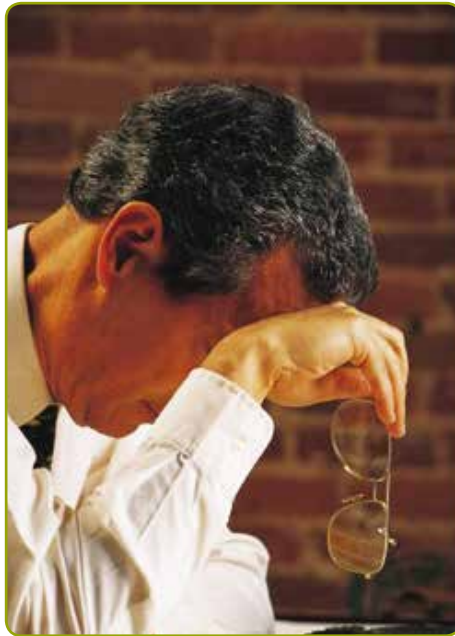
If you have any other health conditions alongside RA speak to your GP to ensure that they are being treated as effectively as possible.

A few small changes to your everyday life may also help to manage fatigue. The most important things to remember are the four 'Ps' – planning, prioritising, pacing, and problem solving.

If you know what you need to achieve you can plan the best way to tackle things. For example, look at spacing out demanding activities over the week. One method we have been made aware of is by doing this visually using the 'traffic light system' where red activities are high energy tasks (they could be physically or mentally demanding), yellow activities are lower energy tasks and green can be used to indicate rest time or very undemanding tasks. This way you can see when your 'red' tasks are and plan

sufficient green time either side of these tasks to conserve some energy and recuperate.

Try to prioritise what needs to be done or which tasks could be delayed or passed over to someone else. Remember it's important to conserve some energy for the things that you enjoy – try not to use



it all up by going to work and cleaning the house!

Look at the way you carry out tasks, and try to break big jobs down into smaller sections taking time to rest between periods of activity. Listen to your body and this should help you figure out your limitations.

For more information on the causes of, and how to cope with, the fatigue of RA take a look at our leaflet, 'Fatigue – beyond tiredness' and the article written by one of our medical advisors, 'Fatigue in RA', both of which are available on the website, or can be ordered by calling us on 0800 2987650. We also have information on managing pain and getting a good night's sleep.

Arthritis Research UK also produces a good booklet, 'Fatigue and Arthritis' which can be downloaded from their website at [www.arthritisresearchuk.org.uk](http://www.arthritisresearchuk.org.uk) or you can call 0300 7900400 to request a copy.

## Dear Helpline

### *I have been asked to choose between the different anti-TNF drugs, but they all look so similar. Which one should I choose?*

This is a question that crops up quite often. Ideally a decision such as this should be a shared decision between you as the patient and your healthcare professionals, so it shouldn't be left entirely up to you to decide. Unfortunately, from what we hear on the helpline, this does seem to happen.

You will probably have noticed in any reading that you have done that these drugs are all quite similar in terms of side effects. This makes sense, as they are all anti-TNF drugs, which means that they are all targeting the same 'cytokine' (proteins that make up the immune system response in the body). However, it does make it hard for people to choose between them.

The important thing to remember is that there are no 'wrong' decisions here. Neither you nor your rheumatology team can know in advance which of these drugs will work best for you, so any criteria can be used in making this decision. Some people decide based on how regularly the drug has to be taken

and how this fits in with their lifestyle. For example, some people might prefer a drug that is taken fortnightly to one that is taken weekly, which might be



easier to fit around travel arrangements for example. Others may prefer a drug that is taken weekly, so they can get into the routine of always taking it on the same day each week.

So, if you have been asked to make a choice between different anti-TNF or other biologic drugs, your opinions as the patient are very important, but you shouldn't feel that you need to do this alone. Your rheumatology team will have valuable experience of prescribing your drugs, so it is always worth asking their opinions or running any ideas you have by them, so that you can make this decision together.

# Fifty shades of RA

By Clare Jacklin

Yes, this is what I had suggested should be the title of the latest NRAS booklet being launched at this year's BSR/BHPR Conference in Birmingham!

'Fifty shades of RA,' why? Because a bit like last year's number one best seller, we haven't shied away from talking about the things that most people want to know about but are too uncomfortable or embarrassed to ask. However, the actual title of this new publication is *'Emotions, Relationships and Sexuality.'* We hope this booklet will help people living with RA, their partners, and their health professionals to bring these important topics out of the shadows and help them to discuss these openly and honestly. Remember the play "No Sex... we're British!"? Well that's not the case here – we're shunning the stiff British upper lip and opening up.

It was very obvious that such a publication was needed given the overwhelming response to an online survey which we ran during December and January. With 1343 questionnaires completed, it was very apparent that people really wanted to express how RA impacted on how they feel, their self confidence and their, self esteem, which in turn has a knock on effect on relationships with their partners and their sex life. The questionnaire was designed after having spoken to many people and their partners via three focus groups hosted by Sarah Collins, psychotherapist and Kate Wilkinson, researcher and editor.

I was personally moved by how open and honest people were in sharing such personal and intimate thoughts and feelings. It is ironic that so many people felt very similar emotions yet so little resource/help is currently available to help you cope with such feelings. 79% of respondents said that having RA had a negative effect on their confidence. Feeling worried and anxious about the future as a result of their RA was very common with 61%



feeling worried about finances and 82% feeling concerned that their therapy may stop working. It is a vicious circle as the more anxious and worried you are about these things, the more it can exacerbate your rheumatoid arthritis.

***Remember the play "No Sex...we're British!"? Well that's not the case here – we're shunning the stiff British upper lip and opening up.***

Knowing how to manage negative feelings and where to turn to for help is not always easy and it is hoped that this new publication will provide some clear signposting and useful tips and techniques to deal with the 'grey' feelings.

Coping with feelings and emotions, as well as the physically limiting impact of RA due to joint damage or side effects of therapy, can play a big role in

how active or inactive your sex life is. Even in the most longstanding, loving relationships telling your partner you want to try something different in the bedroom (or wherever) can be tricky. We humans are creatures of habit and aren't generally too keen on change but experimenting and trying new things can be fun so don't be too coy about finding what works best for you and your partner.

We do hope that this booklet meets an unmet need and reassures many of you struggling to come to terms with how RA makes you feel, that you are not alone. There is help out there and NRAS is always willing to listen and support you every step of the way.

To read the full results of the survey on emotions visit [www.nras.org.uk/surveys](http://www.nras.org.uk/surveys) and for your free booklet on "Emotions, Relationships and Sexuality" order online at [www.nras.org.uk/publications](http://www.nras.org.uk/publications) or call **0845 458 3969**. Bulk orders of this and all NRAS publications are available free to rheumatology departments.

# Nicola takes on the Great North Run in aid of NRAS

I've always considered myself to be an active and healthy person, but shortly after giving birth to my daughter in 2006, I awoke with the most excruciating pain in my shoulder. It was as if a red hot poker was being twisted inside me. After a day of taking painkillers, the agony eventually subsided as quickly as it had arrived. Sadly, by the next morning, the same pain had reappeared in my other shoulder, although once again it faded just as quickly.

I didn't experience this type of pain again for almost a year but then it suddenly it appeared in my wrists and thumb joints, accompanied by redness and inflammation. Multiple visits to A&E came up with no clear diagnosis until eventually I was given the news I feared – a diagnosis of rheumatoid arthritis. At first I didn't quite understand the severity of what I had been told. At 38, with four children, it was unimaginable that I would now have to live with this disease for the rest of my life. I tried to imagine how I would explain it to my family but it was difficult. Everyone understands what you mean when you use the word 'cancer', very few people understand RA and the impact it can have on daily life.

After numerous visits to my consultant, and many tests later, I was eventually prescribed methotrexate but this came with its own complications. After a year, and other treatments too, including lefludomide (no alcohol allowed when on this drug) things seemed to settle down. I was once again able to drive my children to school, do the weekly shop and lead as normal a life as possible. Unfortunately, while on a holiday to France, the pain and inflammation in my joints began to return – my RA had come back.

After six months of monitoring and having periodic DAS (disease activity score) tests carried out, I was given steroid injections to help ease the pain.

During this time I put on three stone and became far less mobile. Finally, in January 2011, I became eligible for anti-TNF treatment and was started on Enbrel – what I would describe as my wonder drug!

From this point on I haven't looked back!

With my life back on track I started exercising – my husband bought me some running trainers for Christmas and my new year resolution for 2012 was to run the Preston Guild Half Marathon. The weight soon dropped off as training progressed and the experience of running my first race, a distance of 5km, was amazing. Quickly I progressed to 10k and finally I ran a half marathon. It was pouring with rain but I was pain free and ready for the challenge!

I have now decided to take on the challenge of the Great North Run on the 15th September in aid of NRAS. Looking back to the early, dark days of my disease I never imagined being able to run up the stairs, let alone run over 13 miles. Since then, my attitude has changed, as has my figure and my wardrobe!



If you would like to take part in the Great North Run this year please contact Val at [val@nras.org.uk](mailto:val@nras.org.uk) or phone **01628 501547** or visit our website at [www.nras.org.uk/events](http://www.nras.org.uk/events)



# Give side effects the yellow card

All medicines have the potential to produce unwanted side effects and different people may react in different ways to the same medicine. Some of these side effects may be harmless, in fact some could be beneficial, but others could be more serious. When first prescribed a medicine, you should always discuss with your doctor the possible risks as well as the benefit of that medicine. You may be willing to accept some of the more harmless side effects in order to gain the benefit.

Before any new medicine is licensed, it will go through a series of clinical trials to ensure it is both safe and effective. These trials are carried out on a relatively small number of people and under very strict conditions. Once licensed however, medicines will be used by a far greater number of people and not under trial conditions so this will inevitably lead to the discovery of some of the rarer side effects, side effects that only develop after prolonged use of that medicine, or even side effects once the person has stopped using it.

It is the Medicines and Healthcare products Regulatory Agency (MHRA), an Executive Agency of the Department of Health, which is responsible for ensuring that all medicines are both effective and safe to use.

The main way MHRA monitors all the side effects is to collect reports of possible or suspected side effects from patients and healthcare professionals. These reports are made using a 'Yellow Card' scheme and are evaluated each week to find previously unidentified risks or other new information. Since the scheme began in 1964, over 600,000 have been received.

that can be used to treat the same condition, and re-evaluate the risk benefit balance of the medicine.

If necessary, it will take action to ensure that the medicine is used in a way that minimises risk, and maximises benefits to the patient. This could include requiring details of a new side effect to be included in the product information, a reduction in recommended dosage, or they may issue warnings about groups of patients who should not be prescribed that medicine. In extreme circumstances it may withdraw a medicine from the market altogether if they believe the risks are greater than the potential benefit.

So how do you take part in the Yellow Card scheme? If you do experience a side effect of your medicine and have concerns then you should seek medical advice, either from a healthcare professional or pharmacist. You can also report any side effect directly by downloading a report form from the MHRA website at [www.yellowcard.mhra.gov.uk](http://www.yellowcard.mhra.gov.uk) or by phoning their helpline on **0808 100 3352**.



▲ The MHRA poster for the Yellow Card scheme

In recent times however, the number of reports from members of the public have declined from a high of 3,584 in 2006 to 1,789 in 2012.

When a potential new side effect has been identified or further information discovered on an existing one, MHRA carefully consider this in the context of the overall side effect profile for that medicine. It also considers this information in comparison with the side effects of other medicines

*By raising awareness of the Yellow Card scheme and through increased reporting by all, it will help to continually safeguard public health and allow people to have a better understanding of the medicines they are taking.*

▲ The form that requires completion for the Yellow Card scheme

# Methotrexate – a safe, effective therapy

By Alison Archer,  
Archer Marketing & Conor Cronin, MEDAC Product Manager

Methotrexate is widely acknowledged to be the anchor drug of RA treatment. Here, we take a look at its effectiveness and long term safety profile and address some of the common issues associated with its use.

Methotrexate is a drug that many NRAS Members will no doubt be familiar with. Considered by Rheumatologists to be the 'gold standard' in RA therapy, methotrexate is undoubtedly an effective, long term treatment for patients seeking remission and relief from the symptoms associated with their condition. However, it is clear that despite its prolific use, there are still some concerns and anxieties that surrounding it.

Methotrexate was initially introduced back in the 1940s as a cancer drug before clinicians realised its value in treating RA. This was at a substantially lower dose however, so whilst a typical dose to treat RA would be between just 7.5mg-30mg per week, in contrast, the doses used in the treatment of leukaemia and certain other cancers are hundreds of times higher.

Belonging to a group of drugs known as DMARDs (disease modifying anti rheumatic drugs), methotrexate works by modifying the abnormal immune processes that can trigger RA, thereby treating the underlying causes, not just the symptoms. The safety profile of methotrexate has been studied for over 25 years and, reassuringly, very few significant adverse events have been reported in relation to the small doses taken for RA. Patients taking methotrexate also have some of the longest continuation rates reported in clinical medicine due to both its effectiveness and safety. In fact, it is common for people to still be taking it for well over five years, an important consideration when treating a long term condition such as RA.

As a patient, you may be taking methotrexate either orally or as an injectable. The oral form tends to be prescribed first and should be titrated quickly to control the disease. It's



not uncommon however, to feel joint improvement but still be suffering from nausea. If this is the case, then switching to the injection may overcome this. If the tablets don't appear to be working well, then the injectable form of methotrexate may also improve its effectiveness. Obviously, there will be many patients who respond well with few side effects, if this is the case, then there's no need to change at all!

Taking methotrexate via injection can overcome efficacy issues, giving a better clinical outcome and perhaps most importantly, with fewer side effects. However, feedback from NRAS Members has made it apparent that some of you aren't aware that methotrexate is available as an injection and that it isn't always being routinely offered as an alternative to tablets. So if you are a patient who isn't coping well with oral methotrexate, don't be afraid to speak to a member of your rheumatology team about the possibility of switching to an injection.

Of course, it is human nature to think that newer must be better and this may be true since the introduction of biologics. Interestingly, a review of trials providing head to head comparisons of both oral methotrexate and biologics showed that they were similarly effective as measured by ACR and EULAR response criteria including remission. It was also demonstrated that the effectiveness of biologics could be significantly improved when prescribed in combination with methotrexate.

Another little known but important advantage of methotrexate can be in the prevention of cardiovascular disease (CVD). Anyone living with a condition that results in some form of ongoing inflammation or auto-immune condition in the body such as diabetes or RA carries an added risk of CVD. The mechanism by which methotrexate reduces the risk of CVD is unclear, but current evidence suggests that its use significantly reduces the risk of CVD, one of the key causes of premature mortality in RA patients.

It may also be reassuring to know that methotrexate is regarded as one of the most useful drugs for the treatment of Juvenile Idiopathic Arthritis (JIA). Subcutaneous methotrexate is already licensed for use in children as young as three years old and BSPAR (British Society for Paediatric and Adolescent Rheumatology) recommend it is used as first line treatment due to its efficacy, side effect profile and good compliance.

So, when you consider all the facts, extensive clinical trials confirm that methotrexate is certainly effective, well tolerated and can be used as a long term therapy, and most importantly, continues to bring remission, relief and often a new lease of life to many people living with RA.

## Christine

In 2002, Christine noticed pain and stiffness in her fingers, especially in the morning. She then started having trouble with her knees which became increasingly swollen. Her GP referred her to a consultant rheumatologist who diagnosed her with aggressive RA.

By this time, Christine could barely walk and felt totally debilitated as every day was governed by how she felt when she woke up. Having RA completely changed her life.



Christine was initially prescribed oral methotrexate at a low dose which was then titrated up. Unfortunately, she experienced severe side effects, especially sickness, which caused her to lose a great amount of weight over just a few months as she simply couldn't eat.

The breakthrough came when a colleague of her husband mentioned that he took methotrexate injections to control his RA. Christine asked her consultant if she could try methotrexate injections in an attempt to deal with the side effects she was experiencing. The result was dramatic, her RA was well controlled and she felt well again with no sickness. She was able to eat properly once more and went back up to a healthy weight. Christine finds the once weekly methotrexate injections not only convenient but quick and easy and in her words "the benefits are fantastic!"

## Jane

Having enjoyed a successful career as a surveyor, Jane describes how, at the age of 23, being diagnosed with rheumatoid arthritis completely changed her life. Today, although her joints can be still be painful and daily fatigue is still a hurdle to overcome, Jane is able to control her flares with the help of subcutaneous methotrexate.



To listen to Jane, Megan and Christine describe in their own words their experience of taking methotrexate and living with RA, visit

[www.nras.org.uk/about\\_rheumatoid\\_arthritis/living\\_with\\_rheumatoid\\_arthritis](http://www.nras.org.uk/about_rheumatoid_arthritis/living_with_rheumatoid_arthritis)

## Megan

Megan was diagnosed with JIA when she was a young after noticing her fingers weren't quite straight and her joints were constantly swollen. She admits to being scared at first but has since learnt to cope with her condition. Megan has been on oral methotrexate for over eight years now. In this time she has not experienced any significant problems and the medication has kept her condition very stable. She takes eight small tablets every Friday and although she still experiences some stiffness in the morning, her pain is well controlled.

When she was first diagnosed with JIA, her condition stopped her doing many normal things. She loved going out clothes shopping with her friends but found she had difficulty doing up buttons and zips and even found opening bottles tricky. Megan didn't tell her friends about her JIA at first, not through embarrassment, but because she

felt that arthritis was a disease very much associated with older people. When she finally told them, many were shocked as they simply hadn't realised there was anything wrong. Now, she doesn't get treated any differently by her peers and she tries to take part in all sorts of activities, even football and rock climbing, and with her JIA well controlled, she can



go out with her friends shopping like any other teenager. At just 17, Megan passed her driving test and is full of confidence having come to realise that most people will never even know she has JIA.



## Individualised aerobic and resistance exercise training improves cardiorespiratory fitness and reduces cardiovascular risk in patients with RA

Cardiorespiratory fitness (CRF) is defined as the ability of your body to transport oxygen to your muscles during prolonged exercise and the ability of your muscles to absorb and use oxygen while you are exercising. This is something that can be measured and if your level of CRF is deemed to be low then this can be a predictor of possible cardiovascular disease (CVD). This study looked at what could be done to improve CRF and the effect this would have on CVD risk in those with RA.



40 RA patients matched for age, gender, body mass index and RA disease duration were allocated to either an exercise group in which participants received six months individualised aerobic and resistance high intensity exercises, three times per week, or they were placed in a control group in which they received advice on exercise benefits and lifestyle changes. Participants were assessed on a range of factors including their individual CVD risk at the beginning of the study and then at three and six months.

At the beginning of the study there were no differences between the groups. Across all the factors assessed at 6 months there were significant improvements in the exercise group, especially in the measure for CRF.

The authors conclude that individualised aerobic and resistance exercise interventions can lead to significantly improved CRF and also to the individual CVD risk factors such as blood pressure, lipids, insulin resistance, body composition, composite CVD risk, and disease activity and severity in RA patients.

You can read more about the role of health and fitness in Wayne Johnson's article on page 22.

### A qualitative interview study:

## Patient accounts of medication use in early rheumatoid arthritis from symptom onset to early post diagnosis

A study conducted in Canada has examined in depth accounts from patients about their experiences and feelings of medication use from symptom onset to early post diagnosis. Results showed that medications were central to how people managed symptoms and disease.

Two main themes were identified, firstly, that before diagnosis, patients self-managed effectively with over the counter (OTC) medications for pain relief and to maintain 'normal life'. This reliance on OTC medications however, contributed to delayed medical consultation, diagnosis and effective treatment and was also potentially detrimental to disease outcome. Secondly, after diagnosis, they found that patient beliefs, priorities and ambivalence towards medications hindered their adherence to their prescribed drug regimen.

The authors conclude that given the drive towards active self management in healthcare and patients' mixed feelings about using strong medications, an in depth understanding of how these combined factors impact patient experiences will help healthcare providers to support effective medication practices. The reported extensive reliance on OTC medications may speak to a care gap needing further investigation in the context of health behaviours and outcomes of patient self management.

## Are people who are taking anti-TNF therapies at an increased risk of developing shingles? Results from two contradictory studies

The first study was conducted by researchers at the Universities of Manchester and Birmingham who looked at data from the British Society for Rheumatology Biologics Register in order to assess the potential link between anti-TNF use and shingles risk.

The researchers found that the risk of shingles was significantly higher among anti-TNF users than among those using non-biological DMARDs such as methotrexate or sulfasalazine and that the anti-TNF group were also more likely to develop skin and soft tissue infections.

Of all the patients in the anti-TNF therapies group, those taking adalimumab seemed to be at the lowest risk of developing shingles and those at highest risk were found in the infliximab group.

The authors concluded that this was a significantly increased risk of shingles in the anti TNF group studied and suggested that it may be beneficial for people using these therapies to consider being vaccinated against shingles. As shingles is a live vaccine, vaccination should be given before starting an anti-TNF therapy.

The second large scale study was conducted by researchers in Portland, USA, who concluded that anti-TNF therapies do not increase the risk of shingles in patients with rheumatoid arthritis and other inflammatory diseases. They also noted

that patients with rheumatoid arthritis typically face a two to three times increased risk of shingles.

In the group that was studied, which included patients with other inflammatory conditions such as inflammatory bowel disease and psoriasis, they found that 310 anti-TNF users were diagnosed with shingles and 160 in the group taking non biologic DMARDs. In the group of RA patients alone they found no difference in shingles rates between anti-TNF and DMARD users and also that the type of anti-TNF used made no difference to this rate either.

The researchers concluded: *"In summary, among patients with rheumatoid arthritis and other select inflammatory diseases, those who were taking anti-TNF therapies were not at higher risk of herpes zoster compared with patients who were being treated with non biologic treatment"*.

Shingles is an infection of a nerve caused by the varicella-zoster virus, the same virus that causes chickenpox. Shingles is normally the result of the virus staying in the system after chickenpox and then, for reasons that are still unknown, it starts to multiply again. The symptoms include pain and a rash on the band of skin supplied by the infected nerve. For more information on shingles, visit the NHS Choices website.

A randomised controlled trial:

## Maintenance, reduction, or withdrawal of etanercept after treatment with etanercept and methotrexate in patients with moderate rheumatoid arthritis (PRESERVE)

The PRESERVE trial was conducted to assess whether low disease activity could be sustained with reduced doses or withdrawal of etanercept in patients with moderately active disease. Although moderately active rheumatoid arthritis is common, treatment effects in moderate disease have not been well studied. Additionally, optimum use of biologics needs further investigation, including the use of induction, maintenance, and withdrawal treatment strategies.

Those enrolled in this multinational trial were between 18 to 70 years old, had been having 15-25 mg of methotrexate for at least eight weeks and had a DAS28 score of  $>3.2$  and  $\leq 5.1$  despite having the methotrexate treatment. Initially all patients enrolled in the trial were given 50mg of etanercept (Enbrel) together with methotrexate for 36 weeks. After this time the patients who had achieved low disease activity  $<2.6$  were randomly assigned into one of three treatment groups: 50 mg etanercept plus methotrexate; 25 mg etanercept plus methotrexate; placebo plus methotrexate. They then looked at the results from these three groups at week 88.

At week 88, 82.6% of patients who had received at least one dose of 50 mg etanercept and one or more DAS28 evaluations had low disease activity, compared with 42.6% who had received placebo). Additionally, 79.1 of patients given 25 mg etanercept had low disease activity at week 88.

The researchers suggest that conventional or reduced doses of etanercept with methotrexate in patients with moderately active rheumatoid arthritis more effectively maintains low disease activity than does methotrexate alone after withdrawal of etanercept.

### NRAS comment

The British Society for Rheumatology has produced evidence that the current eligibility for a first line biologic is set too high and argues that the criteria deny access to a first line biologic for patients with less active disease, who would do just as well on a first line biologic as those with more active disease. NICE is currently reviewing the use of existing biologic therapies and both NRAS and other stakeholders involved in the review with NICE are asking that eligibility criteria for some patients with a DAS of less than 5.1 be considered.

## Publication of a new ARUK booklet on complementary and alternative therapies

At the beginning of the year Arthritis Research UK (ARUK) published a new report on complementary and alternative therapies for the treatment of RA, osteoarthritis, fibromyalgia and low back pain. The report collates evidence from studies into the use of therapies such as acupuncture, magnet therapy, meditation and t'ai chi in rheumatoid arthritis. The report gives each therapy an 'effectiveness' and 'safety' rating for use in each condition where there is trial data available. On the whole there was very little evidence to support the use of complementary therapies in RA, with only three therapies scoring an effectiveness of 2 out of 5- biofeedback, relaxation therapy and tai chi.

For more information the full report can be downloaded from the ARUK website [www.arthritisresearchuk.org](http://www.arthritisresearchuk.org) or give them a call on **0300 790 0400** to receive a copy in the post

◀ ARUK complementary and alternative therapy report



## Trial of possible new treatment for RA

You may have read in the newspapers recently about the trial of a new treatment for RA called BiP, or binding immunoglobulin protein. This is a protein found naturally in the human body which stimulates the body's own mechanism to control inflammation. In the joints of those who have had RA for some time there would not be enough BiP to have any therapeutic anti-inflammatory effect but in previous research an intravenous dose of BiP has been found to successfully boost a patients' anti-inflammatory response. BiP is now being tested in the first 'in human' trial at King's College London and will run for two years. It is thought that this therapy would be more cost effective than biologic treatments, and it is hoped that a single dose of BiP would be enough to put RA into remission for a number of months. It sounds like a promising therapy but we won't know more until the trial is complete.

For further information on the trial contact ARUK on **0300 790 0400** or visit [www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

# Supporting patients with complex medical regimens in rheumatoid arthritis (RA)

By Dr Anna Ferguson - Clinical Psychologist, Department of Rheumatology Guy's Hospital

Long term condition such as rheumatoid arthritis can bring many challenges to a person's life and the need for considerable adjustments, and for some people this may cause distress. One of the key challenges faced by patients is the management of complex medical regimens. People with RA are, in general, reliant on the medicines prescribed to them to manage their inflammation and without such medications greater damage will be caused to their joints, leading to increased disability, greater pain and considerable fatigue.

Taking medication in RA can be complex – it could mean a person needing to take several different medications at different times of the day, in differing combinations, with and without food, and/or avoiding other medicines. For some people managing their medication can be simple, for example one patient remarked: *"I treat medication taking like cleaning my teeth, it has to be done and eventually becomes normal"*

Understandably, for others, such a strict regimen can be difficult to juggle within everyday life. As clinicians it is vital for us to be investigating ways of supporting you as people living with RA to take your medications and we know that the responsibility does not just lie with the patient but also the physician to improve education and awareness of the issue.

## What does research tell us about medication taking in longterm conditions?

Adherence, by definition, means:

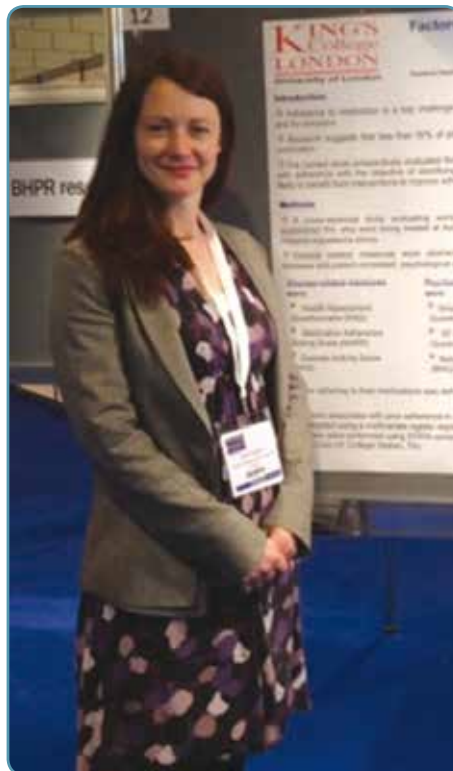
*"The extent to which the patient's behaviour matches agreed recommendations from the prescriber."*

(Horne et al, 2005)

In other words, adherence refers to the degree to which the patient takes their medication as recommended by their doctor. Research tells us that in other long term conditions such as diabetes, cardiovascular disease or HIV, adherence to medication remains problematic. It has been estimated that up to 50% of people with long term conditions do not take their medications as prescribed to them by their doctors and similarly this

has also been found in RA. Not taking medications as recommended has serious implications for health and also has serious financial implications for the NHS as untreated RA leads to a greater burden on resources in the long term.

## What are we doing to help people take their medication in the way it is prescribed?



▲ Dr Anna Ferguson

### Research

I am a clinical psychologist working in a rheumatology service where I have been involved in a research project which has piloted a psychological

approach to improve medication taken by patients with RA. The research was developed with the support of a number of different professionals from differing areas including rheumatologists, senior researchers working in rheumatology, psychologists, health economic advisors and patient experts. The aim of the research was to improve peoples' medication taking behaviour but also their quality of life. The approach is based on a therapy approach called Cognitive Behavioural Therapy (CBT). More specifically the approach targeted two areas known to directly influence whether a person takes their medication.

- 1) Practical problems involved in taking medications (eg cost of prescriptions, amount of medications and issues with regards to remembering to take medication)
- 2) What we call 'perceptual factors' which are our beliefs about our illness (eg if I feel no pain my RA is better) and the treatments we take (eg my medication is toxic). Such beliefs can be unhelpful and often stop people taking their medications correctly.

The pilot study involved inviting patients to take part in the intervention who were attending an outpatient RA Centre in a London hospital and who had:

- a) A moderate disease activity level (as measured by Disease Activity Score DAS-28)
- b) Those who were demonstrating difficulties in taking their medications

We found that those patients who took part in the intervention demonstrated improvements in taking their medication as prescribed whereas a group of patients that we compared who did



not have the intervention did not demonstrate any such improvements. Overall, our research highlights that an intervention to improve medication taking, or key principles drawn from this approach, may be helpfully employed in everyday practice to improve medication taking behaviour. There are however, major limitations of the reported research (e.g. small sample size and female only sample) which indicates the need for further research.

## Development of a patient/clinician leaflet

In our research we also explored patients' experiences of interacting with their clinicians and some reported that they found it difficult to discuss their medication taking in consultation with their doctors. We agreed as a project team that as a side line to our research it might be a good idea to develop two leaflets.

One leaflet will be for newly diagnosed patients alerting them to information they might like to ask their clinicians regarding taking medications and the experiences of others. The other leaflet will be aimed at clinicians to encourage them to communicate more openly with their patients on the subject of medication taking.

With the help of NRAS and its Members, a focus group was run in November 2012 to explore patients' experiences of medication taking and their consultations around medicines. We are currently working with the findings of the focus group to develop the leaflets on adherence.

Please do not hesitate to contact Anna Ferguson (clinical psychologist) at [annaferguson@nhs.net](mailto:annaferguson@nhs.net) should you have any further queries

# RA Awareness Week

This year we are holding the first RA Awareness Week which will run from 24th to 30th June, the first of what we hope will be an annual event.

The week is designed to raise awareness of what the disease is, dispel many of the misconceptions that surround it and educate the general public on the impact it has on such a large number of people. For many people, as you are probably aware, they hear the word 'arthritis' and immediately assume it is something we will all get at some time as we get older and see it as part of ageing, which we all know is definitely not the case!

We want people to understand that it is an autoimmune disease, can strike at any age, and is often a hidden disease in terms of the extreme fatigue and pain which many experience living with RA.

So, to make this work we need your help and are going to be asking you what you can do to help us make this week hit the headlines and reach as many people as possible. We need your help in lots of ways..

- Hold an information day in your local area and let people know what RA is
- Ask your local GP surgery, pharmacy or clinic to put up a poster
- Take a supply of NRAS badges to your GP surgery or pharmacy to sell
- Hold a street or supermarket collection during that week
- Host an NRAS Tea Party to get people together and tell them what RA is
- Take a supply of NRAS leaflets to your surgery, library or community centre
- If you use Twitter or Facebook change your profile picture to the RA Awareness Week logo

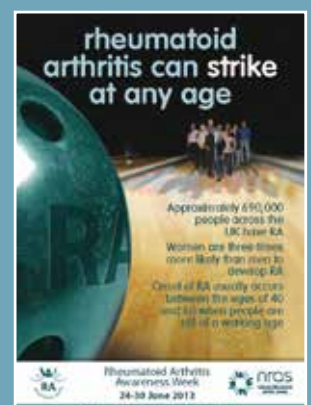
If everyone told at least one person who doesn't know what RA is what the disease is all about, just think how many more people we will have reached. This is the chance to RAise it for RA so please get involved and help us to help you.



## Reader challenge

Here's an idea on how you can help promote RA Awareness Week – ask your local GP surgery /rheumatology unit/pharmacy if they would put one of our promotional posters on their noticeboard.

Once it's up, take a photo and submit it to NRAS to be entered into a prize draw. Email your photos to [media@nras.org.uk](mailto:media@nras.org.uk)



# The role of a health and fitness professional for people with musculoskeletal conditions

By Wayne Johnson, Fitness Supervisor at the University of Birmingham

There are approximately 690,000 people thought to be living with rheumatoid arthritis in the UK. Currently, there is no cure and the management of this long term condition heavily relies on pharmacological therapies. There is evidence to suggest that the inclusion of physical exercise enhances patients' overall health. Introducing exercise into lives of patients living with RA may help reduce the impact of the disease, as well as reducing the risk of other health related diseases such as coronary heart disease, stroke and type 2 diabetes, by reducing cholesterol, blood sugar and resting blood pressure levels.

People with medical conditions sometimes tend not to take up physical activity either in the belief that it may cause more harm than good (particularly in patients with joint problems) and partly, because they do not know who to turn to for help. On the surface, the thought of going to the gyms or health club can be an intimidating one. The idea of seeing fit, young, healthy people, can be daunting but when you delve a little deeper you begin to realise that this is not the case.

Exercise can help a great deal for many. For example, posture can be improved by resistance training, which strengthens muscles, and stretching exercises can improve flexibility. By strengthening the muscles patients can feel better because support for the joints can be improved. Stretching also helps to reduce biomechanical pressure on your joints. A mixture of swimming, walking and cycling (low impact exercises, which are great exercises for RA), combined with stretching eases stiffness and can provide pain relief.

The benefits of exercise are not just about how it can help joints but also about negating any unwanted side effects of medication. For example, weight gain can be an unwanted side effect, particularly when using steroids. The increase in body mass can often put joints under great stress, which could result in more pain. A fitness professional will consider these factors and aim to devise a programme that will help you manage exercise around your condition. They will ensure that you work through your exercise session safely and at a level that allows you to exercise pain free, as well as recover from the session.

Depending on the gym you use the services provided may vary. For those with musculoskeletal conditions devising an exercise programme may require a little



▲ Wayne Johnson

more expert knowledge from your health professional given that there could be many other factors to consider.

If the health club you choose can ensure that their facilities have fully qualified staff to deal with you then you are in safe hands. These professionals tend to be specifically qualified to deal with conditions such as RA, stroke, diabetes and a wide range of other health conditions in some cases. Where we cannot help personally, we will always signpost you in the right direction. Fitness professionals understand that you are, or maybe, more intrinsically aware of how your condition affects you personally and therefore they should regularly enquire about feedback in case an adjustment to your programme

or a referral to a medical professional is needed.

Where I work as a trainer, a variety of people from different backgrounds attend to exercise. This includes those in retirement, academics, students, staff and members of the public. In this environment you will find that everybody has a common goal and which is to improve and maintain their health and to be able to perform their own daily tasks, whatever these may be. This can range from being able to kneel down to do the gardening, to be able to climb the stairs unaided in the home, or more ambitiously, run a half marathon. Whatever your goal, please join a local gym can improve your health and fitness.

## Patient testimony:

*I started to exercise with a trainer. My arthritis affected virtually every joint in my body including my knees, ankles, shoulders, wrists and most of all my hands. My psychological health has also improved vastly. I have much more self belief and confidence and as a result I am much happier within myself. My trainer has not only been an unending source of support and advice but has also encouraged me to try new forms of exercise that I thought I would never be able to take part in. He has also encouraged me to change my diet and I now follow a healthy eating plan with an excellent result. The progress and improvements made since the start have been remarkable.*

# Like millions of young boys my childhood dream was to play for England at Wembley

By Dave Saddington

I was one of those typical sports mad boys that played every sport possible and if I wasn't playing sport, I was watching it.

I left school at 16 to try and make my dream come true as a professional footballer with Leicester city.

Unfortunately, I didn't quite make the grade but roll the clock forward 13 years to 2010 and, at the age of 29, I was still sport and football mad. I was now happily married to my wonderful wife Suzy, a father to my gorgeous daughter Lilia and Suzy was expecting our second child in early February. Life couldn't have been better but then my world came tumbling down with a bang. My life at this point still revolved around sport and fitness. I was playing football for my local team, Holwell Sports, which I had played for since leaving Leicester City, and my typical week would consist of football training twice a week, a game on Saturday plus a game of squash or a trip to the gym if I could fit it in.

One late October morning I woke with a really sore shoulder but thought nothing of it, assuming I had just slept on it in an awkward way. A few days passed but it still hadn't gone away. Then one morning I woke and my other shoulder was now sore, but again I put it down to the fact I had sleeping on that shoulder, as my other was still hurting. I would slowly drag myself out of bed, get dressed, take the dog for a walk and by the time I'd got to work I was fine.

Then one morning I woke up with a swollen left hand and could barely clench my fist. I tried to think of what I had done to cause it, but could not come up with anything. By this time Suzy was urging me to go to the doctors but I shrugged it off as nothing to worry about.

The weekend came and I played football as usual on Saturday afternoon. My shoulders were a little stiff but I managed to get through the 90 minutes comfortably.

I woke on Sunday with sore shoulders as I had done during the previous five days but I was otherwise fine, the odd



▲ Dave (right) and his business partner Matt (left)

sore muscle but nothing unusual. In the afternoon I had gone to see a friend for his birthday when my right knee felt like it was going to explode, I could feel it swelling as I stood so I limped out and got into my car in agony. I just about managed to get home, put on an ice pack and hobbled in to bed.

On the Monday morning I woke up again with stiff shoulders but my knee was absolutely fine. Suzy was urging me to visit the doctors and get it checked out, but again I just put it down to getting on a bit and still trying to do what I did ten years ago.

Eventually, I did go to the doctor who agreed with Suzy that this wasn't normal for a young fit man like me. She offered anti-inflammatories but I said there was no need as I was fine after an hour or so in the morning but she did insist on taking a blood test. A few days had passed when the doctor called to say the level of inflammation was higher than it should be and could I have another test done.

I thought nothing of it at this point but within a week I couldn't get out of bed, there wasn't a joint in my body that wasn't swollen.

I now couldn't bend my fingers

at all and I was experiencing pain like I didn't think was possible. I visited the doctor on a daily basis asking for stronger pain killers until after one night when I couldn't get out of bed and Suzy, who was now heavily pregnant, had to roll me out of bed to get me to the bathroom. By this time Suzy had to do everything for me – get me dressed, open door handles, and even brush my teeth as I couldn't hold my toothbrush. Anything that involved using my hands, I needed help.





My feet were also so painful that it hurt to walk any more than a few feet. My daughter Lilia was now 14 months old and I wasn't even able to pick her up. It was heartbreaking and very depressing that in the space of two weeks I'd gone from playing football to being completely unable to fend for myself.

That morning the doctor reluctantly put me on steroids, she was hoping I could see the specialist first before the steroids dampened down my symptoms. With the steroids, the pain started to subside and I had could now think clearly, rather than just trying to cope and get through the day. It dawned on me that this was serious and not just me overdoing it and I began to think the worst. What would my life hold for me now? Would I still be able to play with the kids? Would I be able to walk in a few years time, let alone play sport and enjoy all the things that I did?

much joy, I struggled to cope with the emotions and at times ended up in some pretty dark places.

All anyone ever wanted to ask me was how was I doing? What was RA? How was it treated? How did it all start and what would I be like in the future? All questions I hated and all questions that left me struggling to find answers. As much I tried to be positive, I couldn't kid myself, I feared the worst. I had completely lost my confidence. I wouldn't put myself in situations where my debilitations became apparent. Situations like taking the kids out by myself, just in case I wasn't able to do something. I stayed away from football as I found it too hard to watch, and it left me frustrated and angry that I would never be able to play again.

One evening my outlook on RA and my life was to completely transform. I was watching the television with Suzy and the babies and there was a military awards programme on that got me thinking. Some of these young men had lost limbs, some multiple, and in their own words they were the fortunate ones, they had made it home to their loved ones while some of their friends hadn't been so lucky. I looked around the room to see how fortunate I was. What did I have to feel sorry about? What did I have to worry about? You only get one shot at life and I was going to make the most of mine. Don't get me wrong, I knew there would still be ups and downs, but I knew I could overcome them.

A week later I returned to work as a commercial print sales rep. If I am honest they were hardly sympathetic to the situation I was in, they had constantly been in touch with me while I was off asking probing questions about RA is and what the future held for me health wise. Again I didn't have the answers.

On my second day back I was asked to go to the boardroom to meet with the three directors, where I was told the company had decided that it was in my best interests to take a position internally rather than have the stress of a role in sales. It did mean that I would have to take a pay cut and lose my company car. The decision was mine but it was made clear what the consequences may lead to if I didn't accept their offer.

Roll the clock back a week and my answer would have been different, but I accepted what was, in their eyes, an offer that was in my best interests. A new job, a substantial pay cut, the loss of my company car and this combined with the fact I had a two week old son, a 17 month daughter and a wife who was now a full time mum at home with only my wage coming into the house. I accepted it as I had already made my mind up, it was time to take my destiny into my own hands. To a certain extent I had lost control of my health, but that was in the very capable hands of my consultant and specialist nurse, so it was time for me to make my own destiny.

I remained in that job for just over a year until May 2012 and by this time my RA was under control. I had spent nearly seven months on methotrexate and DMARDs and these had helped, but only a little, and I was still finding daily tasks difficult. I was unable to exercise, I had tried to swim but even that was proving too painful on my wrists.



▲ Dave with wife Suzy and their children Lilia and Flynn

I slowly slipped into a bit of depression. By this time my doctor had told me she thought it was rheumatoid arthritis and the consultant would confirm it. This he duly did after I had come back off my steroids and by which time Suzy was due to give birth any day. The incredible pain had come back as the consultant needed me off the steroids to properly assess me. Suzy gave birth to our son, Flynn, on February 10th 2011. I couldn't have been more proud or happier on that day. The only problem was that I was barely able to hold my son and that was probably the lowest point in my journey. My state of mind was very poor at this time and I felt anger – why me? I was petrified with what the future held for me. As much as the children and my wife gave me so

I received a few letters and emails from others with the disease after featuring in local newspaper reports about my illness and subsequent retirement from football. They were all very positive stories where they had the disease under control and were leading normal lives. I could only think how that probably wouldn't be me, I wasn't going to be that fortunate.

I also received many compliments on my football achievements and much recognition in the local newspapers. I received a merit award for outstanding achievement at the local paper's annual sports awards. All very humbling now, but at the time I couldn't help but think they were just sympathy votes.

In December 2011 it was decided that I should now start to inject myself every two weeks with Humira and this proved to be an absolute revelation.

In May 2012, along with a friend, we started our own company – a design agency called Magnetic Studio Ltd. It was something that Matt, my business partner, and I had spoken about for years but had never acted upon. That night when I had been watching the television with the family my outlook changed. Although I knew life was going to be different to the one I had planned, having RA had taught me that you never know what is around the corner. Most people would probably think it terrifying to go it alone in business in the current economic climate, but for us it was really liberating to have our destiny in our own hands. I no longer have the challenge of sport in my life but I do have the challenge of running a successful business and we're thriving on it.

I know this will sound pretty mad but I feel I owe a lot to RA. Without it I would probably still be in the same old job. I fell into a trap where I just went along with life and hadn't chased my dreams since my professional football career ended all those years ago. Having RA gave me the kick up the backside I needed. I took a lot of things for granted and that is a mistake I won't make again. In life, certain doors close, but others will open even if they need a bit of a shove at times. RA had knocked me down but I wasn't going to stay down for long, I dusted myself off and came back fighting stronger than ever. In a way RA has made me a better person. I have plans for the future. It is still early days for the business, but all the signs are encouraging and once it is more established I hope to take on some fundraising activities.

It has taken a while to get my confidence back to start to exercise again but it's slowly coming. I'm now involved in football again as I coach the Leicestershire and Rutland County under 16s team. Probably like most people with RA I have to look after myself on a daily basis, know my limitations and resist the urge to run around like I did two years ago.

I'm now able to play golf and walk the dog pain free on a daily basis, and I'm starting to exercise again after becoming the proud owner of a road bike. Bradley Wiggins is someone I'm not, but even so the joy of exercising again is a breath of fresh air. Most importantly of all, I can now chase the kids around the garden and I don't have to explain to them that daddy isn't able to play.



Dave (pictured right) back in his footballing days



# A look at legacies

## Leave it to us to make a difference

Leaving a gift in your Will to charity is a very special way to remember a cause which mattered to you during your lifetime and at NRAS we have been very fortunate to have Members and supporters who have chosen to remember us in this way.

For many people, they feel that this sort of gift is only for those who can give a large amount of money, or a substantial gift, but this could not be further from the truth. A monetary gift of any size can be left or a specific item – a piece of jewellery, an item of furniture or an ornament for example. Monetary gifts can be a fixed amount or a share of a person's estate which can include property, shares, savings or investments.

Here are two examples of how gifts can help us to continue to provide support to all those living with RA in the UK.

In the last year our helpline team took 2,011 calls, an average of 168 per month. A helpline call and the sending out of tailored information costs £18.17, which makes a total of £3,052 per month and £36,631 for the year. During 2012 five new NRAS groups were launched, at a cost of £2,500 to launch

and operate for their first year per group, making a total cost of £12,500 for the year.

Gifts in Wills also give us the opportunity to fund new services and projects, which we would not otherwise be able to embark on. During 2012 we began evaluating services for children with JIA and their parents and carers to identify where there are gaps in the service, and what support is missing for this vulnerable group. Our report will be ready by May 2013 but we are already seeing a gap for a website where people can access all information relating to the disease and also work to be done on delivering a gold standard service for children and young people living with JIA. Without the gifts of our supporters this would not have been possible.

Penny, who has kindly left us a gift in her Will, says 'I have received more help

*and thoughtful concern from NRAS than from any other patient organisation I have approached. I was diagnosed with RA around 10 years ago and that was a bitter blow, similar to when I was told I had cancer... I ventured forth to an NRAS meeting where a new group was starting up. It was so good to let one's feelings 'out' with people whom I had a lot in common with. That was just the beginning... I am the lucky one, and I wish to say thank you in a big way when I depart this life."*

If you would like to talk to someone about leaving a gift, or have any queries, call Tracey on **01628 501546** or visit [www.nras.org.uk](http://www.nras.org.uk) and download the information on how to make a gift in your Will, and to read some other testimonials from people who have a story to tell.



*If you could help us by distributing leaflets to probate solicitors and/or funeral directors in your area we would like to hear from you. By helping us to spread the word, you can help us to make a difference. Thank you.*

# Walk and Talk!

The St Helens NRAS Group recently held a social fundraising event called 'Walk and Talk'. 25 intrepid members of the Group, and staff from the Rheumatology Department at St Helens Hospital braved the torrential rain with their friends and family to complete a sponsored walk round a local park.

Once the walk was completed 50 of the group gathered at a nearby bowling club to enjoy a tea party with a quiz, raffle, photo competition and of course, lots of tempting cakes! They were pleased to receive so much support from local businesses which donated prizes including a massage, a haircut, a fruit basket, flowers and afternoon teas. It was a really enjoyable afternoon and the group was delighted to have raised over £800 for NRAS.

Anne Yates and the Walk and Talk team from St Helens ▶





## Ashford Manor Golf Club Charity of the Year

NRAS was delighted to be selected by Ashford Manor Golf Club as their Charity of the Year during 2012 and in March, Andrew Scott and Oli Hoare enjoyed a trip to the club in Middlesex for the cheque presentation ceremony.

A grand total of £2,592.16 was raised during the year through various events including a golf day, an auction and a collection bottle in the Club House. NRAS is extremely grateful to the Ashford Manor Golf Club for choosing us as their Charity of the Year, it not only raises vital funds for the charity but helps to raise awareness of the disease.

Club Captain Richard Nowicki, and Ladies Captain Debra Aston, nominated NRAS as their Charity of the Year as one of the club stalwarts – Pauline Jarmen – has lived with the disease for nearly a decade and whose daughter was also recently diagnosed. *“Pauline has done a lot for Ashford Manor Golf Club so we wanted to do something for her. The National Rheumatoid Arthritis Society has*

*given her a lot of support over the years”* said Debra Aston. In her 50s, Pauline still chooses to play golf when she can, but after a round will often have to spend the next day recovering.

The Ashford Manor Golf Club, situated on Fordbridge Road in Ashford has been around for 115 years and comprises over 700 members. If you would like to know more about then club then visit their website at [www.amgc.co.uk](http://www.amgc.co.uk).

If you, a family member or friend belong to your local golf club or sports club, why not see if they are willing to support NRAS?

We can benefit from anything ranging from a charity day to a full years support.

**Peter Dawson (Club manager), Oli Hoare, Debra Aston and Richard Nowicki at the cheque presentation ceremony**



## Emma cycles for NRAS

Emma Hannis recently completed a 50 mile cycle in aid of NRAS. She says: ‘In 2008, at the age of 21, I was diagnosed with RA. I was barely able to walk. Since then, Dr Jenkins from the Royal National Hospital of Rheumatic Diseases has managed my condition so well that my disease is now in remission. The support and reassurance I received from NRAS and the team at the hospital made me want to show my appreciation. So, for the first time in over 4 years, I got on a bike and started training with the help of my boyfriend, Dave. In September 2012, we cycled 50 miles at the Wiltshire Big Wheel Ride and raised over £200 for NRAS. Those 5 hours and 20 minutes were the hardest and most gratifying of my life.’

Thank you so much Emma and well done, what an achievement!

▼ Emma Hannis (pictured right)



## Sainsbury's and the Birmingham South Group



For the past year the Kings Heath Sainsbury's store has been supporting our Birmingham South NRAS Group and raising awareness of RA. Jo Connors, one of the Group's coordinators, said “I'm really pleased with the support we have received from Sainsbury's and it was just what we needed to help raise awareness of RA, NRAS and our Group within the local community.” Sainsbury's provided Jo with the opportunity to be in store throughout the year and recently this included a stand for their pancake flipping day and a special Valentine's Day promotion!

We are truly grateful to the store for helping raise awareness of RA and NRAS with their customers, and raising valuable funds for the group, so thank you!

The nominations forms for each stores' next charity of the year will be out now, so if you want to nominate your NRAS Group, please make sure you fill in as form and encourage others to do likewise.

Further details are on the NRAS website and Facebook page or contact Oli to discuss this further on **01628 823524** or [oliver@nras.org.uk](mailto:oliver@nras.org.uk)

◀ Bev McIntosh flipping pancakes at Sainsbury's in Kings Heath, Birmingham

## Santander and the NRAS Yeovil Group

We are very happy to announce that the NRAS Yeovil Group was awarded funding from the Santander Foundation Community Plus Initiative to the value of £1,695. These funds will be used to help increase awareness of RA within Yeovil and the surrounding communities, and raise the profile of the Group and NRAS with local people, encouraging them to support the work of NRAS in their area. Well done Yeovil.

If you are interested in local funding opportunities for your local NRAS Group then please contact Oli on **01628 823524** or email [oliver@nras.org.uk](mailto:oliver@nras.org.uk)



▲ Elaine Denman, Irene Thomason and Tina Mortimer receiving a grant of £1695 from Sally Tilling of Santander

## The NRAS Tea Party is launched

We launched this year's Tea Party in January at the NRAS offices in Maidenhead and are now hoping that as many of you as possible will get involved and hold a Tea Party this year. As you can see there was no shortage of cake!



▲ Members of the NRAS team in Maidenhead holding their own Tea Party



We have been given some great recipes from well known culinary personalities including Lorraine Pascale, The Fabulous Baker Brothers, Gregg Wallace,



Rachel Khoo and Tom Kerridge to give you some ideas.

To register to take part or to download the new Tea Party Pack, along with the

recipes, visit [www.nras.org.uk/teaparty](http://www.nras.org.uk/teaparty). Alternatively email [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk) or call the fundraising team on **01628 501547** to request a pack to be sent in the post.

So get baking, meet up with some friends and help us raise awareness of what RA is all about, and hopefully raise some funds to support us too. Happy Baking!

## IPC Marketforce are supporting NRAS throughout 2013

**MARKETFORCE**

NRAS is very happy to announce that it has been chosen as the charity of the year by IPC Marketforce, the UK's leading magazine sales, marketing and distribution company. We are really excited to be working with IPC Marketforce and will be bringing you updates on their activities in future issues. Some of their staff members have already signed up to take part in a skydive and run the Royal Parks Half Marathon on our behalf!

## New NRAS merchandise



We've rebranded our merchandise products in the NRAS colour! Get your new t-shirt, running vest and wristbands through the NRAS eBay shop at

[www.nras.org.uk/shop](http://www.nras.org.uk/shop)

◀ Oli Hoare and Kim Fitchett of NRAS modelling the new NRAS running vest and t-shirt



# NRAS volunteers

## - a team effort



Spring has sprung and new NRAS groups are springing up in new places across the UK. The North Hampshire and Winchester group got off to a flying start in March with over 100 people attending an information evening with an expert panel answering all sorts of questions on living with inflammatory arthritis, and in particular rheumatoid.

The first official group meeting will take place on Wednesday 22nd May in the ARK conference centre in Basingstoke.

The Cambridge group also got off to a great start in March with a very interactive and informative evening held at Addenbrookes Hospital Post Graduate centre. The next meeting will be in June at the Arbury Community Centre.

Wrexham in Wales played host to another RA Information evening facilitated by NRAS in April and it is hoped that this too will result in a flourishing NRAS group.

Gill and Clare visited the Plymouth group in February and took the opportunity to visit the rheumatology team at Derriford Hospital while in the area. Nikki Day, Rheumatology Sister, and Dr Mark Perry were keen to show us around their working environment, which is not without its challenges. One thing that was very evident was the continuity of personnel that patients really appreciate, and the warm welcome patients get in out patients from the lovely Elizabeth Earl who seems to know everyone by name, something so important when putting patients at ease. I was amazed at the cramped conditions that the lovely nurses have to work in while keeping on top of the mountains of admin that is involved in their patients' care.

For more information about NRAS groups visit the website or call Kim or Gill on **0845 458 3969**.

NRAS Members volunteering their time and energy time and time again.



▲ Clare displaying her 'Impact of RA on Emotions, Relationships and Sexuality' poster at the RCN conference



▲ Members of the rheumatology team at Derriford Hospital wading through the admin

The reputation of NRAS and its Members for being proactive and interactive is exemplary. Researchers, pharmaceutical companies, health care professionals, media and students of many disciplines all want to utilise our unique and wonderful resource – YOU! I often think that you as NRAS Members don't truly appreciate how valuable you are to the developments of new therapies, ground breaking interventions, public awareness and educating the future health care professionals and providers of treatments for RA. Here are just some of the things that YOU have been doing that support the work of NRAS which is "working towards a better life for people living with RA".

- Focus group at Guys Hospital to contribute to the methodology of recruiting patients for a ground breaking clinical trial looking at the possibilities of preventing or delaying RA developing in people categorised as at high risk of developing RA
- Two NRAS Members, John Flower and Susan Cockett, attended a meeting of pharmaceutical staff from UCB Pharma, to share their experience of living with RA and the difference the treatment with biologic therapy had made to their lives
- Angela Hare, NRAS member, spent an afternoon as part of her employer's contribution to charity by allowing her a half day volunteering. As a graphic designer we put her wonderful talent to good work and she has helped us develop a new 'Friends of NRAS' leaflet

Already in 2013 NRAS members have taken part in two very important online surveys one on 'What Remission Means to You' and the other is the NRAS survey entitled "The Impact of RA on Emotions, Relationships and Sexuality". For full details on the latter see page 13.

### What's your number

One of the surprising stats that came out of the remission survey was that 82.4% of people did not know what their DAS score was. Is this you? Next time you see your rheumatologist or nurse specialist then ask them what your DAS score is. There are a lot of aspects of your care that DAS influences, including treatment pathway and progression.

### Royal College of Nursing Rheumatology Conference February 2013 – Edinburgh

Gill and Clare did a hop, skip and a jump from Plymouth to Edinburgh to host a stand at the RCN conference. Networking with rheumatology nurses from across the UK and Ireland is mutually beneficial for NRAS and the nurses. The hardworking committee put on an excellent conference and it is with sadness that they said farewell to Vicky Chamberlain as she steps down as Chair of the committee.



# Launch of the Comorbidities Report and our first RA Summit in Parliament

To mark our first ever Rheumatoid Arthritis Summit held at the UK Parliament on 05 December 2012, we published new research exploring the impact and management of RA related comorbidities in the English NHS.

Sponsored by Roche, The Impact of Rheumatoid Arthritis Comorbidities report was the result of an extensive literature review examining the medical research and policies relating to the management of rheumatoid arthritis, musculoskeletal and long term conditions.

The report uncovered shocking evidence about the range of comorbidities that RA patients are at risk of developing, including problems with the heart,



▲ Linda Riordan MP setting the scene at the RA Summit

eyes, lungs and bones, as well as the psychological impact of living with a long term condition. The research found that up to 80 per cent of people with RA have one or more comorbidities.

Failure to manage these comorbidities effectively can have a serious impact on the RA patient. For example, the presence of comorbidities may add delays to the care pathway, and the



▲ Baroness Masham of Ilton asking a question to the panel during the Summit

research found that comorbidities themselves may increase the patient's overall levels of disability or mortality.

Unsurprisingly, the report found that implementation of NICE guidelines on RA is patchy and that the range of comorbidities for which checks

are conducted is too limited. The report therefore recommended the introduction of ten measures to improve awareness and effective management of comorbidities by RA patients, healthcare professionals, commissioners and policymakers.



▲ NRAS Chief Medical Adviser, Professor David GI Scott, talking about the medical impact of comorbidities with Linda Riordan MP (centre) and Ailsa Bosworth (left)

Key recommendations included ensuring people with RA are given an annual assessment for comorbidities and a personalised care plan, that the content of the Information Prescription on NHS Choices is updated, and that data is made available from the forthcoming national clinical audit on early RA about the proportion of rheumatology teams offering annual assessments and personalised care plans.

The Summit was chaired by NRAS Patron, Linda Riordan MP, and brought together leading health professionals, commissioners, patients, key personnel from within the NHS and representatives of professional bodies to discuss how people can work together to ensure the needs of people with RA are met by the new NHS.

The audience started off by listening to up to date presentations on the patient impact and the public policy implications from NRAS's Chief Executive, Ailsa Bosworth, and our Chief Medical Adviser, Professor David GI Scott. Afterwards, there was an entertaining question and answer session on the actions that need to be taken to improve outcomes for people living with the disease, and participants were also given the opportunity to demonstrate their support for tackling RA by participating in a photo opportunity to promote our new RA Responsibility Deal petition.



▲ NRAS Director of Development, Tracey Hancock, with Huw Irranca-Davies MP

## There has been no let up in campaigning activity over the last four months or so, with NRAS continuing to be involved in major policy developments affecting rheumatoid arthritis patients and maintaining high visibility across the sector.

With the finer details of the welfare reforms still being ironed out, NRAS has been keeping a close eye on developments and advanced the case for the prioritisation of work outcomes for RA patients. In mid November we commented on the draft of a Fit for Work Coalition report outlining new survey data on the impact of musculoskeletal diseases in the UK, which concluded that current policies are keeping hundreds of thousands of people out of work and forcing them to retire prematurely. Our Director of External Affairs, Clare Jacklin, spoke at the official launch of the report in early December alongside representatives from the Department for Work and Pensions, the Chartered Society of Physiotherapy, and the Royal College of General Practitioners.



Elsewhere, the government affairs team has been on the road trying to articulate the likely impact of the welfare reforms on members, and in November Jamie Hewitt presented to the NRAS



▲ Clare Jacklin at the launch of the Fit for Work Coalition report ▲

Solihull group on the Employment and Support Allowance, the new Personal Independence Payment (PIP) and the so called 'bedroom tax'. With PIP now entering its crucial testing phase, NRAS has stepped up engagement

and joined a Department for Work and Pensions stakeholder forum and an Atos stakeholder group.

We would like to stress that NRAS involvement is not an endorsement of PIP or Atos. Rather, the government affairs team is trying to raise awareness of RA and also minimise the impact of the reforms. We will not hesitate to withdraw if we feel our interests are better served by doing so. However, at the time of writing, Atos has asked NRAS to write a Health Condition Insight Report on rheumatoid arthritis that will be used as a reference guide for assessors administering the PIP test, which we hope will improve their understanding. Finally, NRAS also attended a meeting of the Disability Benefits Consortium (DBC) to discuss the latest PIP assessor guidance and, later on, commented on DBC's response to the DWP on this issue.

Meanwhile, there has been a flurry of detailed consultations around the new quality framework underpinning the health reforms in England. The most important of these consultations related to the new National Institute for Health and Clinical Excellence (NICE) quality standard on RA, which contains ten statements outlining what good RA care looks like. As NRAS is involved in the NICE Topic Expert Group, which produced the draft standard for public consultation, unsurprisingly we broadly agreed with contents of the draft. However, we did suggest some further amendments to better align it with proposals contained in the Best Practice Tariff for Inflammatory Arthritis regarding timings for referral and initiation of DMARDs. We also advocated better sign posting of patients to third sector organisations.

As mentioned briefly above, another significant policy development in the sector has been the creation of a new Best Practice on Early Inflammatory Arthritis. Best Practice Tariffs are designed to incentivise hospital providers to undertake certain activities in exchange



for payment. The British Society for Rheumatology, Arthritis Research UK and the Department of Health (with some input from NRAS) have been busy developing the tariff to incentivise early initiation of DMARDs and appropriate follow up care. The tariff is being formally rolled out in England from April 2013 and in March NRAS took part in a stakeholder meeting in the East of England to discuss practical issues around data collection for the tariff and how this will fit with the HQIP national clinical audit on early RA.

Also related to the health reforms in England, NRAS has continued to take a strong interest in commissioning. We are collaborating with the British Society for Rheumatology and Arthritis Care via participation in the Rheumatology Commissioning Support Alliance and are developing an online toolkit for commissioners. Good progress has been made with the development of the website and a potential Clinical



▲ NRAS Chief Executive, Ailsa Bosworth, with Nic Dakin MP

Commissioning Group partner has been identified for the consultancy project phase later this year.

At the same time, NRAS has also been invited to become a partner in a consortium that is bidding to run MSK services in part of the East of England and has participated in several meetings relating to the tender. If successful, NRAS will play a key role in helping to deliver



high quality local RA services and we hope this experience may lead to further opportunities later down the line.



▲ The Right Hon Stephen Dorrell MP

The charity has also tried to encourage scrutiny of commissioning and took part in a summit meeting held by Linda Riordan MP in Halifax. The summit brought together a range of organisations involved in commissioning and providing rheumatoid arthritis services in Calderdale to discuss the area's performance.

There was a lively discussion and a range of follow up actions were agreed

whether the Disease Activity Score (DAS) threshold can be lowered for admission to biologics and whether the sequencing of RA drugs should also be amended. NRAS put together a major response advocating greater access to biologics for people with moderate disease who meet particular criteria and is represented on the expert group that will be considering the submissions and conducting detailed scrutiny of the issues.



▲ Dr Gillian Leng

by participants. This included the possibility of working with the council's Overview and Scrutiny Committee to look at the issue in further detail.

NICE has also been undertaking a major reassessment of biologic therapies and is conducting a Multi Technology Appraisal, which is examining

As part of our work with NICE, NRAS has also been an active member of the Patients Involved in NICE (PIN) coalition. We met with the Deputy Chief Executive of NICE, Gillian Leng, and Chair of the Health Select Committee, Rt Hon Stephen Dorrell MP to discuss issues relating to NICE's role in promoting quality care.





▲ Dr Ben Goldacre

The coalition also arranged a discussion with doctor, author and journalist Ben Goldacre to talk about the relationship between pharmaceutical companies and patient groups. The discussion was positive and Dr Goldacre noted that NRAS was the first patient organisation to sign up to the All Trials campaign, which is calling for all clinical trials data to be published and welcomed news about our plans to disclose further information about the funding we receive from industry.

NRAS continues to be a member of the Prescription Charges Coalition and helped to produce a major report on the impact of charges on people with long term conditions, which was published in March. The government affairs team commented on the draft report, provided media case studies, wrote two political blogs, drafted text for e-campaigning tools and also drafted a submission to the Labour Party Health and Social Care Policy Commission.

Political parties are now beginning to undertake planning for their 2015 general election manifestos, with Labour formally launching a consultation around a Challenge Paper on '21st Century NHS and social care: Delivering integration'. An NRAS submission made the case for a future Labour government to take coordinated action to raise public awareness of inflammatory arthritis and improve GP training.

Meanwhile, in Scotland, the Scottish Public Health Network has continued to take forward the recommendations of its Needs Assessment on RA, which was published in 2012.

Most recently, NRAS helped to draft a new public awareness poster to raise awareness of the disease in Scotland, which is to be published later this year.

Finally, and partly in response to the expanding amount of campaigning work that NRAS has undertaken, the charity has appointed a new Government Affairs Officer to work alongside the existing Government Affairs Manager. Leo Watson is a politics postgraduate and joins us from Cancer Research UK where he was an intern.

## Become a 'Friend of NRAS'

and support people who live with rheumatoid arthritis (RA).

Our 'Friends' are often family, friends and carers of people with RA who want to offer support and keep in touch with what NRAS is achieving.

...follow the easy steps below



### Tell us about you



Title  First Name

Surname

Address

Postcode

Tel No

**To keep our costs low, we would like to communicate with you by email. If you are happy for us to do this, please supply your email address.**

Email



### Become a Friend



**I would like to become a Friend of NRAS.**

Annually: £25  £50  Other £  Monthly £

NRAS was recommended to me by:



### Pay by Direct Debit



Instruction to your Bank or Building Society

Please pay RSM 2000 re National Rheumatoid Arthritis Society Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee.

I understand that this Instruction may remain with RSM 2000 re National Rheumatoid Arthritis Society and, if so, details will be passed electronically to my Bank/Building Society.

Service User No.  NRAS Reference No.

8  3  8  8  9  1

Please fill in the whole form including official use box using a ball point pen and send it to NRAS

Name(s) of Account Holder(s)

Bank/Building Society Account No.  Branch Sort Code

Name and full postal address of your Bank or Building Society

To: The Manager  Bank/Building Society

Address

Postcode

Reference

Signatures  Date

If you would prefer to set up your direct debit through on line banking, please send us a copy.

## Other ways to pay



There are two other ways to pay:

**Cheque or postal order** - Please make cheques payable to NRAS

**Credit/Debit card** - Please complete your card details below

Type of card (eg. VISA, Maestro, MasterCard)

Name on card

Card Number

Valid from / /  Expiry date / /

CVC    (Reverse of card)

Issue no.   (Switch/Solo cards)

Amount £  Date / /

Signature

Step  
4

Gift Aid it

*giftaid it*

I am a UK taxpayer. I want NRAS to treat all donations as Gift Aid donations. This means that every £1 donated by you is worth £1.25 to NRAS.

YES/NO\*

\*Please delete as appropriate

Step  
5

Simply post this form



Thank you for helping people with rheumatoid arthritis. Please send this form (and your payment) to:

**National Rheumatoid Arthritis Society**  
Unit B4, Westacott Business Centre, Westacott Way,  
Littlewick Green, Maidenhead, Berkshire SL6 3RT

## Do you have rheumatoid arthritis?

If you have rheumatoid arthritis and are not a Member of NRAS – please join.

Members receive a care plan, magazines three times a year and access to our online forum.

call us or visit our website

**0845 458 3969**

**www.nras.org.uk**

To join and get your welcome pack

## Free Membership for Healthcare Professionals

One of our core activities and goals is to work as closely as possible with Allied Health Professionals to assist them in any way we can to improve patient information and education.

One of the ways in which we do this is to provide free membership of NRAS to healthcare professionals who deal with RA patients. We have over 800 professional Members throughout the UK and all come into regular contact with RA patients, whether they are specialist nurses, consultants, physiotherapists, OTs, podiatrists or GPs.

*"As a Member I can keep up to date with current knowledge and practice in rheumatology."*

What does free membership include?

- NRAS membership (normally £25 per annum)
- NRAS magazine which includes updates on new developments, patient stories and stories from Health professionals
- NRAS support network, information on local groups and volunteer activities, plus posters to display in clinic
- NRAS lapel badge to show your support of our work
- Helpline cards, general leaflets and RA awareness cards in a quantity sufficient for all patients.
- Copies of our main NRAS publications including 'Your Next steps' for newly diagnosed patients, 'Managing Well' for patients with established RA, an 'Understanding your DAS' DVD and booklet for health professionals and 'Biologics – the story so far'
- Access to NRAS team, helpline and network of volunteers
- All other membership benefits (see our website for details [www.nras.org.uk/join](http://www.nras.org.uk/join))

*"I find it very useful to receive information and publications from NRAS as it allows me to disseminate appropriate information to my patients"*

We know that our Members come into contact with many health professionals throughout their treatment so next time your nurse visits you at home, or your visit your GP, why not ask if they have heard of NRAS and see if they would like to receive complimentary membership?

If you are already a Healthcare Professional Member of NRAS, please remember to keep an eye on the Healthcare Professional area of the website for latest news, make sure you are receiving our monthly e-news and encourage your colleagues to join today!

To join, please contact the Membership Team on **0845 458 3969** or email [membership@nras.org.uk](mailto:membership@nras.org.uk)



# Members' Day 2013

Following the success of our first annual Members' Day last year at Taplow Court, we are pleased to announce our second event will be held on Thursday 19th September from 10.30am to 4.30pm at Solihull College in Birmingham, a modern facility that is easily accessible by public transport.

We have already confirmed our first speaker, Dr Holly John BMBS, MRCP who is a specialist registrar at Dudley Group of Hospitals NHS Trust and is also a clinical research fellow for the RA Comorbidity Research Group. In the past, NRAS Members have contributed to her research through a survey on cardiovascular disease in RA.

Following feedback from last years' event, we have decided to make it a longer event, including a buffet lunch, which we hope will allow more time to meet other Members/staff and also enable us to cover a wider variety of topics. As with last years' event, it will



▲ Solihull College – the venue for Members' Day 2013

be free for Members to attend but we will be asking for donations on the day as a contribution towards refreshments. Non-Members/guests are also welcome to attend for a small fee of £5.

Further information, including a full timetable and directions, will be sent out nearer the time but if you would like to register your attendance for the event now, please email [membership@nras.org.uk](mailto:membership@nras.org.uk) with your full name, postcode and whether you would like to bring a guest(s). The NRAS team are looking forward to meeting as many of you as possible in September!

## Members Tips



### Soxon

One of the best aids I have used is called Soxon – as the name says it is for putting on your socks/tights. Roll the sock on to the end, drop it to the floor and use the loops to pull the sock on

[www.helpinghand.co.uk](http://www.helpinghand.co.uk)

### Computer Voice Recognition



[www.nuance.com](http://www.nuance.com)

For those people who struggle with typing, try using Dragon Naturally Speaking voice recognition software. Just say what you want to appear on the screen rather than type it.



### Gorillapod

For those of you who use a camera and have difficulty with holding and also positioning it to take a picture the Gorillapod is ideal as the bendable legs means it can fasten to anything.

[www.joby.com](http://www.joby.com)

### Walking Pole

If you're sometimes unsteady on your feet but not a regular user of a walking stick then the Craghoppers Compact walking Pole is ideal, lightweight yet effective as a walking stick but tidies away neatly when not needed.



Don't forget that if you order from Amazon you can do so through Give As You Live and NRAS will receive a donation!





A week in the life of...

## A Rheumatology Clinical Trials Nurse

Sally Giles has been a nurse for seventeen years and for most of that time has been working in the field of rheumatology. Living in a village on the Staffordshire/Shropshire border, Sally shares her home with her daughter, Iona, and her dog, a Miniature Schnauser called Wilf.

Sally works at the Cannock Chase Hospital in Staffordshire, a hospital fortunate enough to have a relatively large rheumatology department with five consultant rheumatologists and dedicated teams of specialist nurses, physiotherapists and occupational therapists. People are often surprised to find that there is such a large and successful clinical trials unit, as such departments are usually associated with University Hospitals in big cities, but at Cannock they are proud that they can offer their patients the opportunity to take part in a research study. They have a great team of nurses and administrative staff and the sound of laughter is very commonly heard coming from the office!

One of the things Sally likes best about her job is that no two days are the same. Below is a diary reflecting a typical week and providing an insight into her world.

### Monday

On a daily basis, we go through the diary as a team and are allocated one or two patients, depending on the amount of time each patient will be in our department and the staff available. Today I was allocated to look after a young mum with Psoriatic Arthritis (PsA), who had recently completed a two year clinical trial for a new drug. One of the main concerns when patients come to the end of a study is to be able to manage their condition effectively, especially if the study treatment is not yet available under NHS care. Sadly the treatment that she received and did so well on is not yet available, so after discussion with one of our consultants, she was given a prescription for a standard treatment and this was discussed thoroughly with her. It is important that, as a trials nurse, we are also familiar with all the standard treatments, their side effects and monitoring needs, as we have to discuss these, with confidence, on a regular basis.

She was also given an appointment for follow up care with her consultant at her local hospital. Our team prides itself in the care we give to patients, not only when they are taking part in a study, which can range from six months to five years in duration, but also once the study has been completed.

### Tuesday

Today I am working on recruitment. This can take many forms and effective recruitment is essential to our department. As many of the studies we have at Cannock are commercial, (sponsored by large pharmaceutical companies), they generate a considerable income for our hospital trust. Not only this, but effective recruitment and good standards can lead to more studies being offered to us, something that will ultimately benefit our patient population, as we will have more trials to offer them.

Taking part in a clinical trial is completely voluntary. Often our consultant rheumatologists will identify a patient they see in clinic as being



▲ Sally with her Miniature Schnauser, Wilf

potentially eligible for a study and we would then see them to discuss the study and give them full written information to take away.

All clinical trials have inclusion/exclusion criteria and sadly we often see patients who are keen to take part in a study, but are not eligible. We would find this out by reviewing the patients' hospital notes, or by checking test results from a screening visit against the criteria. It would be our responsibility to ensure appropriate follow on care for any patient who was not eligible.

My colleagues and I often discuss studies with prospective participants as it is vital they are fully informed about all aspects of the trial. There is a commitment from the subject as well

as the study team. Some studies require just the completion of a questionnaire, while others will require the patient to attend hospital on a regular basis, possibly having an infusion (drip) treatment. This can take up the best part of the day and can therefore impact on their work or family time.

Patients have many questions to ask when considering a clinical trial and it is vital that all questions are answered to their satisfaction before proceeding.

## Wednesday

Today I have been allocated to care for a patient enrolled on a study that compares two existing anti-TNF treatments for RA. The main aim of this study is to compare the treatments over a five year period and to determine which group of patients have less cardiovascular problems during that time. The patient receives an infusion lasting one hour and she has to see a doctor before her treatment begins to ensure she is well enough, and then has to stay in the department for one hour to ensure she has no adverse reaction. I will look after her throughout her time in the department, from taking blood tests and checking the activity of her condition, until she goes home. The patient has found that her RA has improved dramatically since commencing the study, which is fantastic!

On Wednesday evening we had a clinical trials social event. This was the second event of its kind, brought about after a patient's comment. The lady expressed that she really missed the contact with her fellow trials participants when her study came to an end. Many of our patients form strong friendships and will support each other during their time on a clinical trial and the event just gives them a chance to meet again. We have tea and cakes and a raffle to raise funds for an RA charity. Our next event is an NRAS Tea Party!

## Thursday

On Thursday I spent the day with a colleague who works for our local CLRN (Comprehensive Local Research Network). We act as facilitators on a Good Clinical Practice (GCP) course. All staff who work on a clinical trial, or intend to, must complete this course to ensure they are aware of the law that encompasses them, the importance of confidentiality of participants and the need for appropriate training of all staff. All of this is essential as the quality of

## Friday

Continued education is very important to all nurses and on Friday, along with colleagues from my department, I went to a study day for professionals working in rheumatology. Doctors and nurses from the West Midlands met to discuss current 'hot topics', new and innovative ways to diagnose and treat. It is only through the sharing of results, including those from clinical trials, that care for our patients can constantly be improved.



▲ **The Clinical Trials Team**  
 Back row L-R: Shelia Littlewood, Elaine Taylor, Denise Shillito & Annette Wilkinson  
 Front row L-R: Sally Giles, Julie Edwards & Jo Logan

trial results is only as good as the data collected by study staff. We deliver the course at many hospitals within our area – to doctors, nurses, pharmacists and other health professionals.

After a busy and varied week so far, Iona and I went to see *Les Miserables* at the local cinema and it was amazing! We both love musicals and the theatre and find this a great way of unwinding and spending quality time together.

I hope that this has given an idea of what a week can be like for me. I am very fortunate to love my job!



## Pledge your car and win a Kindle Fire!

One of the ways you can fundraise for NRAS is by donating your car through the Giveacar scheme. They scrap or auction the car and give the proceeds to NRAS – simple! They are currently holding a competition with a prize of an Amazon Kindle Fire if you pledge your car to NRAS at [www.giveacar.co.uk/pledgeyourcar](http://www.giveacar.co.uk/pledgeyourcar). Pick NRAS from the list and they'll post you a car sticker. Just send them a photo of it displayed on your car and you'll be in with a chance of winning.

For more information on this scheme, contact Ruth on **0845 458 3969** or email [ruth@nras.org.uk](mailto:ruth@nras.org.uk)



## Rheumatoid Arthritis: A Family Perspective

Produced in collaboration with Arthritis Care and Abbvie, 'Rheumatoid Arthritis: A Family Perspective' is now available to download from the NRAS website. This collection of stories, from six families living with RA, aims to raise awareness of the day-to-day realities of living with RA.

All the families that you will meet in this book have faced their own challenges as a result of RA making each story inspiring in its own way.



## The latest NRAS Annual Review is now available

If you want to see a snapshot of our key achievements and success over 2012, request your free copy of the latest NRAS Annual Review by contacting **01628 823 524 / [enquiries@nras.org.uk](mailto:enquiries@nras.org.uk)** or view it online at [www.nras.org.uk/about\\_us/annual\\_reviews/default.aspx](http://www.nras.org.uk/about_us/annual_reviews/default.aspx)

## Take the plunge

Be inspired and sign up today to take part in the Great North Swim in the beautiful surroundings of the Lake District National Park on Lake Windermere. The event takes place on 14th – 16th June. Choose your distance from ½ or 1 mile or 5k courses. Take the plunge and sign up today for NRAS! For further information visit our website at [www.nras.org.uk/events](http://www.nras.org.uk/events)





## Local Awareness

In February the Lions Club in Maidenhead hosted a Volunteers' Day in the town centre where charities from across Berkshire could promote their cause. Events like this are a great way to promote the work done by the charity locally and raise awareness of RA, so if you hear that one is happening in your area please do get involved. Let us know about it and tell us what we can do to support you.



## New publications

Over the last few months a number of NRAS publications have been reviewed and updated. When an employee has rheumatoid arthritis; *Biologics - the story so far*; *Newly Diagnosed with Rheumatoid Arthritis*; and *Benefits and Rheumatoid Arthritis* have all been republished in recent months so download the latest version from the NRAS website. All NRAS publications are regularly reviewed so we'll keep you updated.



## New foot surgery section on NRAS website

Last year we launched a new section on footwear on the NRAS website, covering a variety of topics, including information on looking after your feet, how a podiatrist can help and tips on finding suitable footwear.

To complement this section, we now have an article on foot surgery, which covers a variety of different types of foot surgery, from common procedures to more extensive foot surgeries. This article, and the rest of the Foot Health section can be found in the 'Living with rheumatoid arthritis' section of our website.

## A big thank you

In recent months there have been lots of requests from NRAS for people to complete surveys or submit case studies and we want you all to know how grateful we are to those who have taken part. By getting involved with the work NRAS does, it helps us to better understand the impact RA has and this in turn allows us to do more work on behalf of those with the disease. We're sure there will be plenty more requests in the coming months so please do keep a look out and take part when you can.

Thank  
You!

Don't forget to follow us on

## social media

too:

Join the NRAS Facebook page

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

& be part of the NRAS community

Follow us on Twitter

[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)

twitter



# NRAS website updates

There are some updated areas on the NRAS website so do take a look at [www.nras.org.uk](http://www.nras.org.uk)

## Disease Activity Score

(DAS)

– there is now more comprehensive information on DAS for patients and health care professionals

## Foot Health section

– there is now a new section on foot surgery within the foot health section

## Publication Downloads

– all NRAS publications are now downloadable from the website



[www.nras.org.uk](http://www.nras.org.uk)

# 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 start the evaluation project on JIA services in the UK and update the campaigning area of our website to allow Members to be more involved in issues which matter to them.

A Gift in Your Will Supports Our Future



# Give as you live

Thousands of stores have signed up to donate money to NRAS when you shop with them online. This is a really easy way to support NRAS without it costing you a penny! Simply load the Give As You Live app on to your computer and then each time you shop on the listed stores it will automatically donate a percentage of your purchase to us.

Stores signed up include Tesco, John Lewis, HMV, Marks and Spencer, Amazon, Sainsbury's, Boots, British Airways and many more high street names. Sign up today at [www.nras.org.uk/giveasyoulive](http://www.nras.org.uk/giveasyoulive). If you want to know more email [ruth@nras.org.uk](mailto:ruth@nras.org.uk)



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National Rheumatoid  
Arthritis Society



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*Our thanks go to Abbott for the distribution of this magazine to NRAS Members and Rheumatology Healthcare Professionals.*

[www.nras.org.uk](http://www.nras.org.uk) Freephone Helpline: 0800 298 7650