nras
National Rheumatoid Arthritis Society

NRAS Magazine

Autumn 2013

Riding the ocean waves

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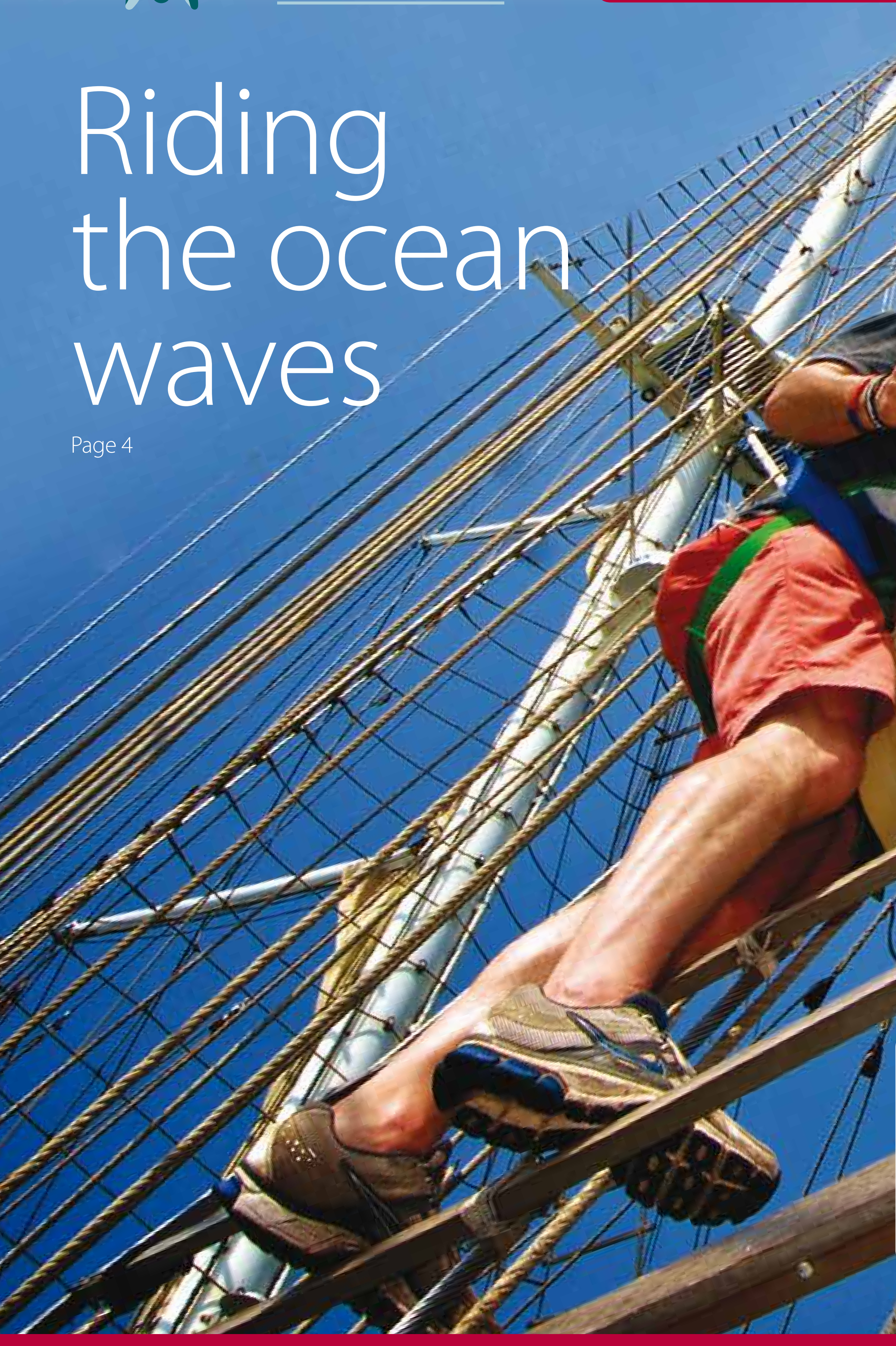

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Dear Members

I hope you all had a wonderful summer. It's a cloudy day in August as I write this but we have had a taste of the BBQ summer we were promised so let's hope we have a warm autumn before the dark evenings set in.

There is so much happening at the moment within NRAS and the health service that there are many things I could write about. However, I attended a stakeholder dinner hosted by the Royal College of Nursing in London a few weeks ago and the highlight of the evening was a poem performed by the student nurse who wrote it. I was moved by it, as were my fellow guests around the table and given the amount of negative media there has been over recent months about the health services generally and nurses in particular, I would like to share this poem with you. Whilst no one should tolerate sub optimal patient care by any healthcare professional, the vast majority of nurses do a fantastic job and where would we patients be without our rheumatology nurse specialists? Also, don't we want to encourage young people to enter the nursing profession? How many I wonder have been put off doing so by so much negative press? So, in praise of nurses, I hope you will enjoy reading this.

Nursing the Nation: *a student's response*

By RI Macey

A woman comes in,
too young to bear this
she's got a disease that will make her miss –
her daughter's wedding day, her first grandchild being born.
How would that feel to have that all torn
away from you?

I can't answer that question,
it's not my place to say,
but I can tell you what we did for her,
how we helped her get through the day.
A cup of tea there and one for all her family,
as they came, throughout the night,
what a sight: there were loads of them.
To help her fight the awful pain of it,
paying last visits, we wouldn't let them miss it –
farewell from a brother,
last kisses with their mother –
holiest love, love like no other.

Maybe there's bad ones,
no doubt that there are,
but for this list I'm writing we don't want the same tar-brush,
crushing our careers before they've even started,
how could you say this about people so big hearted?

Who'd have thought we'd be having to defend?
We don't do this for our families,
we don't do this for our friends,
but for strangers.
Because this is our vocation
and we're sick and tired of hearing we don't do enough for this nation.
So, listen to us, hear us goddamn roar, you say we're not doing enough?
Then we promise we'll do more.
This time, next time, there's nothing we can't handle,
even if you bring us down, show us scandal, scandal, scandal...

You remember that man covered in burns head to toe?
I don't think you do because you were on that TV show:
lip gloss kissed women on daytime TV,
come into our world, see things that we see.

One lady passing had no relatives to stay,
we sang her to sleep, let angels take her away.
Were you there that day when we held her hand?
Told her nothing would harm her,
that there was a higher plan.
Saw her face remember a faith she once held,
watched her breath in the room as she finally exhaled.

Why don't you meet us? Come and shake our hands?
Try to fit it in between drinking tea with your fans.
Your hands are so soft and mine are cracked,
come on, give us a chance on air, let us… air the facts.

We've washed and shrouded people that we've never known,
pinned flowers to the sheet, told them they're still not alone.
Shown families to the faith room and watched them mourn their dead,
then got back to work, bathed patients, made beds.

Hindus, Muslims, Jews and Sikhs,
Christians and Buddhists and just people off the street:
we care for them all and we love what we do,
we don't want a medal, we just want to show you.
So, listen to us, hear us goddamn roar, you say we're not doing enough?
Then we promise, we'll do more.

We shall be holding our third Healthcare Champions Event in parliament before the end of the year where you have had the opportunity to nominate your healthcare professionals to receive the NRAS Healthcare Champions 2013 Award. I believe we have had lots of entries which will have been judged by the time you read this. It's always a great event and nice to have the opportunity to thank those healthcare professionals who have gone that extra mile for their patients. We are moving to a new, larger office (still in Maidenhead) in November. All our phone numbers will remain the same, just the address will change so bear with us during that period as moving premises is always disruptive. The new office will give us additional room to expand and improve internal interaction as we shall all be on one floor rather than split between two offices as we are currently.

With best wishes to all of you and I hope to see some of you at our Members' Day in September.

Ailsa

Farewell to Lindsey

We were very sad to say goodbye to Lindsey Hawley in June, who has retired from her role as a senior rheumatology practitioner at Christchurch Hospital and president of the BHPR Council. Lindsey has worked closely with NRAS and has always been an ardent supporter of the charity so we were delighted to be able to give her a wonderful send off at the East Dorset NRAS Group tea party in June where many of her patients gathered to say farewell. Lindsey very generously asked for no leaving presents but for all proceeds from the tea party to be given to NRAS as a donation and the fantastic total of £870 was raised. Thank you so much Lindsey and we wish her a very happy and fulfilled retirement.

Lindsey, Julie (group coordinator) and Val (NRAS events fundraiser)

Meet the team...*by the team*

Clare talks about Nicky

Nicky joined NRAS as a volunteer one day a week having retired as a rheumatology nurse specialist from Wexham Park Hospital where she'd first gotten to know Ailsa. I think the phrase "if you want something done ask a busy person" was coined especially for Nicky. Not content with filling her retirement with spearheading a village committee to establish a much needed shop in her community she soon took on a bigger role at NRAS too - the JIA scoping project. Both projects being dear to her heart demonstrate that here is a lady that gives 110% with a constant cheery smile she gets the job done. Retirement is so over-rated don't you think?

Ruth on Jilly

Jilly is a long serving member of the NRAS team and has been working hard under various roles at the charity for over 10 years! Currently our Helpline Information Assistant, she ensures that those who request information about RA safely receive their orders. In her spare time, Jilly is a leading figure in the local Grimm Players Theatre Company which has once again chosen NRAS as their Charity of the Year. Jilly recently organised their annual Grimmbourne Gala Concert which was a great success!

Jilly is a tremendously generous and thoughtful person. She always comes in with a smile and very often something sweet to revive us! This and her good humour make Jilly a treasured member of the NRAS team and she is a joy to work with!

Contents

Riding the ocean waves

Have you ever felt like your rheumatoid arthritis was limiting your choice of holidays? Have you ever wanted to throw yourself in to a life changing adventure but were worried about the limitations you may encounter? Perhaps you're anxious that you might not fit in? Fear not – a voyage with the Jubilee Sailing Trust (JST) could alleviate all of these reservations and worries.

JST aims to promote the integration of men and women of all physical abilities through the challenge and adventure of tall ship sailing. On board their two magnificent, fully accessible, tall ships – Lord Nelson and Tenacious – everybody gets the chance to participate in all aspects of running the ship. Since the charity's inception 35 years ago, their philosophy has been that life should be about equality, sharing and celebrating individual differences and working together to achieve greater things.

▲ **Tenacious at sea**

In the past 12 months 82 voyage berths have been by people with some form of arthritis, and these journeys have ranged from short coastal voyages lasting five days to epic ocean passages lasting 28 days or more. The aim is to take an equal mix of able bodied and physically disabled crew on each trip with a maximum of 40 people on each voyage.

Antony Murphy has lived with rheumatoid arthritis since a very young age and was 72 years old when he went sailing with JST on board Tenacious.

"I was one of only two crew members with significant disabilities and was pretty stretched during the rougher sections of the voyage. For this reason I was particularly aware of the good design of Tenacious, using the many handholds as needed and resorting to the lift when appropriate.

My watch leader kept an eye on me when I was near my limits whilst respecting my choice to push myself to those limits. He was also aware of the needs of the rest of the watch and sent them off watch when they needed a break.

The voyage was testing and pushed everybody to their personal limits. As a result, the level of bonding and mutual trust was brilliant. The bad weather was balanced by three perfect days out of Greece, an idyllic port in Gavrio, and good weather in France and Messina. The crew were always boosted by the amazing cooking of the galley crew.

I continue to trumpet the unique role of the JST as the most effective integrated sports venture available anywhere."

Aboard JST ships every crew member has a vital role to play irrespective of ability, disability, age or gender. The success of each voyage depends on teamwork and working to the best of individuals' strengths, not weaknesses. Crewing a tall ship can be a challenge for anyone but with teamwork and understanding this challenge can be met.

Tasks around the ship range from climbing the mast and steering the ship, to keeping watch and assisting in the kitchens whilst on galley duty. Each job or responsibility is valued equally in order to keep the ship running smoothly, so whatever your ability, JST will arrange that you get the most out of your voyage by participating in the tasks that are most suitable to you.

Climbing to the crow's nest

However, that shouldn't stop you from taking part in the more strenuous activities like climbing, steering or setting the sails. The ships are fully accessible to everyone, with lifts between decks, power assisted or joystick assisted steering to enable those with limited mobility to easily manoeuvre the ship and specialist equipment for assisted climbs. Even if you're in a wheelchair they'll get you up the mast... if that's what you want of course!

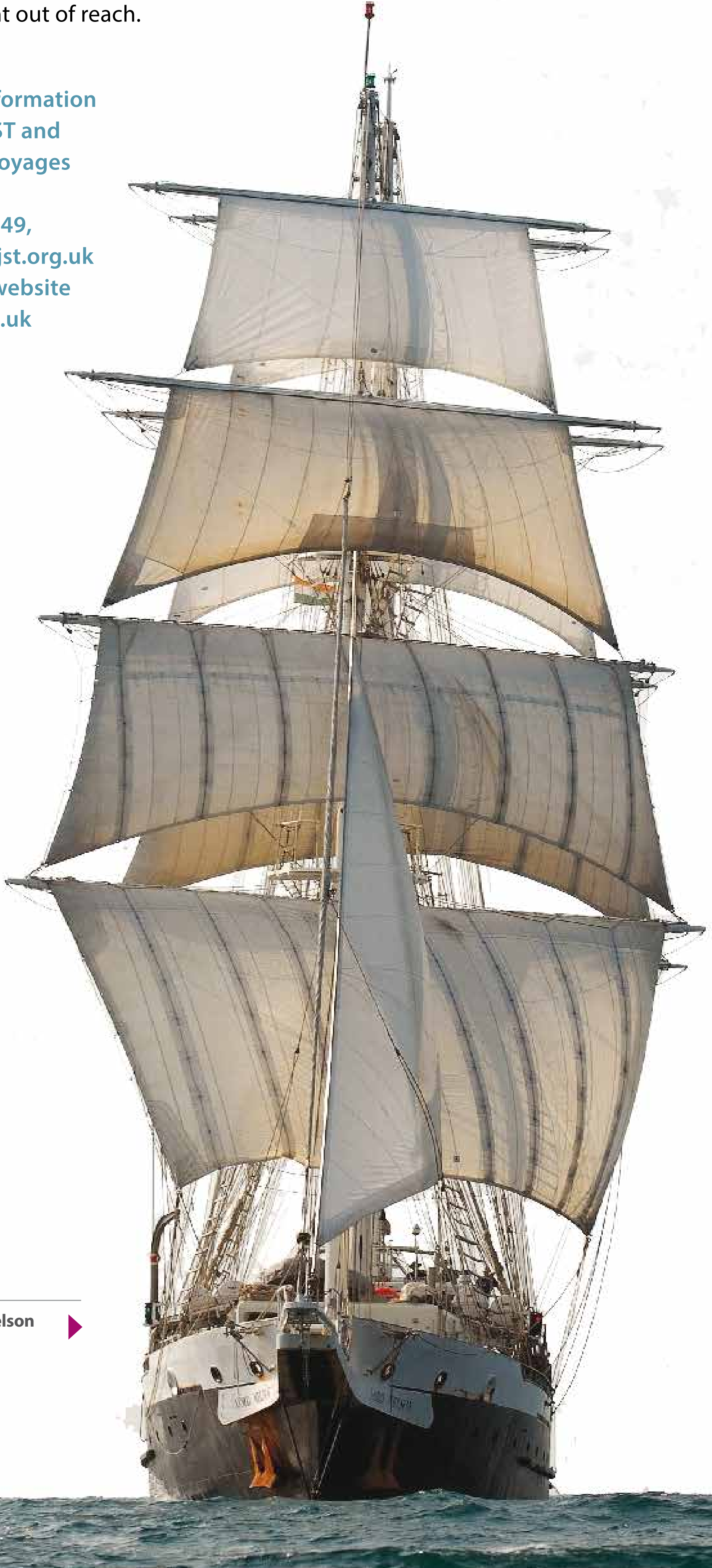
Both Lord Nelson and Tenacious are fully equipped with accessible accommodation. There are cabins suitable for the severity of your condition, for instance cabins with turning areas for wheelchair users. There are also walk in shower rooms and plenty of hand rails to facilitate easier movement around the ships.

The Jubillee Sailing Trust show that disability is no barrier to sailing

For most, sailing with the JST is a fantastic adventure holiday but for many it also represents a life changing experience, affording people the opportunity to rediscover a sense of independence and freedom that they may otherwise have thought out of reach.

For more information about the JST and upcoming voyages contact 023 8042 6849, email info@jst.org.uk or visit the website www.jst.org.uk

JUBILEE SAILING TRUST
changing lives



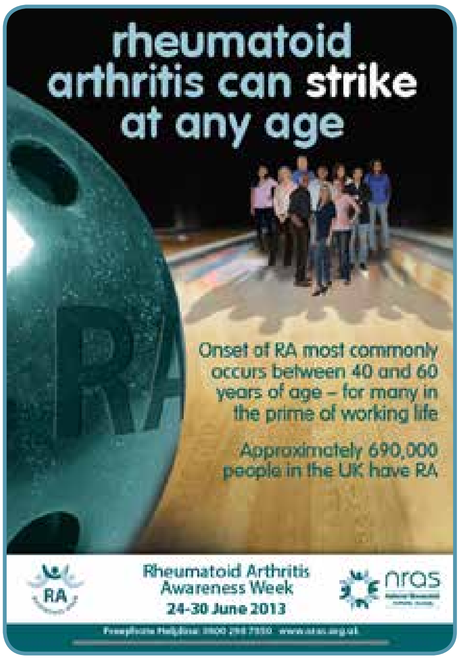
Lord Nelson

You may have heard us mention it before but the UK's first ever Rheumatoid Arthritis Awareness Week took place from the 24th to 30th of June and you can't have failed to notice the level of activity that was taking place during the week!

All over the country information stands and other awareness-raising events were held in public places by healthcare professionals and NRAS members to bring to peoples' attention a disease that is so misunderstood. Hopefully, during these events we managed to dispel a few of the myths that surround the disease. Certainly our mythbuster infographic was extremely popular and was shared across all our social networks, and many NRAS groups, rheumatology units and GP practices and other organisations were asking for copies of them as well as posters and publications so they could put them on display.

A Tea Party in Maidenhead

We never expect others to do what we don't do ourselves so of course we held our own Tea Party in Maidenhead (nothing to do with the fact that we all like cake)! We occupied a vacant unit in the main shopping centre and set up our own coffee shop for the day, complete with tombola and a mobile bowling alley to go with our 'strike any age' theme. Our founding Patron and the Rt Hon Theresa May MP attended, as did the Mayor of the Royal Borough of Windsor and Maidenhead Andrew Jenner.



We launched RA Awareness Week with a bowling evening in Slough (we felt this was quite appropriate as the theme for the week was that RA can strike at any age) and we had a terrific turnout with all the lanes taken.

As well as information stands we had several groups and individuals hosting NRAS Tea Parties, plus others hosting book sales, golf days, plant sales and bag packing. All these events provided an opportunity for us to raise awareness of RA in a slightly more informal manner.

NRAS would like to thank Co-operative Funeralcare in Windsor for their donations that helped support our events.

Back in Maidenhead, where NRAS is based, we held an information evening and expert panel discussion in the local RVS centre. At these events all over the UK people were engaging and showing a genuine interest in RA. Together we really have educated so many more people about this disease so let's hope that continues long into the future.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Arthritis


MALARIA


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nras
Rheumatoid


RA


London
MOSS

rheumatoid arthritis **facing the facts**

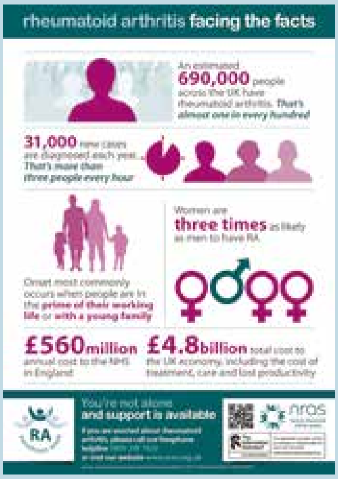
Myth: All types of arthritis are the same

Myth: RA is an old person's disease

Myth: RA is just a few achy joints

Myth: Nothing can be done to treat RA

You're not alone
and support is available



rheumatoid arthritis **facing the facts**

An estimated **690,000** people across the UK have rheumatoid arthritis. *That's almost one in every hundred*

31,000 new cases are diagnosed each year. *That's more than three people every hour*

Onset most commonly occurs when people are in **the prime of their working life** or **with a young family**

Women are **three times** as likely as men to have RA

£560million annual cost to the NHS in England

£4.8billion total cost to the UK economy, including the cost of treatment, care and lost productivity

You're not alone
and support is available

rheumatoid arthritis **facing the facts**

Emma was always active. She would go running in the evenings after work and played hockey at the weekends.

One morning, she woke up with stiffness in her joints and an intense pain in her hands. Her fingers also looked swollen.

The stiffness, pain, swelling and fatigue worsened over the months and Emma struggled at work. Eventually she could no longer cope, and was signed off sick.

After several visits to the doctor, Emma finally got a referral to a rheumatologist and a much needed diagnosis – rheumatoid arthritis. Now her treatment could begin.

Diagnosed at only 29 years old with a disease that many people assume to be for older people... Emma was still struggling come to terms with her diagnosis.

Thankfully, she called NRAS who were able to give her help and support when she needed it most.

You're not alone
and support is available

rheumatoid arthritis **facing the facts**

"There is increasing evidence that aggressive treatment very soon after onset of symptoms can lead to remission"

This same report noted that less than half of those with rheumatoid arthritis had visited their GP within the first three months of symptom onset

KNOW THE SYMPTOMS
& raise them with your doctor

Stiffness

Swelling

Squeezing

Greater Awareness

You're not alone
and support is available

On the social media front, we managed to reach out to a huge number of people and engage with them directly. Hundreds of people participated in our Thunderclap with our message for the week that RA can strike at any age being sent out by each person on Facebook and Twitter at the exact same time – 1pm on Monday 24th – reaching a total of 80,000 people. Across our social networks, thousands of messages were being shared using the hashtags #strikeanyage and #RAweek highlighting our messages for the week and profiling our four infographics and video that we produced.

The success of RA Awareness Week could not have been possible without the support of everyone who got involved. Whether you held an awareness event or a fundraising event, wrote to your MP or wrote to your local newspaper, shared information online or helped in any other way, your actions will have made a difference. If you've educated just one person about RA then that's a positive start.

Thank you for playing your part and we do hope you will join us again next year for RA Awareness Week 2014. This will take place between the 16th and 22nd June so please make sure you put the date in your diary.

JIA at NRAS

JIA

A Focus on Juvenile Idiopathic Arthritis

Our report on services for JIA in the UK has now been published and will shortly be available to download. The aim of the project has been to map as wide a selection of current service models across the UK as possible, to identify unmet need in service provision and document examples of gold standard care and good practice in accordance with ARMA/BSPAR Standards of Care. We also wanted to be able to identify challenges, opportunities and barriers to improving care for families, adolescents and young people transitioning into adult care and to establish how NRAS could add value by providing services where unmet need exists. This is the first time such a comprehensive study has been carried out.

The advice and recommendations gathered from meeting with healthcare professionals, families and young people will now form the basis of our business plan for how we proceed with the goal of developing 'JIA at NRAS' to make a positive difference to the lives of all those affected by JIA and to support the healthcare professionals who care for them.

At last I'm officially disabled

By Clare Cochrane

I have now officially become disabled – I have finally been awarded the Disability Living Allowance. In the letter that confirmed it, I was told I would get the lowest care rate because I can't cook a meal for myself without help.

I don't qualify for the mobility component because I can still get about on my own, albeit at my own pace, ie slowly. Never mind that my difficulties with mobility mean that it costs me more than a non disabled person to lead a life that has both paid work and fun in it, and that the amount of paid work I can do is less than that of a non disabled person. These are things that DLA does not take into account, which is fine, except that there isn't any other scheme to help with living costs that do take these things into account. But that's a campaign for another day!

Anyway, it was a victory – of sorts. It's also an odd thing to be glad about – finally becoming 'crip' enough to qualify for assistance. You'd think that after 20 years I'd be used to the idea that I need help, that I'm not as able as people without a chronic disabling disease, but I still had an emotional reaction.

More recently I finally passed another test. Through a high enough Disease Activity Score and an x-ray displaying the crumbling of my wrist and knuckle joints in irrefutable black and white, I qualified for anti-TNF drugs. It provided another occasion for a little cry, as I faced what my housemate (who has MS) calls "another diagnostic threshold." Another milestone in the biography of my RA.

It had been my second attempt to apply for DLA. I had applied at the beginning of 2012, but was turned down and I found the whole thing so demoralising that I didn't appeal it or even ask for a reconsideration. For one thing, the form is all about detailing everything you can't do when you spend so much of your time trying to stay positive and focus on what you can do. Then there's the confusing and upsetting process of measuring my levels of impairment using their criteria – which don't necessarily reflect the reality of my life. My idea of leisure activities and the way I socialise – which the form asks about – are outdoor environmental activities and permaculture projects, but they won't consider having difficulties 'gardening' when making an award. They won't even consider difficulty with shopping!

Clare Cochrane exploring the environment

I applied for a second time in January this year. I really wanted to make sure that, even if I was refused, I'd be 'in the system' before PIP came in, so that I could get advice from others as I went through a reconsideration or appeal process. I got advice from a friend with many years of experience in dealing with DLA, Incapacity Benefit, and now ESA, who suggested I photocopy my form before posting it. This made all the difference. When I got the refusal letter, with a list of bullet point reasons why I wasn't awarded DLA. I was able write back and refute each bullet point with the page number and question number on the original form where I had, in fact, detailed an inability or impairment.

I don't know how PIP is going to work, but I am absolutely certain that what will make a difference is getting the best, most practical advice you can. This can be from an advice service, a friend who has been through this, or through experience of a similar bureaucratic process. If you have an interview or an assessment, take a friend with you who can take notes of any questions you're asked and the answers you give, and take notes of any phone conversations you have. As I found out, if you do have to appeal then being able to refer to your original statement could make all the difference. Last summer my rheumatoid arthritis turned 20 meaning I've now lived longer with RA than I did without it. This was perhaps the biggest milestone of all. Getting the official seal of 'cripness' wasn't nearly as big a deal as that!

Dear Helpline
I have recently been diagnosed with rheumatoid arthritis and my consultant wants me to take three disease modifying anti-rheumatic drugs (DMARDs). Is this normal? Will I always be on this much medication?

Although not everyone will start on multiple medications when they are first diagnosed and treated, it is not uncommon and is recommended in the National Institute for Health and Care Excellence (NICE) guidelines.

Getting early effective treatment is recognised as being the best way to get the best outcomes for patients and starting newly diagnosed patients on combination therapy (where more than one DMARD is prescribed at the same time, usually with short term steroids) has been shown in research to be more effective in getting the disease under control than just using the drugs individually. Research has also shown that combination therapy does not cause any more side effects than if an individual drug is used on its own. If this therapy works well, it may be possible to reduce or stop one of the medications.

Helpline: 0800 2987650
helpline@nras.org.uk

Combination therapy usually consists of methotrexate and one or two other DMARDs, as recommended in the NICE guidelines. The other DMARDs are usually sulfasalazine and/or hydroxychloroquine. Steroids will often also be used at this early stage, by injection into muscle or joint or in tablet form.

For more information on combination therapy, please see our article on this subject on the NRAS website or call to request a printout.

Dear Helpline
A friend has suggested that I apply for a benefit called PIP. Will I be entitled to claim this if I have rheumatoid arthritis? I have never considered claiming benefits before and don't know where to get started!

PIP stands for 'Personal Independence Payment' and it replaces a benefit called Disability Living Allowance (DLA). Those already in receipt of DLA will continue to receive this benefit until they are requested to apply for PIP which will happen over the next few years. Those who were 65 or over in April 2013 and already in receipt of DLA may continue to receive this benefit as long as they continue to meet the entitlement conditions. Children with disabilities can also still claim DLA until the age of 16. From June 2013 all new claimants must now apply for PIP rather than DLA. The entitlement conditions for PIP are very different from those used for DLA.

The idea behind PIP, as with its predecessor, is that it acknowledges that people living with a disability will often have additional costs in their lives, such as needing to pay for a taxi if they are unable to walk somewhere, paying for someone to help with cooking or with dressing and bathing. It is up to the individual how the benefit money is spent and, as it is not means tested and it does not matter if he/she is working or not.

There is no automatic entitlement to PIP if you have RA. You will be assessed as part of the application process to determine how the RA affects the way in which you are able to look after yourself and your ability to get around. PIP is separated into 2 components: the 'daily living component' and the 'mobility component'. You might be eligible for one or both of these at a 'standard' or 'enhanced' rate, depending on how your condition affects you.

To help guide you through the process, from understanding whether or not you might be entitled to this benefit, to completing the claim forms, NRAS has produced a guide to Personal Independence Payments, which has been written for us by Disability Rights UK.

If you would like to order a copy of the PIP booklet, or our recently updated Benefits and RA booklet, you can do so on the NRAS website www.nras.org.uk or by calling the office on 0845 458 3969.

Roll up! Roll up! The RA rollercoaster is in town!

By Julie Black

In April 2011, I was a 48 year old woman, getting on with everyday life, but then it was my turn to get on the RA rollercoaster, and what a ride it is!

Life is painful and scary when you first get on; you have no idea what's ahead, the twists and turns, highs and lows, ups and downs. You have no idea who will get on with you and of course who will decide to get off. Once on, I realised I could not get off; this is a ride I am on for life.

Two years on, the ride has been a mixture of lows with the occasional high. My RA is not yet fully under control. The inflammation, due to a cocktail of drugs and infusions is better, but as I found out in July, the disease is still very active in my legs. Thank goodness you can sit down on this ride because standing and walking is very painful and difficult at the moment.

My life has changed drastically and the rollercoaster has turned it upside down. But even though there are many times when I want my old life back, the ride has brought in so much good, laughter and love. My body may be failing but my eyes see things in a new, much clearer way. Things and people you thought were important to you no longer are and they can fade away or are left on the sidelines. It's the people who get on with you and stay on with you all the way who matter – family, friends, doctors, nurses, NRAS and even strangers.

It is for that reason that I decided to do something to say thank you and show that you cannot give in to this life changing disease. I had always loved swimming but am no longer the strong swimmer I used to be due to my painful and bent legs. I got off the rollercoaster for one day to swim a mile and raise awareness of RA, as well as funds for NRAS, during their first ever RA Awareness Week. My lovely sisters Allie and Margaret were in the pool with me. Allie swam a mile too and Margaret was there to massage my shoulders and legs to keep me going. Family and friends watched from the sides and in total we raised £1000! Their support was amazing and it was a fantastic, although exhausting day … Allie and Boo's 's-mile' for NRAS... we did it!

▲ Alie and Julie (Boo) after their swim

I am now back on the rollercoaster with new challenges ahead, a new knee, new meds and a new me yet again to face the world. I know there will be many more lows but I also look forward to many more highs and hopefully some settled times in between.

I once read "Step out of the nightmare and pain, wake up and live and love. Start up your heart and living again, it's all good…"

Thanks again to all who are with me now on my rollercoaster, supporting me. Keep smiling and let's try to enjoy the ride!

**** A special thank you to South Charnwood Leisure Centre for the use of their pool and their support doing our swim.***

EULAR 2013 – Madrid

By Ailsa Bosworth

NRAS had a team of five people at the European League Against Rheumatism (EULAR) congress in Madrid this year which is the most significant investment we have ever made in this important European congress. We had submitted five abstracts and all had been accepted; three as posters and two as oral presentations.

As always with this congress, there are more sessions you want to go to than you are able to attend as important meetings with colleagues, partners and other European patient organisations intrude on your desired congress schedule. Having a team of people there did however enable us to cover different sessions to ensure that we gained maximum benefit from attending.

On Thursday I attended a PARE session entitled 'Rebranding rheumatic and musculoskeletal diseases – what is so special about RMDs?' I particularly wanted to hear John Church from Arthritis Ireland who was talking about 'Tackling the image issue of RMDs through marketing' as we have similar ideas when it comes to marketing. Unfortunately, I missed most of his presentation but was able to speak to him separately and see his computer generated imagery (CGI) advertisement about arthritis which is running on Irish TV now. Karim Raza (Birmingham City Hospital, UK) also spoke in this joint session on 'Delays in help seeking and referral: problems and potential solutions in the context of inflammatory arthritis'. This was another subject of great interest to us, particularly in the context of our first RA Awareness Week on the 28th June and the report we had published just a few days earlier called 'Breaking Down Barriers' about public awareness (or lack of it!) in regard to RA and its early signs and symptoms. Karim presented data from Birmingham City Hospital, demonstrating that one third of patients who are diagnosed with RA get treated within the 12 week 'window of opportunity'. They held a focus group of 19 GPs who agreed that there was a need for early intervention and to raise public awareness. Another key session I attended on the Thursday was a Joint Clinical/HPR/PARE Session entitled *'The concept of health in rheumatic disease: the ability to adapt and self-manage'.* Sarah Collins was speaking at this session in a talk entitled *'How can I still be me'*. Sarah authored our latest publication on *'Emotions, Relationships and Sexuality'* so this made her well suited to talk on this subject. I first heard Sarah speak at the BSR conference in Brighton two years ago and she made me cry then too. She has a really insightful way of describing the impact of living with RA which always has the audience completely absorbed.

The symposium attended that evening was on the subject of 'our goal should always be remission or low disease activity' and included the familiar subjects of treat to target strategies and tight disease control. There was a lot of discussion about the redefinition of DAS remission and a recommendation that the Simplified Disease Activity Index (SDAI) or Clinical Disease Activity Index (CDAI) might be better instruments than DAS 28, which remains the most extensively validated activity index for RA. A paper entitled *'The Simplified Disease Activity Index (SDAI) and the Clinical Disease Activity Index (CDAI): A review of their usefulness and validity in rheumatoid arthritis'* by Daniel Aletaha and Joseph Smolen explains that the greatest advantage associated with the CDAI is its potential to be employed in the evaluation of patients with RA consistently, with close frequency, and independently of any calculating device, since it can essentially be evaluated everywhere and anytime, in particular for use in day to day clinical practice. Use of these new indices could contribute new views and create new options to satisfy the calls for more comprehensible indices, both for physicians and patients, and for tools that will allow immediate treatment decisions without being solely based on self-reporting. In addition, the better understanding of the scores by the patients could contribute to improving outcomes, which makes the simple SDAI and CDAI potentially useful not only for evaluation, but also for improving outcomes. Such scores will allow physicians to encourage their patients to keep track of their 'index'. The paper concludes that this brief and clear message to the patients may also ensure better consistency in evaluations, since patients could ask for their 'actual' index value regardless of who their personal physician is, just as patients with diabetes usually want to know their HbA1c results.

On the Friday morning I presented on work we had done looking at what remission means to RA patients which was reported in the EULAR daily news magazine. To understand how patients envisage remission, to learn how clinicians are communicating about it and to help both clinicians and patients better define remission goals, NRAS convened a focus group and drafted a 34 question patient survey to discern what was happening in clinics across the UK. The survey drew over 1100 responses and key findings included:

- Half of the participants had not discussed remission with their healthcare team
- 9 out of 10 were unaware of what constitutes clinical remission in RA
- Three quarters did not share goals with clinicians and half were sceptical or uncertain as to whether such goals even mattered to their doctors

I attended a Chief Executives' Meeting on Friday – this is a forum within EULAR PARE that is relatively new and enables the CEOs of the larger patient organisations in Europe to meet and discuss areas of common interest. This followed an earlier meeting in March of this group in Brussels.

I chaired a session on Friday afternoon with Phil Connaghan (Leeds) who gave an excellent presentation on osteoarthritis that was immensely interesting, followed by Dr Laure Gossec (Universite Pierre et Marie Curie and Hopital Pitie-Salpetriere, Paris) who gave an update on biologic therapies and some of the newer agents in the pipeline which was also very informative and gave the patient organisations in the audience confidence and hope for treatments to tackle unmet needs as there are lots of therapies coming through.

The final symposium I attended on Friday evening, chaired by Prof John Isaacs, was titled *'Different needs, different options: Clinical challenges and considerations in tailoring RA treatments to patients'.* Speakers included familiar faces such as Maya Buch (Leeds), and Andrew Oster (Addenbrookes) and included the subject of medication non adherence in RA, including available data on prevalence, contributing factors and impact on clinical outcomes. This is an important subject and one which we are currently doing research on ourselves, as not taking medication does impact on patient outcomes and I don't think that there is enough information about this.

All in all it was a very good week and I know that my NRAS colleagues and I have all brought back additional knowledge and insights which will help us to continue to provide the most up to date and relevant information to people contacting the charity.

EULAR Edgar Stene Prize Competition 2014

NRAS is pleased to support the Edgar Stene Prize Competition 2014. At the opening ceremony of the forthcoming European Congress of Rheumatology in Paris, France, on the 11th June 2014, the Edgar Stene Prize will be awarded for the essay topic:

"Vision 2043 – my ideal world for people with a rheumatic or musculoskeletal disease"

EULAR would like to invite people with rheumatic and musculoskeletal diseases (RMDs) to write about changes they would like to see to improve their lives and to create a better world for people with RMDs in the future. These changes could include social attitudes, health and social care, the environment, travel and work opportunities. Some changes will take longer to come about than others, so EULAR have set the deadline for their vision for a better future in the year 2043. We hope this competition will provide many inspiring visions for what life could look like for people with rheumatic and musculoskeletal diseases by 2043.

Last year, NRAS Member Caroline Howson was chosen as the UK entry and, although she was not the overall winner, as a finalist her essay was included in the Stene Prize Booklet 2013. Caroline wrote, *"I have always enjoyed writing and, since diagnosis, have found myself with more time for this. I hope that by sharing our experiences we can benefit from the stories of others."* You can read her essay and lots of other personal stories on our website.

▲ Caroline Howson

Entrants should submit an essay not exceeding two pages (A4) to NRAS by the 31st December 2013 by emailing lorraine@nras.org.uk or by posting their essay to:

NRAS, Unit B4, Westacott Business Centre, Westacott Way, Littlewick Green, Maidenhead SL6 3RT

Entrants must be age 16 years or over to participate and each national jury will nominate the best entry from their country. A EULAR jury will select the 2014 overall Stene Prize winner, and this will be announced by the 15th March 2014.

In addition to the prize of €2,000, EULAR provides the recipient with travel to Paris and hotel accommodation in Paris for up to 4 nights as well as an invitation to attend the opening ceremony and the gala dinner at the EULAR Congress.

A more detailed outline of the rules can be found on the EULAR website.

The Edgar Stene Prize Jury 2013 is looking forward to receiving many entries from all over Europe so good luck!

New version of the Health Unlocked community launched in July

Discover your health

Ask questions, get answers, advice and support from hundreds of health communities

HealthUnlocked recently launched an upgrade to their health forums, which includes the rheumatoid arthritis forum on the site which NRAS moderates. HealthUnlocked have worked hard on this upgrade for many months now, in order to make a community that could handle the huge increase in traffic to the site, and offer new and improved features based on feedback from the forum users.

Those of you who use the community will know that this launch did not happen without a hitch and we're really sorry for the problems this caused. However, when all the initial bugs have been ironed out we anticipate a much improved community. Some of the new features you will see include:

- Larger images on posts
- A newsfeed, showing the latest comments on posts and questions
- Automatic 'tagging' of posts, to give people a better idea of which topics are covered in each post
- A 'recommend' button, to help highlight particularly useful posts, questions and responses

As a further development in the future, categories will be created to help you find the most suitable place for your post. Please note that the web address for our community on HealthUnlocked has also changed and is now **www.healthunlocked.com/nras**

Join the Fight

NRAS and Arthritis Care were delighted to be part of a recent AbbVie project, 'Join the Fight', to better understand patients' perceptions of their RA disease management. The campaign announced the findings of a global survey of RA patients which showed that almost two thirds of UK patients did not feel their RA was well managed compared to over 50% of patients globally and only 26% of patients in the UK said they had a disease management plan in place compared to 56% worldwide.

The survey prompted calls for increased collaboration between doctors and patients by encouraging patients to take the pledge to start a conversation with their healthcare professional and collaborate with them to develop a plan to best manage their disease. The findings were launched at the start of EULAR in June and followed up with a radio day at the start of RA Awareness Week which featured Ailsa being interviewed on a number of local radio stations. You can 'Join the Fight' by giving your support at www.RAJointheFight.com to pledge to start that important conversation.

NICE quality standard

I'm sure it was just coincidence but during our RA Awareness Week we were delighted to welcome the publication of a new Quality Standard for RA by the National Institute for Health and Care Excellence (NICE). The Quality Standard will enable providers and commissioners to ensure that high quality care can be delivered, measured and benchmarked against nationally achieved standards.

NICE Quality Standards draw on existing guidelines to identify priority areas for improvement in a particular care or service area and consist of a prioritised set of specific, concise and measurable statements. This new standard is the result of much work and ongoing discussion between NICE and health professional representatives of the full rheumatology multi disciplinary team, including NRAS, which provided detailed lay input as part of the Topic Expert Group who have been working with NICE on this Standard for the last 12 months.

The Quality Standard for RA provides seven quality statements that, if implemented, will provide a patient centred approach to provision of services and the delivery of high quality care to those with the disease and those presenting with early signs and symptoms which may develop into RA. The seven quality statements are:

- People with suspected persistent synovitis affecting the small joints of the hands or feet, or more than one joint, are referred to a rheumatology service within three working days of presentation
- People with suspected persistent synovitis are assessed in a rheumatology service within three weeks of referral
- People with newly diagnosed rheumatoid arthritis are offered short term glucocorticoids and a combination of disease modifying anti rheumatic drugs by a rheumatology service within six weeks of referral
- People with rheumatoid arthritis are offered educational and self management activities within one month of diagnosis
- People who have active rheumatoid arthritis are offered monthly treatment escalation until the disease is controlled to an agreed low disease activity target
- People with rheumatoid arthritis and disease flares or possible drug related side effects receive advice within one working day of contacting the rheumatology service
- People with rheumatoid arthritis have a comprehensive annual review that is coordinated by the rheumatology service

You may wish to measure how your access to rheumatology care measures up to the above Quality Standard statements.

Why as RA patients we've got to keep talking

By Miriam Rivas-Aguilar

Being a patient often means we are prodded and poked, whilst not being entirely sure what is going on, before finally we go home and perhaps tell our story of what happened to our friends and family and decide then what we think about our experience. We don't often speak up to the hospital staff themselves either with questions or with feedback, but if we don't, then how will the staff know what we really need, and if they are getting it right or not? That's where Patient Opinion comes in.

Patient Opinion is an independent not for profit online service that is a go-between, encouraging people to share their stories anonymously about their NHS experience. Patient Opinion makes sure the story is heard by the right people within the health service so they can respond and make improvements to services.

I am one of the team that runs Patient Opinion, and I have always believed in the importance for patients to share their experiences with the NHS, both good and bad. This was really brought home to me when I was diagnosed with rheumatoid arthritis about 18 months ago.

At first my focus was naturally on how I was doing physically, slowly accepting the diagnosis (it took me a while!) and decisions about my treatment. I felt worried about the future with a long term condition and the effect this would have on life as I knew it. I also realised that I needed to tell the staff how much I appreciated their kindness and compassion at times when I was at my lowest and having a flare up – or as it was nicely put – when I was 'in trouble'.

I wanted them to know how much I valued the helpline where I got to speak to a specialist nurse when the tone of her understanding, sound advice and caring attitude moved me to tears at times, and who later followed up with me in clinic; how much I appreciated the consultant calling me at home and slotting me in his clinic when there wasn't an appointment available; the nurses who took my bloods, and at times gave me treatment and the time they all took to answer my questions, even at busy clinic times.

▲ **Miriam Rivas-Aguilar, Guy Brookes and Hilary**

They could have dealt with me in a much more routine way, but by making sure I was listened to and cared for, they made a tough experience so much easier. It was important that they knew what worked so well for me and to keep on doing it. I am, however, all too aware that this is not everyone's experience of services.

We hear stories where things need to be improved, and the importance of telling these stories is never more celebrated then when we see a change in the service as a result of the story. This was the case for Hilary who said: *"My mum, who is in her 90s, was on a geriatric ward where there were no patient phones. I bought her a mobile but there was no signal. I was very frustrated at not being able to talk to her to see how she was or even to tell her when I was coming. So I told my story. I got a message from the hospital saying that they had put a portable phone on her ward that day."*

We've built strong relationships with the health services and worked with them on the value of patient stories, both good and bad. Guy Brookes, Associate Medical Director for Adult Mental Health Services in Leeds, said:
"When I hear the stories from Patient Opinion I am reminded that, though we build our services to be responsive to people's needs, this does not always work for everyone. For me, having that direct contact with people who tell their story provides a lot of detail. It becomes a constructive and collaborative process. It's not about having all the answers all the time but rather about working together on understanding the issues and finding solutions."

Patient Opinion and NRAS

Patient Opinion has teamed up with NRAS to enable you to share your views and experiences of your local RA services. If you're a patient, carer, family member or friend, we'd like to hear from you. Whether you feel there could be vital improvements at your local hospital or you want to say thank you to the staff who treated you, this is your opportunity to share your thoughts with the people that can make a difference to how your local services are delivered. As with all long term conditions, we will encounter these services time and time again – each visit is a separate story of the wider picture of our care.

Patient Opinion aims to make it very quick, easy and safe for people to anonymously share their stories, for NHS staff to be able to read and respond to them, and make changes in their services.

Share your story and help improve services

You can either share your story on the website by filling in a simple form on the NRAS website, or you can talk to a member of the Patient Opinion team on the phone on 0800 122 31 35. For more information about how your story is handled, visit **www.patientopinion.org.uk**

Simple Tasks: a new campaign to raise awareness of rheumatic conditions

The British Society for Rheumatology (BSR) will be launching a new campaign called Simple Tasks during World Bone and Joint Week this October.

Simple Tasks points out that 'the simplest tasks can be impossible for people with rheumatic conditions.' The campaign aims to make more people aware of the wide range of arthritic disorders, the work of rheumatology health professionals, and to increase support for policy that benefits people with rheumatic conditions. Appropriate and timely referrals to rheumatologists, and understanding the importance of rheumatology, will help more people with rheumatic conditions to be treated within the window of opportunity – the first weeks and months after their symptoms start.

BSR are asking for help:

If you're on Twitter, please email policy@rheumatology.org.uk to get the Thunderclap link for a mass campaign tweet. Follow and contribute to the campaign using the hashtag #SimpleTasksUK

Share the website www.simpletasks.org.uk and like the campaign on the British Society for Rheumatology's Facebook page **www.facebook.com/rheumUK**

If you have RA, would you be prepared to let them write about you? Let NRAS know by emailing media@nras.org.uk

"Over one million people in the UK are living with rheumatic diseases, yet many of the policy makers who make decisions that affect patient care don't fully appreciate the scale and severity of these conditions," said BSR spokesman Professor Simon Bowman. *"In addition, they may not be equipped with enough information about the critical role rheumatology services play in providing cost effective and clinically proven care for patients with arthritis and musculoskeletal diseases. We hope this campaign will encourage commissioners across the UK to support multidisciplinary rheumatology teams, and increase the chances of early diagnosis and treatment for patients."*

Simple Tasks was developed by the American College of Rheumatology (ACR) and it has substantially raised the profile of rheumatic conditions in the USA. The British Society for Rheumatology has started with a Sky Sports poster encouraging the public to visit www.simpletasks.org.uk to find out all about the campaign.

Key campaign messages include:

Rheumatic diseases are not just 'aches and pains' and are not a normal part of ageing. They strike children and adults of all ages, but most often strike in the prime of life – and they can be crippling, life changing and life threatening.

The first weeks and months after symptoms begin are a 'window of opportunity'. If patients get appropriate treatment in that time period they can avoid long term complications. Early treatment can prevent damage to joints and other organs and make it more likely that patients will achieve remission.

Over one million people in the UK are living with inflammatory arthritis. One in 12 women will develop a rheumatic condition during her lifetime.

The estimated cost to the UK economy of sick leave and work related disability for people with rheumatoid arthritis is £1.8 billion a year. When appropriate treatment is started early, medical costs, disability and work limitations due to rheumatic conditions can all be reduced.

The experiences of patients and their loved ones are very powerful in communicating the personal impacts of rheumatic conditions and highlighting the need for effective rheumatology services. Share your story as one of the Simple Tasks patient profiles.

Paula's story

Paula has a complex set of symptoms which have made it hard for her condition to be diagnosed and treated. She had to give up the secretarial job she loved when she was only 25 because of pain and swelling in her fingers, wrists and shoulders. Most of the drugs she has tried over the past ten years have had severe side effects, including vomiting, diarrhoea and pain, and she usually has to use a crutch to walk.

Although her swollen fingers distress her – she can't wear rings any more – she tries hard to look the bright side. *"I believe that what doesn't kill you makes you stronger – I no longer complain when I am in pain. I have overcome my fear of needles and decided it is time that I learnt to drive."* Paula feels strongly that the general public believes that "only the elderly get arthritis" and has no understanding of how the different types of autoimmune diseases affect people. *"My friends couldn't understand why it would stop me from being able to cook or wear high heels,"* she says. *"It's taken time for them to realise that some people suffer with invisible disabilities."*

Has your consultant recently started treating you with one of these ‘biologic’ drugs?

Etanercept (Enbrel)	Adalimumab (Humira)	Infliximab (Remicade)	Certolizumab pegol (Cimzia)	Tocilizumab (RoActemra)

If so, you could help research into the safety and effectiveness of these drugs by ensuring that your consultant has enrolled you on the Biologics Register for rheumatoid arthritis patients set up by the British Society for Rheumatology.

As you probably know, most people with RA begin their treatment with disease modifying anti-rheumatic drugs (DMARDs) plus anti inflammatory medication. But if your condition hasn’t improved enough on DMARDs alone, one of the above ‘biologic’ drugs may be tried in combination with a DMARD, usually methotrexate. ‘Biologics’ work by targeting particular proteins involved in the body’s autoimmune response, and are given either by intravenous drip or by an injection under the skin.

Biologics were introduced in the late 1990’s and have revolutionised the treatment of autoimmune inflammatory diseases, however they don’t work for everyone. The use and effects of these drugs are being carefully monitored by the British Society for Rheumatology’s RA Biologics Register (BSRBR-RA, based in the University of Manchester) which registers and follows the progress of patients from all over the UK. As part of routine clinical care, consultant rheumatologists are encouraged to register any patient when they start a ‘biologic’ treatment, with their consent of course.

However, sometimes patients are not approached to enrol in this study, and to be included, patients need to be registered within the first six months of first being given these drugs. Once a person has been registered, six monthly or annual questionnaires are sent to them and to their consultants to track their health over the long term (minimum five years).

The Register isn’t just of interest to researchers, it also can teach doctors and patients more about these drugs as well. By bringing together data on large numbers of patients who are receiving these drugs, researchers can look for patterns to identify certain problems which may arise.

This information can improve rheumatologists’ understanding of the best and most effective ways to use the drugs, provide information which may influence if patients should stay on their treatment and also provide better information for future people who are considering starting these treatments. Because it brings together data on large numbers of people who are taking a particular drug, it may also encourage further research and development by the pharmaceutical companies If so, you could help research into the safety and effectiveness of these drugs by ensuring that your consultant has enrolled you on the Biologics Register for rheumatoid arthritis patients set up by the British Society for Rheumatology.

The Register produces ‘real world’ population level data on large numbers of people, which can be much more valuable than clinical trials which tend to exclude many patients and often only monitor the short term use (months rather than years) in a small numbers of patients.

So if you have begun treatment with one of the above drugs within the last six months, or your consultant is proposing to start you on treatment soon, please do ask them, or your specialist nurse, about enrolling you on the BSRBR-RA Biologics Register. If you or they would like more information about the Register, just visit www.rheumatology.org.uk/bsrbr

10 things every rheumatoid arthritis patient should know

By Mia James

This article appeared on the RA Connection website and, although written for an American audience, there are many points that are relevant to the UK.

One

Find a healthcare team you trust. With any chronic disease, your healthcare providers become your long term partners in managing your health, so find a team you trust. Kelly Young, founder of the website rawarrior.com, says that other patients can be helpful when you're searching for providers. Local advocacy and support groups may be able to help you find other patients in your area. Kelly recommends asking another provider with whom you have a good relationship to recommend additional specialists.

Two

Be comfortable asking questions. When it comes to your health, no question is too basic. Find doctors and other healthcare providers who listen to your questions and offer thoughtful answers. Kelly says that open communication between you and your doctor is a good sign that he or she is listening. For example, *"You'll know they're being open with you if you can have a copy of the doctor's notes,"* she says. Kelly also encourages patients to discuss all issues. She explains that when you're managing RA, you may have many health concerns and it's important that they're addressed. Make a list of what you want to discuss during appointments so that nothing is left out.

Three

You're not alone. A community of other people living with RA can be a source of comfort, support, and education. In-person support groups and online communities can help you connect with others facing similar challenges. As well, Kelly says that living with chronic disease can stress personal relationships. *"The people around you can have a hard time understanding if they're not living with [chronic disease],"* she says. *"It can take some of the stress off those relationships if you have someone who you can talk to and let it out, someone who understands, who's going through it too."*

Four

Understand that RA is more than a joint disorder. Because of the term arthritis, you may be prepared for RA to affect your joints. But be aware that RA is actually a systemic autoimmune disease that can affect a number of organs, including the eyes, heart, skin, and lungs. Kelly says that you can keep track of multiple symptoms by keeping a journal and taking care to report anything unusual.

Five

Know where to find reliable information. Accurate information about RA and available treatments will help you make informed decisions about your care. She recommends looking for resources that provide current, updated content and quote their sources. Be wary, she says, of websites and organisations making claims that sound too good to be true, such as claims to have found a cure for RA or one remedy for all symptoms.

Six

Educate yourself about the disease. Reach out to other patients through support groups, online forum series, and blogs to learn what others experience, and seek information from trusted medical sources. *"Don't expect every symptom that others experience,"* Kelly says, *"and take one symptom at a time if it comes."*

Seven

Keep a record of your symptoms and any triggers that seem to make them worse. A written record of your symptoms and any side effects of medication can help you recognise patterns, such as events that make the symptoms worse, behaviours that make you feel better, and reactions to drugs. This information can help you and your doctors choose treatments and help you avoid triggers that make symptoms worse.

Eight

Be prepared for others not to understand what you're going through. Many people may not understand RA and how it affects you, and because you may appear perfectly healthy, they may not understand the severity of the disease. Kelly recommends preparing yourself by realising that people won't always understand that you have limitations. With this in mind, ask for help when you need it and know that you may have to explain your condition.

Nine

You can live a full, active life with RA. There are a lot of resources available to help you live and thrive after a diagnosis of RA. Learn about the disease, work with your medical team to get appropriate care, and seek support. *"We need to accept that we might not do everything we did before,"* Kelly says, *"but we might be able to do some of those things."* And, she explains, some days will be better than others. Surround yourself with people who understand the challenges you face and encourage you to care for yourself; these friends and loved ones will help you cope with the 'down' days and celebrate the 'up' days.

Ten

Research is making important advances. According to Eric Matteson MD, chair of the rheumatology department at the Mayo Clinic in Rochester, Minnesota, there have been significant advances in RA research in the past 15 years. Treatment advances include drugs that more effectively control symptoms than did previous therapies. And he says that the search continues for even more effective drugs. "We're making huge progress," he says.

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Patients in Focus Awards 2013

The NRAS Patients in Focus Awards, now in their 11th year, were introduced to highlight the good work that goes on in rheumatology units throughout the UK that is of great benefit to patients with RA.

Several very interesting entries were received this year and the winners awarded their prizes at the British Society for Rheumatology Annual Conference in Birmingham in April. The overall winning entry was received from a team at the Derby Royal Infirmary.

Sue Kennedy (Senior Physiotherapist in Education and Rheumatology), Anne Hardy (Clinical Lead Rheumatology) and Ruth Machej (Senior Physiotherapist Rheumatology) decided to look at the negative effects that having RA can have both on the body and the mind and researched how, with better management of the disease, more people could participate in high intensity, progressive strength training programmes not commonly offered to RA patients. The team undertook a literature review to explore these topics and to identify whether they should be changing how they deliver exercise training in the outpatient department. The results from the literature review led to the development of a Progressive Resistance Training Programme (PRTP) for patients with RA, based in the outpatient physiotherapy gym.

Patients complaining of muscle weakness, functional deficits and/or reduced exercise capacity, or those wishing to gain a better understanding of what exercises they can safely undertake, are referred to the class. All patients undergo a full physiotherapy assessment prior to enrolment in the PRTP to assess for patient specific biopsychosocial problems, contraindications to exercise and readiness for participation in exercise. Patient specific goals are agreed with the patient. The patient's baseline strength measurements are assessed and a working weight calculated based on best practice advice and the research literature. The PRTP takes place at the physiotherapy outpatient gymnasium within the Royal Derby Hospital and consists of cardiovascular warm up and cool down exercises, stretches and progressive strengthening exercises. The programme is gradually progressed over time and as the muscles gain in strength.

▲ **Robert Field, President of the British Health Professionals in Rheumatology, presents Sue Kennedy, Anne Hardy and Ruth Machej with their certificate and cheque**

Once patients have completed their ten weeks in the PRTP they are encouraged to either join a local gym or to sign up to the Royal Derby Hospital Gym Membership Scheme. The latter allows patients to use the hospital gym as often as they choose (recommended two to three times per week) to continue their cardiovascular and strengthening programme at a cost of £30 per three calendar months. It is hoped that this initiative will help with long term patient adherence to exercise, something that has been highlighted as a major problem with exercise prescription.

Other winners this year included Heather Hasthorpe, Rheumatology Specialist Nurse at Norfolk and Norwich University Hospital, whose submission outlined her experiences of setting up a nurse led treatment escalation clinic for newly diagnosed adult patients in Norwich. Dawn Homer (Nurse Consultant) and Erica Gould (Nurse Practitioner) submitted an entry that described the work they are doing to ensure a good quality service is being delivered to those being managed in a community based rheumatology service.

You can read more about all of the winning entries by visiting the 'Rheumatology in Practice' section of the NRAS website. Applications for Patients in Focus Awards 2014 will be accepted from September 2013 and details can be found on the NRAS website or by calling the NRAS office.

A week in the life of… The rheumatology educators team at The Royal Derby Hospital

Kate Gadsby (Advanced Clinical Educator and Nurse Specialist): I have been qualified for 29 years and before coming to rheumatology I worked in cardiology, general medicine and renal dialysis and transplantation. I started working in rheumatology 24 years ago and have been privileged to have been able to develop the nurse specialist role to an advanced level.

About 10 years ago I was asked to deliver rheumatology teaching, within the department, to medical students from the University of Nottingham medical school. Since then I have combined my rheumatology specialist nurse role with that of the teaching role. As you can see below, the team has expanded from just me to me and the five other rogues who I work with. We support all the rheumatology consultants in Derby in different ways, both with the teaching and in our own specialist field. I can honestly say that we are delivering true multidisciplinary teaching to the medical students that hopefully will create a better awareness of their allied health professional colleague's skills. I think I probably have the best job in the world and the thing that makes it so good are the patients who I work with and for, and my supportive colleagues.

Kate (third from right)and her team at Royal Derby Hospital

Joanne Rayner (Senior Clinical Educator and Occupational Therapist): I have been qualified for 17 years and have worked in several clinical areas. I have always had an interest in rheumatology and have worked as a clinical educator in this speciality for eight years. It's rewarding to work together with the students and volunteer patients.

Sue Kennedy (Senior Clinical Educator and Physiotherapist): I have been qualified for 29 years and have a background in upper limb physiotherapy and education. I have a special interest in progressive strength training in patients with rheumatology conditions.

Clare Webb (Senior Clinical Educator and Occupational Therapist): I have been qualified since 1997 and have worked as an OT in many different specialities around the country including rheumatology. I started work at the Royal Derby Hospital in 2009 teaching medical students in rheumatology. I love the mix of patient and student contact.

Adam Munks (Senior Clinical Educator and Nurse Specialist): I am a former paratrooper who has worked in nursing for the past 12 years within orthopaedics and am one of the Trust's spinal injury specialists. I have been in rheumatology for a year and have enjoyed the new challenges this brings.

Sandra Haywood (Clinical Educator and Staff Nurse): I am a registered nurse qualified for 18 years and clinical educator for four years. I enjoy the mixture of patient care and facilitating students.

Teaching medical students happens for almost 52 weeks per year. From February to June we teach the students in their first experience of clinical practice (CP1) followed by the more senior final year students in their final clinical practice year (CP3). This article was written during our CP1 weeks when we have 12 students a week for 14 weeks, so repeat the same timetable each week. Some people might think this is perhaps a bit repetitive like 'Groundhog Day', but each week we see different students and have the assistance of different volunteer patients to make every week different.

Monday

The week begins with coffee and a team chat at 8.30am while we plan the week ahead. Half an hour later the students arrive and Kate welcomes them to the department explaining the timetable and giving them a guide to the rheumatology department. After that the hard work starts with our first rheumatology patient workshop where the students will take a history of the patient before presenting their findings and discussing the inflammatory process and management of RA with Dr Deighton* who has taken time out of his busy presidential duties to join us for some teaching and clinical work! *(*as well as being a rheumatology consultant in Derby, Dr Chris Deighton is also the President of the British Society for Rheumatology)*

Finally it is lunchtime, although it is certainly not a lunch 'break'. We all get together to grab a bite to eat and catch up on our morning's work. Kate also uses the opportunity to complete the prescriptions for her patients who are on anti-TNF drugs and who need repeat prescriptions.

In the afternoon Adam and Sandra both run a nurse led clinic while the students look at cases of different rheumatological conditions. They need to think of possible differential diagnoses and the investigations they would want to order to confirm the diagnosis and what a typical management plan for this patient would be. Next we do what we call 'spectrum of conditions quiz' where points mean prizes for the students who aim to get the answers right and in the quickest time. It is amazing how the reward of sweets can encourage education!

The day ends at 4.30pm and Adam goes home to get ready for his JuJitsu training while Kate, Clare and Sue walk their dogs and Jo takes her sons to water polo.

Tuesday

Tuesday morning is our staff planning meeting where we discuss forward planning of teaching, new changes to our workshops and any evaluations we have done or need to do.

Sue will then meet students on the orthopaedic wards to take histories and discuss orthopaedic issues. Clare meets patients who have been invited in for history taking sessions. Jo and Kate go on to the day case unit for students to take histories and practice clinical skills such as cannulation. Emphasis on the histories taken on the day case unit is not so much on disease activity but rather on the psycho-social side of disease and the effect rheumatological conditions can have on a person's life, both at home and at work.

Tuesday lunchtime is slightly more relaxed and Clare, Jo and Kate take the opportunity to escape the confines of the hospital to get some daylight and exercise by walking around the perimeter.

In the afternoon the students watch a video and practice using the GALS (gait, arms, legs and spine) examination on each other before trying it out on patients with pathology. The aim of this session is to help students recognise the normal range of movements of the joints and to identify different rheumatological conditions.

Before the day is over, Kate attends the departmental management team meeting.

Wednesday

Wednesday is a busy day with Kate juggling day case patients, joint injections and teaching the students often all at the same time. Several students visit the consultants in clinic to observe how things are run and how the patients are managed.

Again there is no lunch break as Kate catches up with consultants and colleagues regarding research projects and future plans.

The afternoon begins with Sue and Clare running an outpatient clinic in OT and physio while Sandra books patients for upcoming sessions and Adam catches up on professional development, an important part of the continuing education process for all healthcare professionals. Kate catches up on management and clinical issues before finishing her NHS work for the week.

Once the day is over, Kate dashes off to attend her Pilates class with her husband, whilst Sue goes home to walk her dog before it gets too dark to be alone on the country roads.

Thursday

Students arrive and are split into groups to have a mixture of day case, invited patients and orthopaedic work depending on what has been covered previously in the week.

There was a bit more of a break on this particular Thursday as a member of staff was retiring so there was plenty of cake. Excellent! Jo and Clare then went for their walk round the outside of the hospital to try and move that cake from their hips!

In the afternoon, all the students had to attend an osteoporosis workshop. We discuss the definition of osteoporosis, risk factors, management and provide a patient's perspective of living with the condition. This is carried out using a mixture of interactive quizzes, history taking and powerpoint presentation.

Jo sets up for an evidence based patient education group for a small group of patients to learn about RA and learn new ways of managing their lives in order to deal with the condition.

As Thursday draws to a close it is the end of the paid working week for Clare and Jo, although not necessarily the working work as they begin their chores at home and taking care of their families.

Friday

The final day of the week begins with Adam and Sue finalising any student issues, including the signing off of the students log books, before carrying out an interactive presentation on interpreting musculoskeletal x-rays. Students learn a simple approach to interpreting x-rays and then try to identify any abnormalities in some patient x-rays before leaving the department to return to the medical school for further teaching.

In the afternoon, Sue carries out her NRAS Patient in Focus award-winning resistance exercise class for people with RA within the physio department.

At the end of the day everyone looks forward to the weekend ahead and Sue takes the opportunity to Skype some of her family.

Company fundraising favourites with a festive twist

In previous issues of the magazine you have probably noticed that we regularly talk about the very generous support we receive from companies across the UK and this issue is no different! Within the fundraising section you can read all about the support we are receiving from Marketforce UK as their charity of the year.
If your employer doesn't offer a charity of the year programme, but wish to support NRAS in a different way, we would welcome their support and here are some festive fundraising favourites to inspire you:

If your company is sending out Christmas cards this year, why not consider the NRAS cards we have for sale? Details can be found on our website.

Maybe your company has decided not to send Christmas cards this year and wants to donate the money it would have spent on cards to charity; if so why not suggest NRAS?

Perhaps you are buying gifts for colleagues, or festive hampers for those who have reached a recent target, are rewarding someone for a particular achievement or just to say thank you, so why not buy it online through Give as you Live (www.nras.org.uk/giveasyoulive) and raise money for NRAS at no extra charge to you?

Gigging for NRAS

Bernard Thain, whose wife Jill lived with RA for many years but sadly died in September 2012, held a gig with his band, The Banned, on the 1st June in memory of Jill. It was a great evening and £1,240 was raised. We're sure Jill would have been impressed. Kirsty King held a music night in April at the Woodville Bar in Lurgan, Northern Ireland and raised £900.

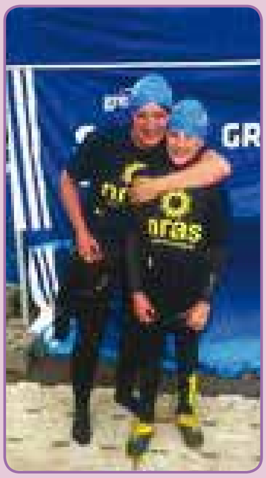
What great musical fundraisers!

Golf Days

We have had two golf days held for NRAS – one in the Midlands and one in Nottingham. Peter Gill, one of our long term supporters, is captain of his local club during 2013 and chose to hold a golf day during RA Awareness Week as part of his fundraising for the year. It was generously supported and raised £2,509. Nigel Fincher, husband of Marie who coordinates the North Birmingham NRAS Group, is currently supporting NRAS as his charity of the year and held his captain's charity day in July. A great day was had by all who went along and £1,000 was raised.

▲ Peter Gill

If you, or someone you know, belongs to a golf club then why not ask if they might consider choosing NRAS as a beneficiary of a golf day? Please contact Oli at oliver@nras.org.uk if you have any queries or want to know more.



▲ Holly Silvester (pictured left) and Catherine Cannon (pictured right)

Great Swimming in the North

On the 15th June, three of our supporters, Holly, Hannah and Catherine, all took part in the Great North Swim in Lake Windermere in the Lake District.
Holly, who has RA, said: *"Since being diagnosed with RA, I have been presented with my fair share of battles to fight and challenges to overcome. I thought it was about time I set myself a personal challenge, something which I hoped will be fun, and try to raise some money for an important charity along the way. And I got to drag my dad along with me!"*

Between them, a total of £2,848 was raised, wow!

London to Paris Cycle

Liam's sister Natalie was diagnosed with RA around two years ago at the age of 23 and he has seen her struggle to get her disease under control whilst coping with two young children. He wanted to do something to raise awareness of the disease and highlight that it can affect people at a young age, so decided that he would take on the huge challenge of cycling from London to Paris.

He set out from London on the 5th June for the four day challenge with a large group of riders, not knowing what to expect but determined he would cycle all the way. Despite aching legs, sunburnt face and saddle sores he made it to a rapturous welcome in Paris from Natalie and his family.

Liam Byde with his sister Natalie following his London to Paris cycle ride

Liam says: *"I have watched Natalie over the past years struggle as she tries to bring up my niece and nephew and her bravery and willpower to do her best for them is enough to inspire anyone. If you're thinking of doing a big challenge like London to Paris, do not hesitate for a second as it was the most uplifting experience I've ever had."*

Liam's incredible effort has so far raised £2,483!

Our London Marathon Runners

This year, four runners chose to use their London Marathon places to raise funds for NRAS. Joe, Scott, Ian and Phyllida all ran the 26.2 miles and raised a total of £7,285 which is phenomenal! We are, as always, very grateful to those people who manage to secure a place in this iconic race and use it to support the work of NRAS, so thank you.

Phyllida Jones after the London Marathon

NRAS Tea Parties

You have all been very busy holding tea parties and the cakes have looked delicious! A huge thank you to all those who have joined in with the NRAS Tea Party so far this year and good luck to all those who are still to hold their parties.

Eileen Hutchinson's Tea Party

There have been parties with book sales and plant sales and parties with 'wear a special hat', Ascot or Wimbledon themes... nurses have held parties in rheumatology units, NRAS Members have held parties in their gardens and we even had one huge tea party in a hotel in Bournemouth!

Elaine, one of the Yeovil Group Coordinators who helped organise a Tea Party during RA Week, said: *"Muriel (a group attendee) was kind enough to host a Tea Party in her beautiful garden and also donated plants for sale. We held a prize draw and combined with the plant sale and entrance fee, a fee that allowed visitors as much tea and cakes as they could consume, we amassed a total of £290. We owe thanks to all who helped set up the garden, helped tidy up afterwards, to all those kind enough to donate cakes, plants and draw prizes and not forgetting all those who turned up to spend their money and enjoy the day. A good time was had by all."*

So far £5,397 has been raised through Tea Parties which is fantastic, so please keep brewing and baking. It's not too late to register to take part, just visit www.nras.org.uk/teaparty and register online or call 0845 458 3969. There are lots of ideas for Tea Parties too and you can either download your fundraising pack or ask for one to be sent in the post.

Getting married on behalf of NRAS

Okay, so it is likely that John and Avril were getting married anyway, but as Avril had lived with RA for the previous ten years, the happy couple decided that instead of wedding gifts, donations would be accepted on behalf of NRAS. In total they raised £962. The couple got married on 6th April before heading off to Madeira on their honeymoon. Congratulations and thank you John and Avril!

Avril and John's wedding

Why I fundraise for NRAS

I'm Paul Johnson and am married to Heather who was diagnosed with RA in March 2009. We were married in May 2008 and our lives appeared to be full of hopes of dreams as we planned and commenced our married life together. Heather was working full time in a job she really enjoyed and was fit and healthy. As we stepped off the plane from our honeymoon in Austria we didn't know how quickly life would dramatically change as a result of being diagnosed with RA.

Heather became ill in the autumn of 2008 and was hit with excruciating shoulder pain and constant fatigue. Some days she could barely move and didn't know where to put herself. I watched helplessly as she couldn't get relief from the pain and saw how she struggled to get comfortable in bed and obtain any sleep. We were backwards and forwards to the GP to try and ascertain what on earth was going on. I found it so hard to watch the woman I love go from being such a fit and well person to someone who could barely move sometimes. I asked myself why? What has changed? Heather underwent various tests and had many different painkillers but nothing was helping.

Eventually, after being referred to a Consultant Rheumatologist in March 2009, Heather was given a diagnosis of RA. Heather commenced methotrexate by tablet but was more able to tolerate it by injections. She was also given steroid tablets and then six months later was started on a biologic drug. I watched her suffer the side effects of the drugs as well as the disease effects. I felt ,and still do feel, extremely helpless. I so want to help Heather to take away her pain and discomfort but I can't. I struggle to know when to let her maintain her independence and when to intervene. I have watched the RA go to different joints and seen the restrictions it places on Heather. She finds it very difficult to pace herself and on a good day overdoes it, which she subsequently pays for in the days ahead.

NRAS has been a tremendous help to both of us since Heather was diagnosed, so I decided I wanted to fundraise for them to help say thank you. This September I will be taking part in my 3rd Great North Run and I have previously done the Yorkshire Three Peaks Challenge. My pain after these events is only temporary and disappears after rest: for RA sufferers it is a daily event. If I can raise funds to assist in keeping the helpline available for people then this helps me to cope.

Heather and Paul Johnson

We have had to rethink our plans and dreams to fit around Heather's RA. It is very hard to ever plan anything as everyday is different. Some days Heather really struggles with fatigue, walking, moving and carrying out daily activities whilst on other days she is amazing. She now swims regularly as this really helps her pain and she also manages to go to the gym on good days. I try to always remain positive for her and will always be there to support her with this disease, however I do feel a tremendous sadness that our lives have been transformed by it. I don't know where this disease will take Heather, but I always tell her that we will walk this road together.

RA Awareness Week Fundraising Event

From Denise and Duncan

Our event was a coffee morning with plant sale/swap. The Lancashire weather did its worst, which probably kept a few people away, but we displayed the plants on the patio in the rain!

A steady stream of visitors enjoyed coffee and cakes, gave donations for plants and chatted and reminisced about former residents of our house. Posters were displayed by the cakes, where no-one could miss them, along with leaflets to take away.

I contributed to "RA awareness" more than I had intended by having a flare-up during the previous night. A neighbour came to the rescue and manned the kettle. I hobbled about with a wheat-bag around my neck. My neighbours normally see me out riding, walking the dog or gardening. They do not see me at all when RA is misbehaving. I hope that they now have more understanding of the implications of the illness.

We had a very pleasant morning with our lovely and generous new neighbours, and we coped with the numbers. At the end, people took a goody bag of extra cakes and scones (more donations). Already I have been asked if I will do it again and give more notice so they can contribute plants – we will!

Skydiving for NRAS

Four very brave souls were ready to jump for NRAS in May only to have their hopes dashed at the last minute when the event had to be cancelled due to high winds and rain. They were not put off however, and jumped instead on the 11th July in glorious sunshine.

Rob, Emma, Sharon and Michael all landed safely and between them raised £1,573, so thank you!

Emma Carey, Michael Gittins and Sharon Davies preparing to skydive

Charity of the year update - IPC Marketforce

In the last issue we brought the fantastic news that IPC Marketforce had chosen to support NRAS as their Charity of the Year. Marketforce has been working very hard to raise valuable funds for NRAS since the beginning of the year and have really made the most of some unique and fresh fundraising ideas. Earlier this year they started things off with a charity quiz. NRAS participated and were flying the knowledge flag, albeit it at half mast, ranking around the middle of the table. The quiz was followed by a cake sale and a 'guess the weight of the Easter hamper' sweepstake, with donations from Mars and Lindt.

More recently Marketforce held a summertime 'Pimms and strawberries' event (which went down very well as I'm sure you can imagine), a 'guess the weight of the royal baby' sweepstake and a company bake off competition with the theme 'Best of British'.

As if they weren't busy enough with all these activities, a member of the Marketforce team jumped out of a plane in the NRAS Skydive in July (see above) with another member of staff booked in for later this year. Other staff members are signed up with places in the Great South Run and the Royal Parks Half Marathon, both in October.

With more activities in the pipeline, Marketforce has certainly been busy and, with no sign of letting up, we are excited for what they will achieve later on in the year.

Try a Triathlon...

John and Darren completed their first triathlon in June in Windsor, the first of a series of challenges during the year. Both have personal experience of RA – John has RA and Darren's mum also has it – so they felt there were two very good reasons to raise funds for NRAS. In a moment of madness they decided that it was time to get fit and really challenge themselves!

John is now planning to take part in sprint triathlons in Dusseldorf and London during the summer and Darren has a darts evening planned in August. So far they have raised an incredible £2,389 and you can sponsor them by visiting www.justgiving.com/saffsanddaleysummeroffun.

Another triathlete, Keith, took part in the Llandudno Triathlon in June and completed it in 1 hour 30 minutes and 32 seconds and will compete in the Ealing Half Marathon in September. Keith decided to take on these challenges, the first of which was during RA Awareness Week, because he feels more people need to be made aware of what RA is. We will give you an update in the winter issue of the magazine! Keith can be sponsored by visiting www.justgiving.com/keith-FREEGARD1.

Rheumatoid arthritis, anti-tumour necrosis factor therapy, and risk of skin cancer: nationwide population based study from Sweden

Raaschou P, Simard JF, Holmqvist M, Askling J, ARTIS Study Group; British Medical Journal (BMJ) 346 f1939 (2013)

This was a population study from the Swedish Registry ARTIS which is similar to the British Registry (BSRBR). They studied patients with rheumatoid arthritis treated or not with TNF inhibitors and matched and compared them with members of the general population.

The good news is that, patients with rheumatoid arthritis do not have an increased risk of developing melanoma. However, patients treated with biological drugs had a small but significant increased risk of developing melanoma. This has previously been demonstrated in other registry studies.

Non steroidal anti-inflammatory drugs and risk of cardiovascular disease in patients with rheumatoid arthritis

Lindhardsen J et al

Results from a longitudinal study conducted in Denmark suggest that the cardiovascular risk associated with NSAID use in RA patients was modest and in fact significantly lower than in those individuals without RA. The study found that the use of rofecoxib and diclofenac was associated with increased cardiovascular risk, but no increased risk was found with other NSAIDs (not specified).

The authors conclude that NSAIDs should not be avoided due to concerns of severe cardiovascular outcomes alone, but that individual patients should be assessed based on the indication for pain relief and risk factors for adverse effects.

New study suggests that rheumatoid arthritis is linked to an increased risk of type 2 diabetes

New research from scientists at the National Changhua University of Education and the Institute of Biomedical Sciences in Taiwan suggests that people with rheumatoid arthritis may face an increased risk of developing type-2 diabetes. The scientists studied data on 600,695 Taiwanese citizens, including 4,193 with rheumatoid arthritis and a further 799 with type-2 diabetes.

The researchers observed that both men and women had a heightened risk of developing type-2 diabetes if they had already been diagnosed with rheumatoid arthritis. Men were 68 per cent more likely to develop type-2 diabetes and women 46 per cent compared to healthy individuals.

Although the reasons for the apparent association between rheumatoid arthritis and type-2 diabetes are not yet clear, there may be a common link due to underlying inflammation not dissimilar from the known increased cardiovascular risk.

Overweight and obese patients are less likely to achieve successful remission in early rheumatoid arthritis

The results of a study presented at European League Against Rheumatism (EULAR) 2013 suggests that overweight and obese people who have recently been diagnosed with rheumatoid arthritis are less likely to achieve remission in their first year of treatment than people who are of a normal weight.

Researchers at the Catholic University of the Sacred Heart in Rome studied 346 patients with early rheumatoid arthritis of less than one year's duration. The study divided the participants into three groups, depending on whether they were normal weight, overweight or obese. They were all treated with the goal of achieving remission, starting with methotrexate, up to 25mg per week, together with steroids and for those who did not respond, a tumour necrosis factor (anti-TNF) drug was added.

An analysis of the data indicated that overweight and obese patients were less likely to have achieved remission at both the six and 12 month follow up visits than their normal weight counterparts, and that after 12 months of treatment, anti-TNF therapy was more common among obese and overweight patients, than those of normal-weight. Obese and overweight patients responded less well to methotrexate and steroids and required to go onto anti-TNF therapy 2.4 times more than normal weight patients in order to achieve the same degree of response.

One of the authors of this study, Elisa Gremese, commented: *"These data reinforce the link between obesity and inflammation, and establish that BMI is one of the few modifiable variables influencing the major outcomes in RA. There is an urgent need to address the issues of overweight and obesity to improve patients' chance of successful remission."*

Major new research centre aims to find out more about the causes of rheumatoid arthritis

The Arthritis Research UK Rheumatoid Arthritis Pathogenesis Centre of Excellence, a collaboration between the Universities of Glasgow, Newcastle and Birmingham, aims to address the unmet needs of all those who live with RA.

Researchers at the new centre, headed by Professor Iain McInnes at the University of Glasgow, will investigate the underlying causes of rheumatoid arthritis. They will focus on the mechanisms of autoimmunity that cause rheumatoid arthritis to start, and why it doesn't stop. This results in chronic inflammation in the joints which cannot be suppressed in at least a third of patients, despite treatment with modern biological therapies.

Although much of the research will be laboratory based basic science, the ultimate aim of the centre will be to develop new therapies that will provide patients with specific treatment that will work best for them early in the course of their disease, without the need to try an array of different drugs.

> *"There is a massive unmet need for better treatments for RA - there is no cure, and many people are still suffering. We now have a fantastic chance of doing something about it."*

"We're really excited about the opportunities this new centre brings, and the consequent collaboration with basic scientists, clinicians and industrial partners who all want to make a difference," said Professor McInnes. *"There is a massive unmet need for better treatments for rheumatoid arthritis; there is no cure, and many people are still suffering. We now have a fantastic chance of doing something about it."*

NICE appraisal of Tofacitinib suspended

In previous editions of the NRAS magazine we have mentioned the development of a new oral medicine called tofacitinib (Xeljanz) which is designed to block the action of enzymes called Janus kinases, which play an important role in the process of inflammation and joint damage in people with rheumatoid arthritis. As with all new drugs, tofacitinib has been subject to an appraisal by NICE to ensure its safety, efficacy and cost effectiveness and the Institute has determined not to give its approval and so this drug will not be available for prescription here. NICE will monitor any developments in regard to the drug and NRAS will keep you updated if the situation changes.

Assessment of CVD in patients with RA by strain imaging

Sherine Gabriel et al

A recent study conducted in the USA has looked at a new imaging technique (strain imaging by speckle tracking echocardiography) based on standard echocardiograms, to assess if this technique can detect early cardiovascular abnormalities in RA patients.

The conclusions of this study suggest that this type of imaging may well be effective at detecting altered heart function at an early stage, at a time when the abnormalities could potentially be reversible.

Danish study looks at the importance of rheumatoid factor and ACPA in the diagnosis of RA

A Danish study followed up nearly 10,000 Danish people over a 28 year period to see whether the presence of a raised rheumatoid factor would lead to the development of rheumatoid arthritis. Patients were divided into 4 groups, those with a negative rheumatoid factor (less than 25 units per ml), those with a slightly raised rheumatoid factor 25 -50 u/ml, 50-100 u/ml and those greater than 100 u/ml.

Only 183 people developed rheumatoid arthritis over these 28 years. Less than 1% of rheumatoid factor negative patients developed RA (as expected from known epidemiological studies). The presence of rheumatoid factor did increase the risk of developing RA and this correlated with the strength of the rheumatoid factor – a doubling in the level of rheumatoid factor was found to be associated with a 3.3 fold increased risk of developing rheumatoid arthritis. Having a strongly positive rheumatoid factor of more than 100 u/ml was associated with a 26 fold increase in developing RA. The median time to developing RA was seven years for these patients, and also for those in the 50-100u/ml group but it took longer before the RA started in individuals with lower levels of RF – 12 years for those with 25-50 u/ml.

This research confirms previous knowledge that a raised RF does not necessarily indicate that individuals will go on to develop RA and currently experts do not advocate the use of RF as a screening tool. However if people are found to have a strongly positive rheumatoid factor greater than 100 u/ml then they need to be vigilant for the development of joint symptoms and should be encouraged to stop smoking (another risk factor for developing RA).

Running away from RA

By Ann Jones

In 2010, at the age of 35, I was unexpectedly diagnosed with rheumatoid arthritis

The pain throughout my body was excruciating, particularly in my hands and feet, so I was immediately put on steroids to help stop it. I then spent most of 2011 at the Royal National Hospital for Rheumatic Diseases in Bath having scans and tests to try and find out the correct mixture of medication and treatment that would make the crippling pain stop and allow me to come off of the steroids and care for my family.

In September 2011, because of my young age and the aggressiveness of the disease, I was put forward for funding for a trial drug called Infliximab through the Primary Care Trust. After numerous tests, scans and medicals, I got the call to say that I'd been accepted for funding for one year starting the following week.

Ann celebrating her finish at the Olympic Park Run

It meant I'd have to travel to Bath from Taunton every two weeks, then every four weeks and finally every eight weeks and sit with a needle in my arm whilst the pioneering drug was infused into me over three hours.

It was during this time that I eventually decided to stop feeling sorry for myself and turn my life in a positive direction after feeling very depressed and scared for the past year. My husband Matt and two little girls, Lauren and Ella, had been so supportive but were initially a little worried about how my new view on life would affect the disease within my body and whether I was going to make the condition worse.

Straight after I'd had my first infusion of Infliximab, I joined WeightWatchers in order to lose the two stone that I'd gained whilst on the steroids and then I went for a walk.

Going for a walk around the block may not seem like much to some people, but I'd been unable to move very far for over a year so this was a huge achievement for me. For two months all I could do was walk and then I started power walking before progressing on to jogging. A group of mums had started a Thursday morning jogging group from the school gates and at first I just watched them, until one day I plucked up the courage to ask to join them. They were all immediately accommodating and the Run Leader listened to my concerns and worries about running with RA and supported me right from that first run. I couldn't run every week as sometimes I'd be too sore or too tired, but the girls at the group always welcomed me back with open arms and words of encouragement.

As motivation to keep jogging and working hard at staying fit and healthy, I signed up for the 5km Race for Life in Taunton and managed to jog the whole 5km. I was an emotional wreck as I crossed the finish line with the other 3,000 women who were there! I also became a Gold member with WeightWatchers for hitting my goal weight by losing over two stone in six months.

Ann prior to the Olympic Park Run

On what had been the hottest day of the year so far, I then ran the Bristol 10km Race for Life with my running partner and best friend, Tiff. It was an emotional experience and physically exhausting but I managed to complete the run in 1 hour 5 minutes. Tiff has been beside me since day one of meeting her at the running group and constantly keeps me motivated, even if I am only able to walk because of the restrictions of my RA.

My 18 months of positivity and hard work in learning to run were rewarded on Sunday 21st July when I was selected from a public ballot to take part in the Lottery Anniversary Olympic Park Run, a five mile run around the site of London 2012. From start to finish the whole day was truly amazing and a once in a lifetime experience. Tiff and my good friend Kerry came along to provide support and cheer me along, as my husband works abroad and I only had two guest passes so my daughters weren't able to come.

Article continued on page 29

Sir Chris Hoy started the race and Paula Radcliffe, Victoria Pendleton and Mel C (from the Spice Girls) were on the front line. The run felt very long, very hard and very hot, but all that was forgotten when I entered through the dark tunnel into the bright lights of the stadium at the 300 metre point of the running track. I waved to the 20,000 cheering crowd, including Tiff and Kerry, and somehow found the energy to sprint the 100 metre straight in my best Usain Bolt style! I completed the five mile run in 48 minutes and 42 seconds, which is a personal best.

I'm going to keep running from this disease until my legs physically don't work anymore!

Ann with Oli Hoare of NRAS

10 year certificates

nras

CONGRATULATIONS

on

10 years of NRAS membership

Thank you for your continued support

Signed

Date

Many of our Members have now reached a key milestone as dedicated Members of NRAS for over 10 years!

This is such a noteworthy achievement that we felt it had to be recognised, so all those eligible will be receiving certificates in the post very soon – we hope they will be displayed proudly. A huge thank you from all at NRAS for your support of our work and we hope you continue to enjoy being a member for many years to come.

Healthcare Champions Awards 2013

Earlier this year, NRAS Members had the opportunity to nominate their health professional for the 4th biennial Healthcare Champions Awards. This event enables Members to put forward the individual, or team, that has gone the extra mile in caring for them and to acknowledge their hard work. The team of judges, made up of NRAS trustees, medical advisors and health professionals, has now made its decisions. The ten winners that have been chosen, together with the Members who nominated them, have been invited to a high profile awards ceremony in November. A full report, including all the winners and photos from the day, will be featured in the winter edition of the magazine.

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

Step 1 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

Step 2 Become a Friend

I would like to become a Friend of NRAS.

Annually: £25 ☐ £50 ☐ Other £ Monthly £

NRAS was recommended to me by:

Step 3 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.

Please complete overleaf

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

Members' Day

As this magazine goes to press, we will be welcoming Members from all over the country to our 2nd Members' Day being held this year at Solihull College, Birmingham. We are delighted to have such an array of guest speakers including Dr Holly John BMBS MRCP, who will be speaking on the cardiovascular impact of RA. Our members will also be able to choose between various workshops, including exercise, fatigue and podiatry. To end the day, we will be holding a Q&A session with the rheumatology team from Solihull Hospital. We are sure that this event will be just as successful as the first day held last year and we look forward to meeting even more of you at our 3rd Members' Day, to take place in the North, in 2014!

▲ Dr Holly Johns

Members Tips

Getting Dry...

If you struggle to dry yourself after a bath, shower or swimming, try this handy tip from Kate in Bournemouth. Put on a towelling bathrobe when you get out of the water and allow the robe to absorb the water while you carry on with other things. This is great if you struggle with stiffness and pain in your hands.

Kate, Bournemouth

Exercise with Schwartz...

If your hands ever start to get uncomfortable then a Schwartz spice bottle is the perfect shape and size for providing gentle exercise. The contours of the bottle are ideal for your fingers as you can turn it round to suit the size of your hands and your fingers can bend so far without digging into your palm.

Matt, posted on Health Unlocked

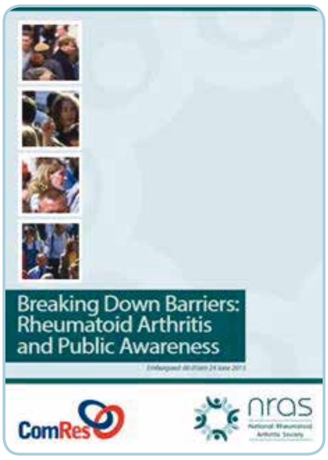
Launch of the Breaking Down Barriers report

To kick start the launch of the UK's first ever Rheumatoid Arthritis Awareness Week, NRAS published a report called 'Breaking Down Barriers' to explore the overall level of public awareness and the misconceptions surrounding RA.

The report consisted of an extensive literature review about public awareness of the disease and a specially commissioned ComRes opinion poll conducted with 2,074 British adults aged 16 and over. To our knowledge, this was the first time a detailed survey of this type (one that analyses public perceptions of the disease) has been conducted.

The S Factor

The literature review highlighted academic research which showed how extensive delays are jeopardising healthcare professionals' best efforts to treat individuals within the 12 week 'window of opportunity', with evidence showing that the average delay in patients seeking help from their GP is 12 weeks and thus obliterating this key clinical target for achieving early diagnosis and treatment.



The Breaking Down Barriers Report

Furthermore, the literature review illustrated that neither England, Scotland nor Wales have managed to introduce a comprehensive approach to raising public awareness of the disease. The closest candidate so far has been Scotland where a needs assessment has taken place and a national pamphlet has been produced on the signs and symptoms of RA. However, it is unclear whether this is a standalone activity or not.

By comparison, Wales has developed a vision that includes reference to the role of enhanced public awareness but there is no evidence of any planned activity by the Welsh Government or its institutions. The UK Government also has an unsatisfactory track record, having rejected earlier widespread calls for a nationally funded public awareness campaign on RA and having failed to include any meaningful reference to the role of enhanced public awareness across its main strategic documents governing long term conditions and public health.

The opinion poll uncovered further fresh evidence of the British public's lack of knowledge of RA, showing a very limited understanding about the disease's symptoms, health impacts and risk factors. This underscored the ongoing challenges we face in getting members of the public to urgently seek out medical advice from their local GP.

In particular, the poll found that just 10% of the British public believed their government was doing a good job of raising public awareness of long term conditions, including RA. A mere 10% of survey respondents had seen information displayed in public about the symptoms of RA and only 41% said they understood the symptoms of the disease.

Among the survey results there were a few surprises, as although younger survey respondents exhibited poorer levels of understanding about the disease compared to other age categories, a very high percentage did manage to correctly identify the main symptoms of the disease.

The report therefore recommended that the UK and devolved Governments undertake reviews into the effectiveness of existing approaches towards raising public awareness of RA and initiate more comprehensive approaches to raising public awareness that go beyond the provision of simple poster campaigns. This should include a more coordinated and effective approach to displaying public information in GP surgeries, community pharmacies and other healthcare settings and adopting a more nuanced approach to deploying messages about RA that takes account of different levels of understanding about the disease found between different age groups, genders and even ethnic backgrounds.

Campaign Update

A major focus for the government affairs team over the last four months has been campaigning around the new Personal Independence Payment (PIP).

National Voices
People shaping health
and social care

News story

Government publishes Care Bill

Organisation: Department of Health
Published: 10 May 2013
Policies: Treating patients and service users with respect, dignity and compassion • 3 others

The Care Bill will modernise the law to put people's wellbeing at the heart of the care and support system

Published today, the Care Bill introduces legislation to provide protection and support to the people who need it most and to take forward elements of the government's initial response to the Francis Inquiry.

The Care Bill will give people peace of mind that they will be treated with compassion when in hospital, care homes or their own home.

https://www.gov.uk/government/publications

Continuing our engagement with Atos, at the beginning of April we wrote to them setting out the case for the appointment of Musculoskeletal Champions to help drive up the quality of PIP assessments for people with musculoskeletal disease and we orchestrated endorsements for this approach from the Arthritis and Musculoskeletal Alliance (ARMA) and the Fit for Work Coalition. At the same time, NRAS joined a working group of several charities to help review Atos training materials on fluctuating conditions.

In June we met with officials from Capita to investigate how NRAS could help improve the quality of training materials for their PIP assessors and in July we worked with our coalition partners, the Disability Benefits Consortium, to orchestrate an open letter (which received national media coverage) about the tightening of the 'moving around' descriptor in the PIP and responded to a major consultation on the topic. In this we undertook a membership survey and series of member case studies, so our sincere thanks to all those who took part. To further develop the evidence base, the government affairs team also submitted a Freedom of Information request to the Department for Work and Pensions (DWP) and worked with Baroness Brinton to table several Parliamentary Questions about the numbers of people with RA claiming the Disability Living Allowance and accessing the Motability scheme.

The Care Bill was also published on the 10th May and NRAS has been working extensively on the 'care and support plan' element of this, in conjunction with the Care and Support Alliance (CSA) and National Voices to ensure it better reflects the needs of our members. We submitted a number of amendments to the draft Bill with some important amendments being accepted by the Department of Health. However not everything we would like to see changed was incorporated. Therefore, working with a sub-group of the CSA, NRAS produced a briefing paper for Peers ahead of the second reading in the House of Lords which included a snapshot poll of NRAS members.

With NRAS's expanding interest into the field of Juvenile Idiopathic Arthritis (JIA), the government affairs team researched for NRAS's new JIA report on existing approaches to commissioning of paediatric rheumatology services and the relative prioritisation of these services across the UK. To ensure people with JIA have a strong voice in the configuration of these services in England, we have also helped to recruit a patient representative, Helen Berger, to NHS England's Clinical Reference Group for Paediatric Rheumatology Medicine. At the time of writing, the team is starting to undertake activity to disseminate the findings of the report to policymakers in Wales.

NRAS continues to take a strong interest in commissioning in England. Through our partnership with the British Society for Rheumatology and Arthritis Care – under the banner of the Rheumatology Commissioning Support Alliance (RCSA) – we have been invited by Bath and North East Somerset Clinical Commissioning Group and Wiltshire Clinical Commissioning Group to undertake a consultancy project to advise on how to improve the quality of their local rheumatology services. Several meetings have taken place and at the time of writing, the RCSA is now undertaking a stakeholder engagement exercise with healthcare professionals and service users to help the clinical commissioning groups understand local views about the service.

Also within the field of commissioning, NRAS work has continued at pace with a joint bid to run musculoskeletal services in Bedfordshire. The consortium of clinician led and patient led organisations, which includes Circle, Horizon, Pennine MSK Partnership, NRAS and Arthritis Care has been awarded preferred bidder status and is conducting contract negotiations with a view to start running services in spring 2014. During the course of the bid process, NRAS met several times with its consortium partners and fed back extensive comments into the associated bid documents.

At our recent volunteer training days in Maidstone, Bristol, Manchester and Solihull, the government affairs team presented to NRAS members about the impacts of the health reforms, and to local NRAS groups in Tunbridge Wells, Ashford and Dorchester on the likely impacts of both the health and welfare reforms.

In a follow up to the summit meeting held in Halifax last November, which brought together a range of organisations involved in commissioning and providing rheumatoid arthritis services in Calderdale, the government affairs team provided a briefing to Linda Riordan MP in preparation for local discussions about the possibility of working with the council's overview and scrutiny committee to instigate a review of services.

NRAS also continues to support the work of the Prescription Charges Coalition. Over the past few months we attended a meeting with Department of Health officials where we discussed the Coalition's Paying the Price report, uptake of the Prescription Prepayment Certificate following our help to design and distribute new leaflets on the subject, simplification of the NHS Low Income Scheme and whether the department should issue new guidance on 28 Day Prescribing rules. Sir Bob Russell MP secured a debate in the House of Commons on exemptions to prescription charges for people with long term conditions and although the Minister responsible, Anna Soubry MP, maintained the Government line on this issue, the debate was still useful way to raise the profile of the problem. In other news, the Coalition secured a meeting with the Shadow Health Secretary Andy Burnham MP to discuss future Labour Party policy on prescription charges exemptions for people with long term conditions.

Andy Burnham

NRAS contributed to a National Voices submission to the Health Select Committee inquiry on long term conditions, where we advocated for the need to clarify its approach around the production of integrated health and social care standards for diseases in ongoing discussions about integration of services. In addition to this, NRAS has also joined a new National Voices working group on long term conditions to help advance policy discussions with officials.

As part of our ongoing programme of parliamentary meetings, NRAS also met with Nic Dakin MP to brief him about issues relating to RA medicines policy and met with Jessica Morden MP to discuss the impact of the welfare reforms on her constituents. Jessica kindly agreed to table a series of Parliamentary Questions for NRAS on the process of Employment and Support Allowance reassessments for people with RA. This is part of our ongoing work with Parkinson's UK, the MS Society and the Cystic Fibrosis Trust to improve the Work Capability Assessment for people with progressive conditions.

Jessica Morden MP

As covered on page 31, we produced a report called 'Breaking Down Barriers' for RA Awareness Week. In the lead up to the report launch, we worked with NRAS patron, Linda Riordan MP to table an oral Parliamentary Question about the Government's approach to raising public awareness and this resulted in a meeting between Linda and the Minister for Care and Support, Norman Lamb MP.

Minister for Care and Support, Norman Lamb MP

We worked with politicians in England, Scotland and Wales to table a series of parliamentary motions and orchestrated a series of e-campaigning actions resulting in several hundred letters to politicians. The team also achieved media coverage of the report on several leading online platforms, including Total Politics, PoliticsHome, Left Foot Forward, Liberal Democrat Voice and GP Online.

Meanwhile, NRAS has continued to expand its presence in Scotland. Visiting the Scottish Parliament in Holyrood, the team met with Helen Eadie MSP to discuss the state of rheumatology services in Scotland and ask for her support in raising the profile of the Breaking Down Barriers report within the Parliament. We also took advantage of our time there to attend a meeting of the Cross Party Group on Arthritis and Musculoskeletal Conditions, where NRAS Scottish Ambassador Sheila MacLeod continues to provide the secretariat.

Helen Eadie MSP

Best Practice Tariff for Early Inflammatory Arthritis

By Dr Chris Deighton, President BSR and consultant rheumatologist
at Royal Derby Hospital

The National Audit Office Report on rheumatoid arthritis services published in 2009 demonstrated that high quality services are patchy, with parts of the country still experiencing significant delays in seeing patients with new disease.

We know what good services should look like from the NICE RA Management Guidelines, NICE Quality Standards, BSR guidelines, and international guidelines such as EULAR and ACR. The challenge is in translating recommendations into practice. In the current economic climate, and with yet another huge round of changes in the English NHS, this can seem more daunting than ever.

In the English NHS there are some levers to help implement guidelines. This might be agreed locally, with services designed that are consistent with the guidelines, or nationally with sticks and carrots to ensure recommendations are implemented. One such national carrot is called "Best Practice Tariff". This is a payment rewarding system for hospitals for implementing aspects of best practice. If guidelines are followed in patient pathways, extra payments can be claimed by the hospital. This has worked successfully for osteoporotic fractures of the hip, where predominantly elderly patients should be seen quickly, operated on where appropriate, rehabilitated, and their care supervised by a 'health care of the elderly' physician with prompt discharge home. This has been successful in improving outcomes and income for participating hospitals. At the British Society for Rheumatology and Arthritis Research UK, we wondered if a similar incentive scheme to encourage patients with potential early inflammatory arthritis to be seen quickly in hospital and put on to disease modifying drugs quickly where appropriate, would also result in improved outcomes and decrease the variation in practice around England.

After a lot of hard work with the Department of Health, an early inflammatory arthritis best practice tariff was introduced in April of this year. If a patient is judged on the basis of the referral letter to have a potential early inflammatory arthritis and is seen within 3 weeks of receiving the referral, this attracts payments above those normally secured for a new patient appointment. If they are followed up regularly over the course of the first year with measurements of disease activity, and appropriate escalation of disease modifying drugs, this secures further payments. Finally, for those patients found not to be responding to conventional disease modifying drugs, there is a further payment for those patients identified as needing biological treatments in their first year of care

It is early days to judge the success of this incentive scheme. Feedback from colleagues has been mixed. Most rheumatology services welcome this, because it has highlighted the area and enabled conversations to take place between rheumatology teams, commissioners and hospital managers that were not happening before. Some services that have struggled to provide an early inflammatory arthritis service are using this as leverage to introduce one. However, some services with established early inflammatory arthritis clinics have complained that the payments that have been calculated for the tariffs would financially penalise them, because they offer more than is required by the Best Practice Tariff. Feedback to the Department of Health has introduced more flexibility into the arrangements, so that if established early inflammatory arthritis clinics can show that their activity additional to the Best Practice Tariff can be justified to commissioners, this activity should attract appropriate supplementary payments. Nobody wants an incentive scheme to perversely under fund excellent established services and destabilise them.

▲ Dr Chris Deighton

In time we will be able to judge whether this Best Practice Tariff is helping or hindering. If the latter, it needs to be modified or thrown out. If the former, then we should see more uniform adoption of early inflammatory services across England, proving prompt diagnosis and making a big difference to long term outcomes; we would all welcome that. We would not want a national audit in a few years time to show that we have not improved since the National Audit Office report of 2009.

NRAS staff reaching out to healthcare professionals across the UK and Europe

By Clare Jacklin

It is important that NRAS networks with healthcare professionals and other patient organisations to ensure that we can communicate the needs of people living with RA as well as learn more about developments in treatment and support for RA patients from fellow stakeholders. In April the biggest event in our diaries is always the British Society of Rheumatology (BSR) conference which this year was at the International Convention Centre in Birmingham.

The NRAS stand is always very popular as clinicians and healthcare professionals look for the latest NRAS magazine and publication which this year was the *'Emotions, Relationships and Sexuality'* book, which was flying off the display stand.

Two of the highlight sessions for me were 'Commissioning in a cold climate' and 'Clinical research in RA'. The first session demonstrated that, while there appears to be a big move as part of the shakeup of the NHS to move more care into primary care setting, when asked 'where should rheumatology services be based?' 72% of those attending answered that they should have a hospital based service that is integrated with the community. The second session really appealed to me as it highlighted the impact 'real' patient involvement in research can have on the development of future treatment and care.

This year was the first time NRAS had been present at the Primary Care Conference, which was also held in Birmingham. As a common message for both RA and ankylosing spondylitis (AS) is the importance of early diagnosis, NRAS joined forces with the National Ankylosing Spondylitis Society (NASS) to share a stand that proved very popular, especially with physiotherapists and podiatrists.

Shortly after this I accompanied Ailsa, Lorraine and Jamie to EULAR, where I had the unenviable task of presenting at a PARE session on our research into the impact of RA on relationships, both on the family and the individual. Flatteringly, as a result of this, we have been asked for permission to translate our new booklet into two European languages and the University of Cyprus wishes to replicate our research into the impact of RA on the family. They say imitation is the sincerest form of flattery, so may I pass on such a compliment to all our Members who participated in these two pieces of research.

The NRAS Stand at BSR

NRAS and NASS making a joint effort at the Primary Care Conference

Federico, Phil, Liam, Debbie and Clare at the CSP reception

NRAS works closely with other organisations and I enjoyed meeting up with Federico Moscoqiuri (ARMA), Phil Baker (Arthritis Care), Dr Liam O'Toole (Arthritis Research UK) and Debbie Cooke (NASS) at the Chartered Society of Physiotherapists Summer Reception as part of their Fit For Work campaign.

NRAS Members volunteer their time and energy

As an NRAS Member there are many opportunities that arise when you can get involved in the work of NRAS and within the world of rheumatology. Here's a flavour of just a few of the events and activities that Members have volunteered for over the past few months.

Three NRAS Members gave up their Sunday on the 7th July to represent NRAS at the King's College Hospital's 100th birthday celebrations. King's is home to the TV series '24 hours in A&E'.

Globetrotting volunteers were required in May to represent NRAS and people with RA at two events organised by AbbVie, the biopharmaceutical company. The first event, hosted in Barcelona, was for AbbVie UK staff to have the opportunity to hear from patients what it is like to live with a disease like RA. Eileen Hutchinson from North Yorkshire and Deborah Whitehouse from Sutton Coldfield attended and were happy to share their experiences with the inquisitive and attentive audience. Jean Burke, NRAS Member and Trustee, also attended this event and presented to the entire delegation on what is important to an RA patient.

Eileen and Deborah share their experiences with AbbVie staff

The following week in Brussels, Kate Betteridge had the opportunity to help a chef to demonstrate the difficulties people with RA encounter with the everyday task of cooking.

Lesley Nell from Oxfordshire has volunteered to participate as a patient partner on the Curriculum Development Committee for the MSc Clinical Sciences Blood Sciences course at the University of Birmingham. As blood monitoring is a key component in the treatment of RA, ensuring an RA patient has input into the development of education for future phlebotomists in this disease area is vitally important.

Carolyn Carter, Teresa De Matos & Bhagyawanti Shah with Bhagyawanti's daughter and Jo Dobson (CNS) at the 100th King's College Celebrations

> *"Volunteers are not paid, not because they are worthless but because they are priceless."*

The King's Open Day poster

The NRAS Group leader from Basingstoke, Marion Woods, visited homecare delivery company Alcura, in Alton, with Oli from the NRAS office. Alcura staff really appreciated having the opportunity to learn more about the work of NRAS and what living with RA is really like. Likewise, NRAS Members Paul Burris and Sue Faithful visit the UCB offices in Slough to talk to their staff, which they find really helpful. Teresa Shakespeare-Smith from Hertfordshire accompanied Tracey, from the NRAS office, to the MSD Pharmaceutical headquarters in Hoddesdon for a 'Lunch and Learn' event with staff.

NRAS would like to sincerely thank all Members who have volunteered, too many to mention here, and have done so much to forward the aims of your society and hence help to improve the lives of those living with RA. You may think that manning an information stand or making a phone call to a fellow patient or helping to edit/contribute to a new NRAS publication is only a small thing but it all counts and together go a long way to making a BIG difference.

Thank You!

Discover what other NRAS volunteers have been up to, and what further opportunities there are, by following them on Twitter @Volunteers_NRAS

Members training days across the UK

75 NRAS Members attended the regional training days to find out more about the work of their society and how as individuals they can get involved. The interactive days included sessions on peer to peer telephone support volunteering, supporting your rheumatology team, NRAS fundraising, the changing NHS, patient partners in research, setting up and running NRAS groups as well as the highlight of each of the days – 'an audience with Ailsa'!

Manchester Metropolitan University was the venue for the northern training day

Solihull training day

A sunny day in Bristol for our final training day

Leafy setting for the Maidstone training day

This was the first year we used this new format for the training days, opening it to all NRAS Members in addition to Group Leaders. It was great that 19 groups were able to send delegates but it is our goal to get at least one person from each group next year. Gill and Kim are already checking out venues and booking in dates as we go to press to ensure that everyone is given as much notice as possible to book onto them. Watch out for the winter NRAS magazine that will have full details of dates and venues.

> *"Everything was very professionally run and I feel proud of my charity. Thank you everyone. I will be more proactive with my RA nurse."*

> *"I really enjoyed meeting such wonderful people. I will be working to join a patient advisory group and will offer my services to NRAS as a speaker."*

We're on the move...

We have outgrown our current office space and will shortly be moving to larger premises in Maidenhead. This will not affect anything we do but will give us the space to continue to grow over the coming years as we anticipate we will need to do to meet the demand on our services. Look out for some pictures in the New Year issue when we will hopefully be settled and organised!

Publication of individual surgeons' outcomes data

Approximately 3,500 surgeons have agreed to have their individual surgical results published enabling patients to understand far more about the nature of a surgeon's work and their recovery after an operation.

For the first time, patients and the public will be able to read information which gives details of a surgeon's performance by looking at the outcomes of particular procedures or operations, such as a hip replacement or surgery for obesity.

The measurements, based on national clinical audits, are a way of measuring performance against a set of professional standards relating to survival rates, length of stay in hospital following a procedure and repeat operation rates, as well as the number of operations performed.

More than 20 surgical procedures are covered in the information, which is on the NHS Choices website and on the websites of individual surgical specialty associations.

Christmas Cards

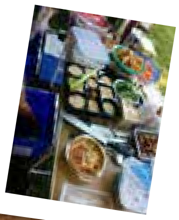
This year we have 7 new Christmas Card designs to choose from and you can now order these online at www.nras.org.uk/christmascards, complete the form enclosed in this magazine or call us on 01628 501547. All packs contain 10 cards and are £4 each, with no charge for postage regardless of how many packs you order. We also have a small number of last year's cards available at the reduced price of £2.50 per pack which are available online. All profits from the sale of cards goes directly to supporting our work so please do consider supporting us by buying your cards for the festive season.

Are you missing out?

We are often offered media and research opportunities that provide us with a tremendous opportunity to raise awareness of RA or advance our knowledge of the disease. We regularly pass these opportunities on to you through email so that you can take part, however if we don't have your email address then you could be missing out. If you'd like to be kept informed of the latest developments and opportunities regarding RA then please email enquiries@nras.org.uk with your full name and we will add you to the list.

NRAS picnic

To celebrate the success of the first ever RA Awareness Week, the NRAS team decided it was time for a mini social so headed over to the office park lake for a celebratory picnic and some party games. It was a great opportunity to let off some steam and have some fun.



In the last magazine

...we said that if you are flying then you will not be able to take an ice block on board the plane to keep your medications cool. We did however have one person write in saying that they have managed to take an ice block on their flight. This just shows how important it is that you contact your airline in advance, and the airport you are travelling through, to check what their local policy is.

Did you know...

Do you enjoy a Jacuzzi? The Jacuzzi was in fact invented to help relieve the aches and pains of rheumatoid arthritis. Almost a century ago, seven Jacuzzi brothers moved from Italy to the US where they spent their time developing aircraft engines then hydraulic pumps. The son of Candido Jacuzzi suffered badly with RA so Candido invented a machine that generated a whirlpool using agricultural water pumps and so provided a soothing effect that helped relieve the pain. Thus the Jacuzzi was born.

GMC

What to expect from your doctor

The General Medical council (GMC) has published a guide for patients on what they should expect from their doctor. The principle behind it is that patients receive the best care when they work in partnership with doctors, so the guide explains how they can achieve this. The guide is based on the standards the GMC sets for doctors in their core guidance good medical practice and features four main areas:

- Doctors must provide good care
- Doctors must put patients' safety first and make sure the care they provide is safe and effective
- Doctors must treat patients as individuals
- Doctors must be honest and trustworthy

To access the guide, visit the GMC website at www.gms-uk.org

General
Medical
Council
Regulating doctors
Ensuring good medical practice

Shop online this Christmas with Give as you Live!

Many of us now use the internet to do some or all of our Christmas shopping and during the process you could be raising money for NRAS at no cost to you!

Simply download the Give as you Live app on to your internet browser and if you visit an online shop that has signed up to the scheme, they will automatically donate a percentage of your purchase to NRAS at the end of the transaction.

Stores which have signed up include Amazon, M&S, Argos, Apple Store, Sainsbury's, Topshop, Lego, Harrods and many more. Sign up today at www.nras.org.uk/giveasyoulive and support NRAS while you shop this Christmas! For more information, please contact fundraising@nras.org.uk

Give as you Live®

Medac launch Metoject® electronic patient guides

Patients being prescribed Metoject® pre-filled methotrexate syringes can now access important administration guidelines and safety information via their mobile devices. The electronic patient guides, specifically developed for adolescents, children and adults, allow patients easy access to safety, travel and administration information.

The guidelines were developed to assist patients with the correct administration of Metoject® including adults and teenagers who usually self inject or parents who administer it to their children. For further information, visit www.medac-uk.co.uk.

Don't forget to follow us on

social media

too:

Join the NRAS Facebook page

www.facebook.com/nationalrheumatoidarthritissociety

& be part of the NRAS community

Follow us on Twitter

Twitter@NRAS_UK

To see what is happening on Helpline follow them

Twitter@helpline_NRAS

For up to date membership information follow

Twitter@members_NRAS

The NRAS Lottery is Launched

We have just launched a brand new NRAS Lottery which gives you the chance to win £25,000 each week. For just £1 per week you have a 1 in 63 chance of winning a cash prize of £5, £25, £1,000 or £25,000! You are allocated a six digit number which will remain yours for as long as you play the lottery. Winners have to match 3, 4, 5 or all 6 digits in the correct place in the sequence to win and you can enter as many times as you like.

The draw takes place every Saturday and prize cheques are sent out directly to you so there's no need to claim.

The NRAS Lottery is part of Unity Lottery, a specialist organisation which runs lotteries for charitable causes and unlike most other lotteries, gives 50p from every £1 to NRAS. So, if 500 supporters signed up that would generate £13,000 towards our work in raising the profile of RA with politicians and key policymakers within the new NHS structure to maximise your access to the best treatment and levels of care.

To play the NRAS Lottery you can either join online at www.nras.org.uk/lottery or fill in the form in the leaflet included with this Magazine. You can pay by direct debit or by sending a cheque made payable to Unity with your completed form to Freepost, NRAS Weekly Lottery, Barrow in Furness LA14 2PE (to be completed once we have full registration details)

By joining our lottery you can help us to help you.

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**. If you want to know more email **ruth@nras.org.uk**

Give as you Live™

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The Information Standard
Certified member
This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

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www.nras.org.uk Freephone Helpline: 0800 298 7650