



nras
National Rheumatoid
Arthritis Society

SPRING 2014
Magazine

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FEATURE

Keep taking the pills
The critical importance
of adherence in the
management of RA



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**CUTTING EDGE
BOARDS**

Graham Drummond shares a unique range of cutting edge chopping boards to help cooking lovers in the kitchen. P8

FUNDRAISING

**TEEING OFF
FOR NRAS**

Peter Gill continues to raise a staggering amount of money for NRAS. His fantastic support has raised an incredible £8,942. P15

GENERAL ARTICLE

**RA AWARENESS WEEK
16-22 JUNE**

Let's be vocal and make RA visible! This is our second awareness week campaign and we need you to help us raise the profile of RA as much as you can to change the public perception of this condition. The week will take place from 16th-22nd June so get this date in your diaries! P27

Please read and feel free to share

FOLLOW US ON FACEBOOK

KEEP UP TO DATE WITH
OUR LATEST TWEETS



NRAS LOTTERY

Join the NRAS lottery
Find out how on P18

GET IN TOUCH

www.nras.org.uk
01628 823 524

Dear members...

It is so nice to have some days of sunshine after all the endless grey and rain we've had, as I write this in early March. Spring is my favourite season of the year and sun, tulips and daffs coming out alongside the early blossom just fill me with feelings of hope and renewal and stick a smile on my face.

We are now installed in our new office which we all love. We're all in one space now instead of between 2 offices so the whole team is together but with enough space that we're not on top of each other and with room to grow. We've already taken on 4 new staff this year and plan to take on 4 further staff during the course of 2014. We are in the process of having video conferencing installed in our meeting room thanks to the generosity of Carillion Communications Ltd, an audio visual services integrator based in Maidenhead which has donated the installation to us (I had to sleep with the Managing Director of Carillion to get this, but as he's my husband, I guess that's OK!). This will enable us to communicate more effectively with some of our partners and Skype with our Ambassadors in Scotland and Wales and save us some travelling.

The first two of our NRAS roadshows have taken place in Elstree and Bristol with more dates around the country, do check the website if you'd like to come along and find out more about NRAS and how to get involved. There are lots of interesting ways to work with us and we look forward to seeing some of you at a roadshow soon – we can achieve so much more with your help!

We launched our report mapping JIA services across the UK in February – if you are interested you can see the report at www.nras.org.uk/jiareport and I am delighted to confirm that we shall be launching our new JIA service at a family day in the West Midlands on 19th July – for more information call Maria-Benedicta Edwards at NRAS or email her at maria@nras.org.uk. Also, we have a new logo for our children's service – hope you like it! There is a short summary on what has been happening with JIA in this issue.



We shall also be reviewing diet in this issue, as promised in the last magazine, as this is always a topic of interest to people, so check out page 32.

In March we took a film crew down to Bournemouth to film Robert Field and colleagues running a podiatry course which has been available for a number of years, but is sadly coming to an end. When Robert



originally told me last year that they would have to stop running it I suggested that we apply jointly for some local funding to film it so that we could put it on to our website for the benefit of everyone in the UK. We were successful in obtaining funding from a local trust at the end of last year and the film is now being edited and we shall be launching it at the BSR this year.

Finally, I would like to draw your attention to the article on annual reviews (see page 19) as carried out at Newcastle. Having been on the NICE guideline development group for both CG79 – Guidelines for adults with RA, and the Quality Standard Topic Expert Group which produced Quality Standard no 33 for RA in June last year, I am not aware of many units in the UK which are conducting proper holistic annual reviews in line with both the Guideline and the Quality Standard, and so it was with great interest that I spoke to Dr Martin Lee about the review process they have initiated at Newcastle. I'd be interested to know how many of you are getting annual reviews similar to this. Please do drop me an email and let me know – ailsa@nras.org.uk.

That's all for now. Have a great summer and my best wishes to you all!

Ailsa

Happy New Home

We are now settled in at our new office in Maidenhead and it feels like we have been here forever! The extra space we have, and all being together in one open plan office, rather than spread across two in our previous building, has worked really well and everyone has settled in very happily. In early January the Deputy Mayor of Maidenhead officially opened the office for us.

This has meant we have been able to comfortably accommodate our new staff and have space for further expansion over the coming years. We are always happy to see any of our members so if you are in the Maidenhead area do give us a call and come to visit.



The Deputy Mayor of Maidenhead officially opened the office

NRAS Welcomes New Staff

We have had a busy start to the new year with 4 new members of staff joining the team.

Beverley and Sally have joined the Helpline team as Helpline Information and Support Coordinator and Deputy Manager Information and Support, respectively. Having undergone their initial training, they are now taking calls and responding to your emails as well as replying to posts on Health Unlocked and our Facebook page when you have specific queries.

Laura and Julia have joined the Government Affairs team. Laura joins us as Government Affairs Officer, replacing Leo who left the charity at the end of last year, and will be overseeing our work in Scotland and the Scottish Ambassador programme and also work on welfare reform. Julia has joined us as part of the Rank Foundation's Time to Shine intern scheme and will be with us for a year, establishing our work in Wales and beginning the task of developing our policy work in the new area of Juvenile Idiopathic Arthritis (JIA).

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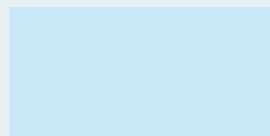
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NRAS Members help shape future awareness and treatment



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Meet the Team...

Gill about Bronwen

I was delighted when Bronwen joined the fundraising team as it meant I was no longer the 'new girl' in the office! It seemed that Bronwen slotted into the team seamlessly and it was in no time at all that it felt as though she had always been there. She has THE most infectious laugh in the office and often has us helplessly laughing when we don't really know what for.

As you might guess Bronwen has Welsh roots which today as I write meant that she has brought in some homemade 'Bara Brith' to belatedly celebrate St David's Day! Bara Brith is a traditional Welsh Tea Bread – full of fruit and spices soaked in cold tea overnight before baking. I can certainly recommend this and all Bronwen's baking skills.

It is lovely to have such a happy person in the office.



Tammy about Nicky

Nicky is Ailsa's new PA and she joined us at the end of last year. It was my pleasure teaching her the ropes after I had been taught them all myself all that time ago. It is really amazing and lovely how quickly Nicky has adapted to us and our society. I know that has been mentioned a lot in past Meet the Team excerpts, but it just shows that we select the right people for the job.

Although I do not work closely with Nicky on a day to day basis, she is one "diamond in the sky" as the song goes! Nicky is extremely hard working, proactive and a conscientious individual who closely works with our Directors, Tracey and Clare, and above all Ailsa, our Chief Executive. When not busy trying to keep a few steps ahead of Ailsa, Nicky is in charge of coordinating the Rheumatoid Arthritis Self Management Programme. In her spare time she runs a busy household and is married to a toyboy(!) and has two teenage children. At lunch breaks I see her rushing off to take her dog for a lovely long walk - this may be her secret to looking so young and energetic! Lastly, she is a smiley new member to the NRAS team that helps out in any situation given.



NRAS has passed re-certification for the Information Standard

Some of you may be aware that NRAS has been a member of something called the 'Information Standard' for the past 3 years. For those of you who have not heard of this, it is a certification scheme for health and care information which was set up by the Department of Health in 2010. Successful organisations can use the quality mark on materials to confirm that the processes they follow in information production meet the strict criteria set out by the scheme, demonstrating good quality information. You may well have seen the logo for this scheme on NRAS Members' magazines, such as this one, and it now appears on the majority of NRAS publications.

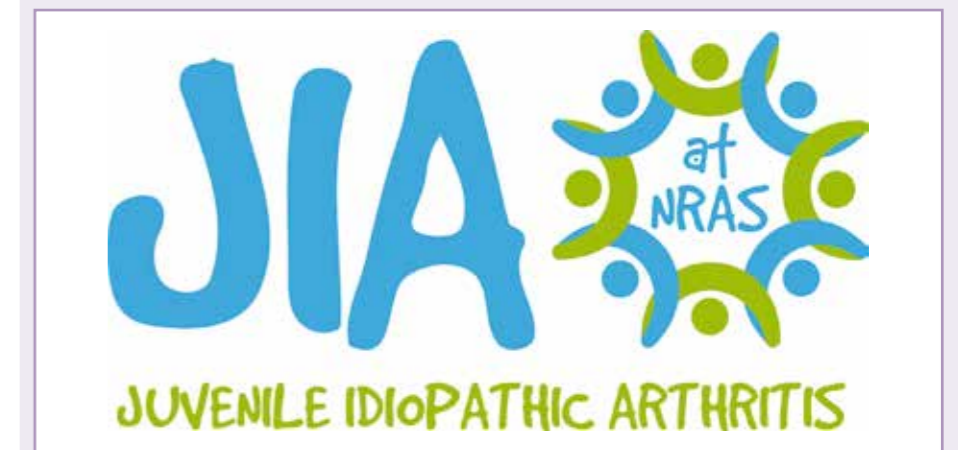
Membership of this scheme is reviewed on an annual basis and certification needs to be re-applied for every 3 years, and we are pleased to say that NRAS has recently passed this re-certification. Some of our Members have also made invaluable contributions to our involvement in this scheme, particularly those who have attended focus groups or reviewed some of our new and existing publications, for which we are very grateful.



So what's happening with JIA-at-NRAS?

It has been a busy first three months of 2014 for the new JIA team organising the launch of our much anticipated report "A Focus on Juvenile Idiopathic Arthritis" in February and beginning to plan the launch of the service in July.

It's also been full steam ahead with our plans to set up a new website for parents to provide information on all things JIA, from pre-diagnosis through to day-to-day living with JIA. Planning the official launch of our new service on 19th July with Tea on the Beach at the Heart of England Conference Centre in Fillongley in Warwickshire, is going well. This is planned to be a fun afternoon for all the family, where children can take part in all sorts of exciting activities and parents will also have the opportunity to "Ask the Professionals". More details of the day are to follow so if you know of a family living with JIA get them to make a note in their diaries to come along for a cup of tea and a piece cake because we'd love to meet them. We have also chosen our new logo for JIA-at-NRAS which is fun and funky and chosen not just by us old 'fuddy-duddies' here at NRAS but by the overwhelming majority of 290 children at one of our local schools. Last, but not least, we have been out and about meeting young people and their parents, as well as health professionals who care for them, and hearing how we can raise awareness of JIA, help and support young people and families living with the disease and bring them together as a community. As part of this challenge we are working towards setting up a national JIA youth network to give JIAthriters a voice. If you, or someone you know, would like to be part of our network please email me, maria@nras.org.uk, as I'd love to hear from you.



JIA at NRAS logo

Get involved...

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



Membership

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



Fundraising

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



Volunteers

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

T: 01628 823524 WWW.NRAS.ORG.UK ENQUIRIES@NRAS.ORG.UK

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

My story... By Major Jake P Baker JP (retired)

I retired from the Army on 30th April 2013 after nearly 42 years' service – man and boy. I enlisted 6 days after my 15th birthday, taking the Queen's Shilling on 26th August 1971 at the Army Careers Information Office in Salisbury, Wiltshire. I was brought up as a foster child and, though I did not appreciate it at the time, was extremely fortunate to have remained with that family from the age of only a few weeks old.

My father was from Nigeria and my mother is English. In those days it was looked down upon for white English women to be seen to be having a relationship with a black man, and so my mother was compelled to have me fostered. My father read Law at Exeter University, was called to the Bar (Lincoln's Inn) and rose to very high office in Nigeria and was also the 10th Ezennia of Ndikelionwu – the king of the tribe! One could say I am of royal stock and so should be perfect in many ways! Well, not so, indeed when many of us are young, we believe we are infallible and can do anything. Rather immaturely, I believed that for many years and eventually, like most, grew out of it.

I have had a fulfilling life and extremely enjoyable Army career, starting from

bed-bathing Field Marshal Montgomery in the Cambridge Military Hospital in Aldershot, to exercising in the Falkland Islands 29 years after the conflict! I served and travelled in many parts of the world, in Northern Ireland many times and Cyprus twice – once with the United Nations Peacekeeping Force for a period of two years. Sport was in abundance wherever one served and I have raced to a good standard in cross-country running, middle distance and long distance athletics, run over a dozen marathons and half a dozen ultra-marathons raising money for various charities, played tennis and squash, trained as a Class 3 football referee and learned to water ski with difficulty!

As a result of Army service, I became an accountant, a Regimental Administrative

Officer, intermediate level German speaker and basic level speaker in Greek too.

I remember when I was a child I hated the cold and used to get chilblains. I believe serving in Germany and being on exercise in the extreme cold, mixed with being exposed to extremely hot conditions in Cyprus led to the onset of my Rheumatoid Arthritis in later years.

In May 2010, having played a cracking game of squash with my son the day before, I woke up to find my fingers had swollen, were quite stiff and my wrists ached. Were it just my right ones, I would not have been too concerned and merely put it down to playing too much squash, but it was both and I suspected something like a glandular malfunction at worst. Always the sort to see the

doctor as soon as something was not right, I reported sick to the Regimental Medical Officer, who quickly suspected RA. So, I had blood tests, and a week later it was confirmed.

Despite initial training in the Army as a medical assistant, I rather ignorantly thought only women suffered from this condition and that it is usually genetically linked or down to one's lifestyle. I now understand this is not the case, but personally I'm not convinced.

I was most fortunate to be swiftly referred to a rheumatology consultant at Headley Court, near Epsom in Surrey, where the Defence Medical Rehabilitation Centre is located primarily responsible for looking after our very brave service personnel who have become casualties following operational tours, especially those who have become amputees during their service in Afghanistan. Whilst RA is not easy to live with in the Army, I managed to cope with it because my condition was relatively mild, had a desk job and, because I was an officer, I had a degree of leeway in terms of what I did and when. Fatigue was the only problem and initially, for at least six months, I was staying overnight in my office on training nights and other days, especially if I had to have a very early start the next day driving somewhere as far as Bristol from Luton.

I have since learned to manage my fatigue and 3 or 4 flare ups a year much better, and have changed my diet too, eating much more healthily these days so as to maximise my energy levels. I find walking up to an hour a day, at least five days a week, helps to energise me and keep my weight down, because for about 18 months I suffered from sleep apnoea too! I know I am most fortunate to have been seen swiftly and so brilliantly managed by the whole of the military rheumatology team from day one until my last day in the Army. I consider myself lucky too to have to take the maximum dosage of 3000mg of sulphasalazine, which for me is a most effective DMARD. My wife, family and friends have been most supportive and understanding - to most, I live as normal a life as anybody else, so I really do count my blessings because since joining NRAS I have learned so much more and unfortunately have met people in a far worse situation than myself. I even joined the NRAS Lottery and make monthly contributions to support a great charity that helps RA sufferers in need; it truly is a great cause and one I am happy to help.

Since leaving the Army, I have been transferred to the care of my local NHS consultant rheumatologist and whilst I had my concerns initially, I am actually in great care, get my blood taken and monitored regularly and whilst I am only scheduled to be seen by the consultant and his nurse annually, I am confident that should I have any concerns or issues, I can make an appointment to see them anytime I wish. I think if truth be known, I had gold star treatment whilst serving in our great armed forces, so I can't complain. Life goes on as normal, despite the few flare ups I get, manageable problem of aching wrists and fingers from time to time and then what feels at times, never ending fatigue.

As the motto says in the Royal Army Medical Corps

"In Arduis Fidelis"

– Faithful in Adversity.



From foster child to army officer



I've got what?

The doctor said, "Graham, you have Rheumatoid Arthritis" and I replied, "What's that?" I was 20 years old and had just begun a career in land surveying and remember thinking at the time this could be a bit inconvenient. I was to learn a few years later it really sucked!

I had begun experiencing joint pain in my early teens and my doctor said it was 'growing pains'. Not an uncommon diagnosis in the early 1970s, here in New Zealand.

Despite being diagnosed with severe erosive rheumatoid arthritis I continued surveying for another 17 years. However, my condition progressively worsened to a point where I had to eventually give up the job I loved.

Arthritis stops play

We all have defining moments in our lives; I was bowling a cricket ball to my young son in the cricket nets, something we did most evenings during the summer. I stepped up to bowl the ball and suddenly was unable to my roll my arm over. I have never been able to throw or bowl a ball again.

Numerous surgeries followed including joint replacements and fusions, from my ankles to the top of my neck.

It's been impossible to repair all the arthritic damage to my joints, especially my hands which now have limited function, resulting in a very poor grip.

A new drug and an idea

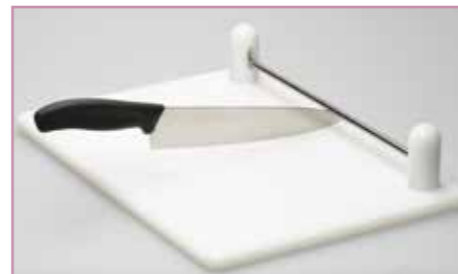
In 2008 I was put on Humira. Almost overnight I regained a quality of life I had not enjoyed since my mid 30s. I was now living with minimal pain and was no longer getting fatigued. If I felt any better I would be dangerous, and then I got an idea!

I love to cook, but had become increasingly frustrated at my inability to hold and use a cook's knife while preparing meals in the kitchen. If cooking becomes hard work, it's no longer fun.

To compensate for my poor hand grip I held a chef knife in one hand and instinctively placed my other hand on the tip of the knife, enabling me to cut and chop more effectively.

I thought if I made a food cutting board that retained the tip of the knife, beneath a bar, it would free up my hand to hold the item being cut. As a result, the knife becomes a lever pivoting on the bar and requires very little effort to hold.

The bar needed to have a biasing arrangement to allow the tip of the knife to move in a forward and vertical direction to enable a chopping and slicing action and so the Cibocal Food Cutting Board was born.



The Cibocal Food Cutting Board

People have said to me, "...it's so simple it is a wonder no-one has thought of it before!" I reply, "someone probably has, it's just they did nothing about it, so I did!"



Cibocal Food Cutting Board in action

I've spent four years developing the idea, obtaining patents, making the boards and creating a website. Boards can be purchased online from www.cibocal.com.



Graham is now able to enjoy cooking like he used to

Members Top Tips...

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

Hot water dispenser

My wrists and hands are very weak and painful so I have a hot water dispenser instead of a kettle. It's no good for large quantities but wonderful for a cuppa without the need to pick up large amounts of boiling water which is obviously dangerous.

Tilstongal – Health Unlocked



Share your ideas...

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

TePe Angle interdental brushes

I saw your request for tips for making life with RA a little easier on Facebook, and I would like to suggest TePe Angle interdental brushes with handles. They were recommended by my dentist to help prevent gum disease and I find them much easier to use than dental floss when my fingers are a bit sore and swollen.

Catherine



NRAS Annual Conference – Date for your Diaries!

We are delighted to announce that our 2014 Annual Conference (previously known as Members' Day) will be held at Gomersal Park Hotel, West Yorkshire on Friday 19 September. The venue is in its own parkland setting, easily accessible from the M62 and just a short drive from both Leeds and Bradford. As in previous years, it will be free for NRAS Members to attend, with a small charge of £5 for non-members, family and friends who wish to come along.

We have lots of exciting speakers and workshops planned for the day. Spaces are limited so do register soon if you would like to attend.



Members' Day 2013 – Solihull

Further information, including a full timetable and directions, will be sent out nearer the time but if you would like to register your attendance for the event now, please email membership@nras.org.uk with your full name, postcode and whether you would like to bring a guest(s). We look forward to seeing you all in September.

Keep taking the pills

– the critical importance of adherence in the management of rheumatoid arthritis

Catherine E Swales, NDORMS, Botnar Research Centre, Nuffield Orthopaedic Centre, Oxford, and John D Isaacs, NIHR Newcastle Biomedical Research Centre, Institute of Cellular Medicine, Newcastle upon Tyne

Adherence is often easier said than done. In broadest terms it is defined as “the extent to which a patient’s behaviour follows medical advice” and whether it relates to taking medication, following a diet, or adopting lifestyle changes, there’s no doubt that it can require psychological stamina. The vocabulary may have moved on from compliance (or concordance) which, in the era of increasing patient involvement in decisions and a more collaborative approach to care, now seems judgemental and implies obedience, but is something with which we all still struggle. For chronic disease in general, the best evidence suggests that patients take their treatment only half of the time, and for patients with RA, that figure varies between 30% and 80%. To make matters worse, such difficulties often go unreported or unnoticed. Patients often feel reluctant to admit to non-adherence, fearing disapproval, and studies suggest that physicians are bad at asking about it, assuming that a failure to respond to therapy requires a medication change, rather than a frank discussion. In addition, a recent study has suggested that doctors can only reliably identify those patients who do take their medications rather than those who don’t, thereby failing precisely those who need the most support. The result? Sadly, the evidence is unequivocal, the success of RA therapy hinges on adherence - and patients who don’t take their treatment run the risk of flares of disease and continuing pain and stiffness, joint damage and disability. Recent studies have shown that disease activity scores (DAS28), inflammatory markers (ESR and CRP),

x-ray damage and functional impact are all significantly lower in patients with good adherence to treatment.

Better adherence should mean better quality of life, but we must accept that sometimes it’s a tall order.

Patients may struggle with DMARDs intermittently or constantly, and for very different reasons, but non-adherence generally divides into unintentional or intentional patterns. Unintentional non-adherence is often either due to physical difficulty with, or simply forgetting, to take medications. On one level, these may be the easiest issues to overcome, and there are ‘tricks’ that patients can use such as reminder alerts on mobile phones or, for the less e-minded, sticky-notes on bathroom mirrors or fridges. One of my patients wraps a ‘horrendous pink hair-band’ round her toothbrush – whatever works to jog the memory. With the commonest DMARD, methotrexate, where adherence to weekly medication can be difficult, adopting a habit of Methotrexate Monday (and Folic Acid Friday) can make a big difference. Difficulty with physically taking tablets or injections can also be troublesome, but specialist nurses are often able to help and advise in this regard.

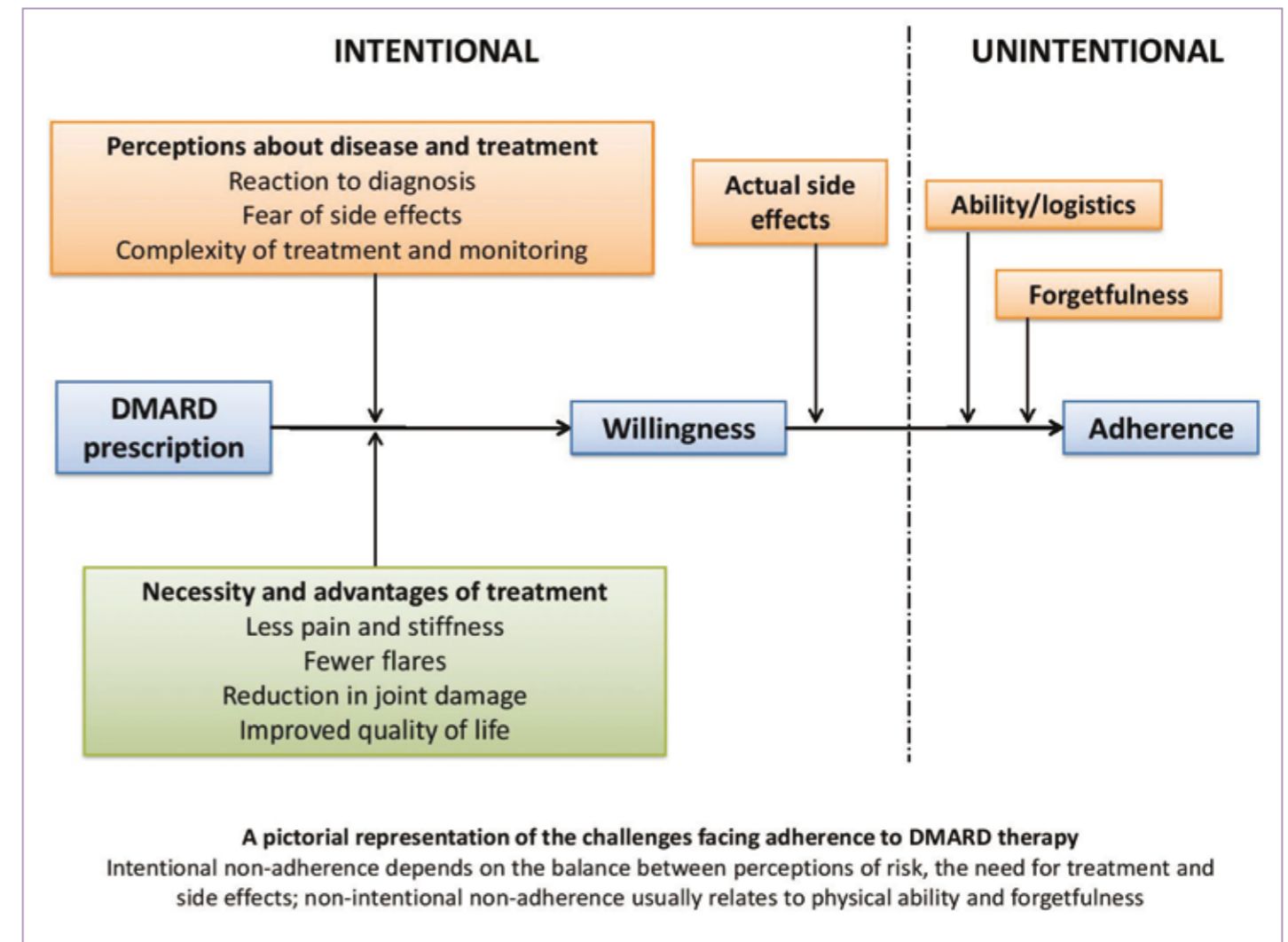
Unfortunately, the more difficult type of non-adherence is intentional. This signifies a concrete decision not to take medication, and is often based on personal beliefs around the balance

between the need for the drug and the perceived risk, side effects or thoughts and fears about taking it; sadly DMARDs often lose out in this risk-benefit analysis. It’s sobering to think, for example, that NSAIDs are better adhered to than any of the DMARDs, including biologic therapies, as they are familiar, give immediate relief and are still (incorrectly) considered to be risk-free: “...if I can buy it from the chemist and it

doesn’t need monitoring, it can’t be bad for me”. This intentional non-adherence is dynamic, susceptible to several influences and is understandably sometimes hard to

discuss and address. Patients may not start treatment due to grief/anger at their new diagnosis, difficulty understanding the disease or its treatments, the perception of risk of treatment versus the risk of disease progression and so on. It’s critical that they have the time and space (and indeed the courage) to raise and discuss these issues early, when new beliefs and behaviours are being adopted. The slow onset of action of many RA drugs is an additional factor here. Later on in disease, problems might still be linked to differences between a patient and their healthcare team in the ‘belief of need’. This particularly applies to patients in low disease activity states (DAS 2.6-3.2) may feel that they’re “actually doing ok for now” and be reluctant to increase their therapy further, although their doctor or nurse may recommend escalation in order to reduce residual disease as part of Treat To Target.

“If I can buy it from the chemist and it doesn’t need monitoring, it can’t be bad for me”



A pictorial representation of the challenges facing adherence to DMARD therapy

Without honest dialogue at every stage, and by all parties, valuable opportunities are lost.

Greater understanding of the risk factors for non-adherence might allow for better support for those who are really struggling to take their DMARDs. The main factors associated with non-adherence are socioeconomic and healthcare factors (especially a poor doctor-patient relationship), condition and therapy-related (complexity of treatment and side-effects, both feared and real) and patient-related (beliefs and the presence of other psychological factors, particularly depression). However, as with everything else in RA, there’s no ‘typical’ patient or risk profile - although as expected, a recent study has highlighted that patient’s beliefs

about the necessity for treatment and a good doctor-patient relationship are crucial. Most patients with RA actually do have positive beliefs about the necessity of their medication, but levels of concern about side effects are also high (particularly when a treatment requires regular blood tests to monitor for side effects), and perhaps it’s human nature to recall most profoundly the one bad story about treatment in the face of several better ones. In general, if the feeling of necessity outweighs their concerns, patients will take their medication – until such time as their perceptions change, and then a different psychological landscape will need to be negotiated.

However, recognition of the problem, both by patients and their healthcare

team, is half the battle, and an honest and open dialogue about difficulties with adherence at all stages of disease is crucial. Patients need to realise that they are not alone. They should feel empowered to recognise why they are struggling and to find the courage to articulate the concerns that dominate their treatment decisions; seeking help from family, friends, GPs and NRAS can be invaluable here. Healthcare professionals also need to ask the right questions, and be flexible and open-minded about the answers they get. Sometimes the simplest solutions really are the best, and support can go a long way to changing negative beliefs, thereby improving adherence and outcomes for patients with RA.

Government Affairs

The recently published (December) Independent Review on the Work Capability Assessment (WCA), unfortunately did not make any recommendations to change the WCA to better accommodate fluctuating conditions. Building on our 'progressive conditions' dossier work, which was published in 2013, we have continued to work with charities including Parkinson's UK and the MS Society to table further parliamentary questions and persuade politicians to hold a debate on the issue of progressive conditions within WCA.

Problems have continued with the roll out of the new Personal Independence Payment (PIP) with a new National Audit Office report showing that long delays are occurring in the claims process. In the last quarter NRAS attended meetings with officials from the Department for Work and Pensions, Atos and Capita to discuss how to improve PIP for people with musculoskeletal (MSK) conditions and is helping to review Capita's MSK training materials as well as pushing for the creation of MSK Champions to help audit the work of other PIP assessors. Atos has stalled on making a decision, but Capita's response has been favourable in early discussions and we are working with ARMA and its member organisations to collect more evidence about this.

CAPITA

With the 2015 General Election fast approaching, the main political parties are developing their political manifestos. In late February, Labour published the results of an independent review by Sir John Oldham that set out a number of recommendations to improve 'whole-person' care, including the suggestion to merge health and social care budgets and restructure some NHS organisations.



To help inform discussions, we have started work to produce our own short manifesto document which will be published in the next quarter. We hope that NRAS members will be able to use the document to lobby local politicians in the run up to the General Election.

As part of RA Awareness Week 2014 we intend to publish some new research exploring the impact of chronic fatigue on people with RA. NRAS will be working with rheumatology units to encourage as many people with RA as possible to complete an online survey to inform this research. We are also planning a series of 'meet the patients' events helping politicians to meet constituents with RA.



Transparency of Lobbying, Non-Party Campaigning and Trade Union Administration Act 2014

In January, the UK Government passed new legislation to govern lobbying, which contained provisions that affected the way that charities will campaign in the future. The legislation received a lot of criticism from charities, who believe it will impede their ability to campaign freely in the build up to elections. NRAS worked with the Commission on Civil Society and Democratic Engagement to challenge many aspects of the Bill, with mixed results. We set up an e-campaigning action for NRAS members to contact local MPs, sent out separate briefings to all MPs and also lent the charity's logo to a series of adverts in national newspapers drawing attention to deficiencies in the Bill.



Dr Paul Litchfield published a review of the Work Capability Assessment in December

With the launch of the new JIA report in February, the government affairs team has been contacting politicians in England, Scotland and Wales to discuss campaigning priorities and identify opportunities to present to policymakers about the new report. An opportunity to present to the Cross Party Group on Musculoskeletal Conditions in the Scottish Parliament in the autumn has arisen and, at the time of writing, discussions are underway about the possibility of presenting to the Cross Party Group for Children in the Welsh Assembly.

Elsewhere, we have submitted written evidence to a government consultation on the Clinical Commissioning Group Outcome Indicator Set (CCG OIS). The CCG OIS is one of the main documents underpinning the quality framework in the new NHS and is one of the few documents that does not now contain an RA indicator. Responding to the government's consultation, NRAS argued for the inclusion of three new indicators on RA that were originally put forward to the NICE CCG OIS Advisory Committee by the NICE Topic Expert Group on RA, but rejected. The indicators, if introduced, would seek to measure whether comprehensive annual reviews have taken place for RA patients, whether people with RA are assessed by a rheumatology service within 3 weeks of referral, and whether people with newly diagnosed, active RA are offered a combination of disease-modifying anti-rheumatic drugs and short-term glucocorticoids within 6 weeks of assessment by a rheumatology service.

NICE

Rheumatoid Arthritis Summit 2013

On 11 December 2013, NRAS held its second annual RA Summit in the House of Lords to discuss the true impact of poor public awareness on rheumatoid arthritis patients and the NHS and showcase findings from NRAS's *Breaking Down Barriers*, which explored these challenges in detail. The UK Public Accounts Committee published a report in 2010 stating that there is a clear opportunity to save the NHS money and improve clinical outcomes for patients through better public awareness and early diagnosis of the disease.

The Summit, therefore, sought to tackle these issues head on, with a rare opportunity for the audience of assembled guests - including MPs, clinicians and chief executives of major charities - to hear perspectives from leading national experts in the field of RA about the state of national policy, the latest academic research and the challenges faced by commissioners in improving public awareness.

Chaired by NRAS Patron, Baroness Sal Brinton, other keynote speakers at the event included Professor Peter Kay, National Clinical Director for Musculoskeletal Conditions at NHS England; Professor Karim Raza, a leading expert on public awareness of rheumatoid arthritis and Professor of Clinical Rheumatology at the University of Birmingham; and Minesh Patel, Executive Member of the National Association of Primary Care.

During the event the National Clinical Director decried 'scandalously' low levels of public awareness of the disease and claimed it is now the most important issue standing in the way of improved health outcomes for people with RA. Professor Kay publicly committed to take action on poor public awareness through holding a stakeholder event to develop a plan of action and called on the National Audit Office to instigate a fresh review of implementation of its recommendations.

Professor Karim Raza from Birmingham University also commented during his presentation that excellent treatments are now available for rheumatoid arthritis but to be most effective they have to be started early. Too few RA patients in the UK begin treatment within the critical window and that needs to change.



Baroness Brinton talking to Baroness Howe of Idlicote at the RA Summit

The speaker panel line-up:



Professor Peter Kay
National Clinical Director for Musculoskeletal Conditions at NHS England



Ailsa Bosworth
Chief Executive of NRAS



Professor Karim Raza
Leading expert on public awareness of rheumatoid arthritis and Professor of Clinical Rheumatology at the University of Birmingham



Minesh Patel
Executive Member of the National Association of Primary Care

Leave it to us to make a difference

Leaving a gift in your Will helps us to continue to help all those who live with RA and JIA, their families, friends and carers and is a perfect way to give ongoing support to something which has mattered to you in your lifetime.

Whatever the gift, small or large, it does make a difference. Whether it's an item of jewellery or furniture or a monetary gift, it will help secure the future of NRAS to ensure we can continue to help all those who live with RA and JIA, in the ways which, we hope, we have supported you, as well as helping us to expand and develop both existing and new services.

A gift such as this is a very personal way of giving, and one which we realise is sensitive and sometimes difficult to

think about. However, we are here to help and very happy to talk to anyone who wants to discuss this in more detail, understand how such funding is used, or just be assured about giving in this way.

Penny, one of our members, said "I have received more help and thoughtful concern from NRAS than from any other patient organisation I have approached. I was diagnosed with RA approximately 12 years ago... I ventured forth to an NRAS meeting where a new group was starting up.

It was so good to let one's feelings 'out' with people whom I had a lot in common with. That was just the beginning... I am the lucky one, and I wish to say thank you in a big way when I depart this life."

To discuss leaving a gift please call Oli, in confidence, on 01628 823524 or email him at oliver@nras.org.uk for more information or to request a leaflet to be sent to you with more information. There is also a section on our website with useful information and case studies.

The NRAS Tea Party 2014 – A Vintage Twist on Afternoon Tea

The NRAS Tea Party has to be one of the best ways of fundraising out there - what could be better than supporting a worthy cause by enjoying a big slice of cake, a mug of freshly brewed tea (or coffee, we won't tell) and the loving company of friends and family? It is simply unbeatable as no training is required!

This year you will notice we have added a 'vintage' twist to the theme, so why not use this as your inspiration? Pick a date, get out the china and invite your loved ones over to learn about what RA is and the latest work of NRAS, and raise some funds for us too. Prominent dates in the calendar make the best occasions, so how about doing a Tea Party over the May Bank Holiday or hosting a party during RA Awareness Week (16th-22nd June), or how about hosting a party with a Pimms theme, making best use of the fine weather we must be due this summer!



Gill, Jane and Dani at the launch of our Tea Party

If you want to host your own NRAS Tea Party, our new Tea Party Pack is crammed full of useful ideas, help and support. Contact Bronwen in the Fundraising Team at bronwen@nras.org.uk or call 01628 823524 for your copy. Alternatively, all the information and support materials can be downloaded from the website.



NRAS Tea Party leaflet

Helly and her wheelchair take on the Great North Run again!

Helly Berger, an NRAS member and group coordinator, is once again taking to the streets of Newcastle to take part in the Great North Run.

Helly will be taking part in her trusted wheelchair and will have a team of 'pushers' taking it in turn to take the helm and get her around the 13.1 mile course. Chris Deighton, President of the British Society of Rheumatology, is once again showing his support and will be part of Helly's team of 'pushers'.

As always, the team will be in fancy dress. Past themes have included super heroes and gladiators and this year Chris will be the pub landlord and Helly will be his buxom barmaid! Ideally, they would love a few more pushers so if you would like to join them on the 7th September, contact our Events Fundraiser Val, who would love to hear from you and can be contacted at val@nras.org.uk or call 01628 501547.

If you would like to sponsor Helly please visit her Justgiving page at <http://www.justgiving.com/teamnras>.



Helly and her team of pushers

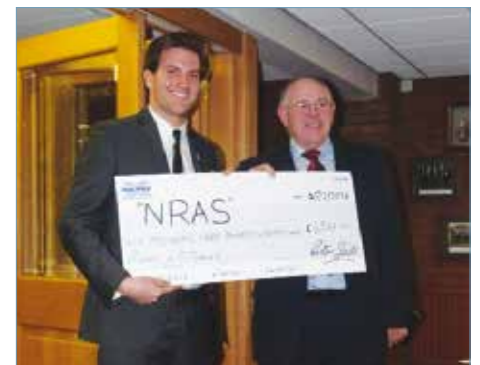
Good luck to all our runners taking part in this year's run, you are all stars!

Teeing Off for NRAS at Stoke Rochford Golf Club

For the last seven years we have been lucky enough to receive the dedicated support of Peter Gill, who has made it his mission to both raise awareness of NRAS and to provide us with much needed funds. Peter has been supporting us annually with a charity golf day, which we are delighted to say has gone from strength to strength, and last year alone it raised over £2,000 when it was held during RA Awareness Week in June.

For 2013 we were fortunate that Peter became Captain of his local Golf Club, Stoke Rochford Golf Club in Grantham, Lincolnshire, and decided to support us further throughout the duration of his Captancy. In total, for 2013, Peter raised an incredible £8,942.57, a truly remarkable achievement. Thank you Peter and all those who supported you over the year.

If you, or someone you know, are about to become Captain of your local golf club, why not consider supporting NRAS throughout your term? We have a wealth of experience and can help you really make the most of your year. Get in touch with Oli on 01628 823524 or email oliver@nras.org.uk.



Oli and Peter Gill

New Collection Boxes

The fundraising team are delighted to bring you our new brand new NRAS collection boxes. Whatever fundraising task you have set yourself for 2014, whether it is an NRAS Tea Party, sponsored silence, sponsored car wash or dress down day, this new collection box will make your fundraising look much more attractive! Best of all, it only costs NRAS the price of posting an A4 envelope to send it to you and can be included in any publication or materials order. To get yours, please email fundraising@nras.org.uk or call 01628 823524.



New NRAS collection boxes

NRAS Christmas Carol Concert

Although Christmas is a long forgotten memory for most at this time of year, we wanted to share with you the exciting news that our 2013 Christmas Carol Concert welcomed more friends to the festivities than ever before, over 150, and also raised almost £1,000, more than we have ever raised before! Thank you to all those who came along to support us and we hope to see some new faces this coming December... but let's not think about Christmas yet!



Tim Brooke Taylor reading at the Carol Concert



All Saints Community Choir singing at the carol concert

Colnbrook Amateur Stage Theatre act up a Storm for NRAS

Colnbrook Amateur Stage Theatre or CAST, have chosen to support NRAS as one of their two charities of the year. CAST put on 2 or 3 performances during the year and Dani, Tracey and Oli went along to see their winter production of Jack and the Beanstalk, the first show of the year to support NRAS. An enjoyable evening was had with plenty of laughs and many of the trademark panto lines we all love, "He's behind you!"

We are delighted to be one of CAST's charities of the year so head over to www.cast-online.org.uk to see when their next show will be held!



Colnbrook Amateur Stage Theatre's Christmas production

Katie's Skydive for NRAS

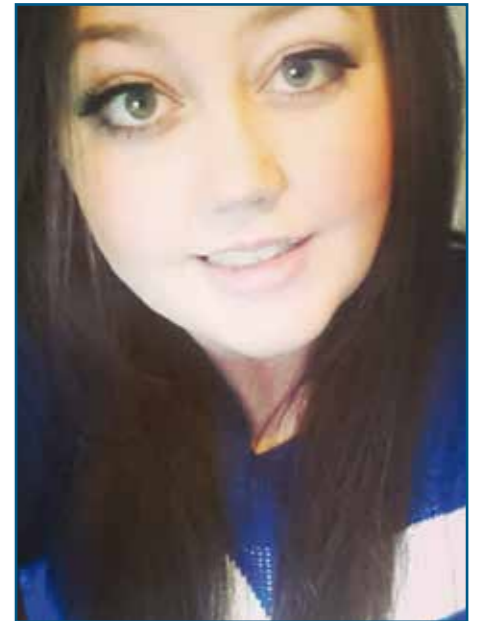
At aged just 13 Katie was diagnosed with JIA (Juvenile Idiopathic Arthritis). That was 8 years ago, and in 2014 Katie has decided to take on a huge personal challenge and skydive for NRAS. Katie is doing her jump with two other friends and they have all chosen charities close to their hearts.

As Katie knows about living with JIA she is keen to raise awareness and funds for NRAS. "NRAS is an amazing charity, and I wanted to give something back to it. There are so many people that suffer from this disease that need help and support. When I was being put on new medication, speaking to someone else that had been through the same experience helped me come to terms with the new medication and side effects. It would mean so much to me that I can help those who need it and support them through the struggle of this unfortunate illness."

Katie is holding a few smaller fundraising events to help increase her overall total. In March she held a quiz night at her local pub, The Cat and Fiddle in Radlett in Herts. She approached local companies which were very supportive

and donated some great raffle prizes for the night. Katie also managed to secure the venue for free and is grateful for all the local support she has been given. She is also planning a Bake Sale at her workplace, another very popular and easy way to raise some extra pennies to add into the overall total.

Katie is excited about her skydive, as it is one of the extreme challenges that is accessible to all. She will make her jump in Cambridge on April 23rd, shortly before we go to press, so watch out in the next issue to see how she got on. If you would like to join her and jump for NRAS at various venues around the country, or want more information about Skydiving for NRAS, please contact Val Eyre, our Events Fundraiser, on 01628 501547 or email val@nras.org.uk.



Katie Baker

Get your trainers on and run for NRAS!

Running has becoming a very popular pastime with more and more people taking part in a variety of different events. Would you consider running for NRAS and help us to raise much needed funds?

Once again we have charity places in the Great North Run on the 7th September, the largest half marathon in Europe, and if you are a keen runner this one is not to be missed! We also have places in the Great South Run on the 26th October, another popular 10 mile race which takes place in Southsea in Portsmouth and is a great race for first time or established runners as it is both flat and fast!

Perhaps you have already signed up to take part in a run? If you have would you consider running for NRAS? We will supply you with a running vest, a training programme and lots of useful information on raising sponsorship, and we will be there to help you every step of the way!

Whatever you choose to do we would love to hear from you. Contact our fundraising team at fundraising@nras.org.uk who will support you with whatever challenge you choose to take on.

Get your running gear on. Make 2014 the year you make a difference!



My Half Marathon in memory of my late Mum

By Anne O'Neill

I arrived in Longford, Ireland, on Friday 23rd August 2013, to get ready for the 12th annual Longford Marathon. Sunday soon arrived and it was a nice sunny morning with a friendly atmosphere with everyone getting ready for their different marathons ranging from the half, the full to the ultra marathon.

I was competing in the half marathon, 13.1 miles, and as I lined up on the start line I began to think of my mum, Kathleen Anne O'Neill, who lived with RA, and my other relatives, proudly wearing my NRAS t-shirt with my mum's photo on the back and my message saying 'sadly missed and always in my thoughts'.

The gun went off and with the spectators cheering and clapping, I ran across the line, still thinking of mum and my other relatives, especially my Auntie Rita, who also suffered severely from RA.

The race itself was hard and so I had to walk most of the way with some intermediate running. The locals provided refreshments along the route, which was most welcoming. As we were running/walking along the route the other runners were encouraging by saying "well done, keep going", which helped me along the way. To keep my spirits up I ticked off every mile completed as another £152.67 raised. It was a unique experience for me to run along the lanes and roads of my mum's hometown and country, but also as it was a smaller race than other marathons, there were long stretches where I was

on my own, but myself and some of the other competitors bunched together to cross the line together.

Seeing the finish line, I ran across it with a smile on my face and a sense of pride on what I achieved in my mum's memory, despite suffering a stress fracture in my right foot and very sore cuts on my toes. The half marathon medal was put around my neck which made me feel very proud. I finished in a time of 3 hours 18 minutes and 6 seconds, not bad considering the injuries.

In total, £2,000 was raised in memory of mum, which meant the world to me and I know will go a long way to helping others who are living with RA, their families, friends, and carers.

I would love to think my mum was looking down on me and helping me on my weary way through a poignant, but happy day, having completed my most special and important half marathon. I will be going back to Longford in 2014, God willing, to run the full marathon, because it will be 26 years since I sadly lost my mum, so it will be a mile for every year since she passed away.



Join the



We launched the NRAS Lottery in September and a huge thank you to all those who have signed up already. We now have over 260 players, and are seeing a regular stream of winners each week.



But we need more

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

Help us grow the NRAS Lottery and raise funds to help us continue to help you. Thank you!

A view from Newcastle

by Dr Martin Lee, Consultant Rheumatologist, Newcastle upon Tyne Hospitals NHS Foundation Trust & Newcastle University

The British Society for Rheumatology (BSR) and British Health Professionals in Rheumatology (BHPR) published a 20-point document in 2009 that provided guidelines for the management of RA¹.

This document has been superseded by the National Institute of Clinical Excellence (NICE) guidelines which were also published in 2009². Both these sets of guidelines recommended that all patients with Rheumatoid Arthritis (RA) have an annual review that incorporates disease assessment, damage, functional outcomes and evaluation of co-morbidity. Patients should have their cardiovascular risk and fracture risk assessed and should have the opportunity to be referred to other members of the health care team such as physiotherapy or occupational therapy. Quality Statement 7 in the NICE Quality Standard 33 for RA, published in 2013, states: People with RA have a comprehensive annual review that is coordinated by the rheumatology service³.

The quality outcomes framework (QOF) is a framework that provides guidance for GPs about conditions such as cardiovascular disease and diabetes. The aim of the framework is to reward GPs who deliver high quality care to their patients. In 2013/2014, largely based upon evidence and documentation submitted by the BSR, the Primary Care Rheumatology Society and NRAS, four RA indicators were included in QOF:

1. The general practitioner (GP) should maintain a register of patients aged 16 or over with RA
2. The percentage of patients on the register who have had a face-to-face review in the preceding 12 months
3. The percentage of patients with RA aged between 30 and 85 who have had a cardiovascular risk assessment in the preceding 12 months

4. The percentage of patients with RA aged between 50 and 91 who have had a fracture risk assessment in the preceding 24 months

Due to these new indicators, many patients will have been asked to see their GP in the past year for a check-up and review of cardiovascular risk factors and fracture risk assessment. From April 2014, sadly, indicators 3 and 4 have been 'retired' from the QOF and therefore there will be less drive for GPs to assess patient's cardiovascular and fracture risk. We are aware of the increased risk that patients with RA have of cardiovascular disease and fracture risk (largely in those patients with uncontrolled disease or who have taken repeated courses of steroids in the past) and that is where an annual review clinic in hospital fits in.

Currently, the Newcastle Upon Tyne Hospitals NHS Foundation Trust provides an annual review service which is available for all patients with RA. The service is a 40 minute consultation with a Rheumatology Specialist Nurse and allows the patient the opportunity to discuss any problems or concerns that they may have about their condition. During the clinic appointment a number of assessments are carried out including the QRISK2 score for cardiovascular disease and FRAX score for bone health. The assessment also looks at any functional problems the patient may have (such as issues with activities of daily living), the effects of RA on the patient's quality of life and mental health and the possible need for referral to other health care professionals. The clinic also provides an opportunity for the patient's medication to be reviewed and a disease activity score to be completed. During the consultation, patients can be educated about their condition and a plan of care can be agreed. These aspects of the consultation can be tailored to the individual needs of the patient.

We have recently conducted an audit of our annual review service in Newcastle. The overall consensus from patients is that they have really valued the time spent in the clinic. They felt that 40 minutes was about the right amount of time for the appointment and that they were given the opportunity to discuss things that sometimes they had not had with their GP or rheumatologist. We continue to assess and further develop the service for our patients.



An annual review

¹ British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (after the first 2 years). Luqmani R, Hennell S. et al. Rheumatology 2009

² <http://www.nice.org.uk/CG79>

³ <http://guidance.nice.org.uk/QS33/PublicInfo/pdf/English>

Smoking and RA

Smoking is recognised as a risk factor in the development of RA, although how the number of cigarettes smoked and the length of time spent as a smoker affect that risk remain unclear.

Researchers at the Karolinska Institute in Stockholm undertook an analysis of ten studies to try to determine if the risk of developing RA was dependent on the number of cigarettes smoked and the period of time as a smoker. The measure used was a pack-year (one pack-year of smoking would mean that someone had smoked one pack of cigarettes (20 cigarettes) daily for one year).

The researchers found that the risk of developing RA was 26% higher in moderate smokers (one to ten pack-years) compared to never-smokers. The risk of developing RA was doubled in heavier smokers (more than 20 pack years), but did not increase further in heavy smokers (more than 40 pack years).

The risk of RA was higher for rheumatoid factor positive cases than for RF negative cases. This again suggests a link between smoking and anti CCP antibodies.

The authors concluded that lifelong cigarette smoking was positively associated with the risk of RA, even among smokers with a low lifelong exposure. The risk of RA did not further increase for an exposure higher than 20 pack years.



A study looking at the best practices in treatment for early arthritis patients

Research carried out in Canada compared the differences in the way patients with early arthritis were treated in early arthritis clinics across several different sites. The aim of this study was to determine best practices in the treatment of patients with early arthritis.

The researchers compared changes in DAS28 scores, the number of patients who were in DAS28 remission and the treatment strategies used. The study included 1,138 patients in 8 different sites.

The results showed that those in the two largest sites had the best changes in DAS28 score and one of those centres also had the most patients in remission at 6 months. In these sites subcutaneous methotrexate was used more overall and earlier, and one of these sites also had the second highest use of triple therapy. Both these sites used less steroids. Medications were increased more in 2 of the 3 smallest sites. Biologics were used more quickly (within 9 months) in the smallest sites (50%) than the largest sites (19.6%).

The study highlights the differences in outcomes for early inflammatory patients dependent on the site where they receive treatment. The authors suggest that better outcomes may have been achieved by early and initial treatment with early combination therapy and/or subcutaneous methotrexate, and required less progression to biological therapies.

Patients with rheumatoid arthritis are more likely to have reduced kidney function

The findings of a US study from the Mayo Clinic in Minnesota, indicate that people living with rheumatoid arthritis are more likely to suffer from reduced kidney function than those who do not. These conclusions were based on the research carried out by the team in Minnesota which compared the renal health of 813 patients with rheumatoid arthritis with that of 813 healthy individuals.

The study followed these 2 groups over a 20 year period and the report which was produced revealed that people with rheumatoid arthritis were significantly more likely to experience reduced kidney function over this time period, than the healthy individuals, and that those who were also affected by cardiovascular disease (CVS) were also shown to be at greater risk of developing kidney problems.

Reduced kidney function alone did not appear to be associated with reduced lifespan for these RA patients, although they did experience an increased risk of morbidity from heart disease development, especially in those who had advanced kidney disease.

The study also revealed that there were some characteristics which were associated with a decreased likelihood or a protective effect of developing reduced kidney function, including having a BMI (body mass index) below 20 or the use of non-steroidal anti-inflammatory agents (NSAIDs) as a means of treatment.

Interestingly the study also revealed no link between the use of NSAIDs and the development of cardiovascular disease, hypertension or diabetes during the 20 year follow-up period.

NRAS comment: This was a relatively small study and not powered enough to detect differences in CVS diseases. Nevertheless one would have expected a trend. However the study highlights the need for regular renal monitoring in patients with RA particularly if they are on regular NSAIDs or have CVS risk factors.

Patients with severe active disease, who are waiting to go onto a biological therapy, should be routinely screened for depression by their doctors

This is the suggestion made by researchers at the Arthritis Research UK Centre for Genetics and Genomics at The University of Manchester, based on the findings of their recent research. The team, led by Professor Anne Barton, also suggests that the way that disease activity in rheumatoid arthritis is currently recorded should be changed in order to improve the way that patients are managed.

The team carried out an observational study of 322 patients with severe rheumatoid arthritis who were waiting to go on biologic therapy. The aim of the study was to investigate the impact of psychological factors upon each of the different parts of the current measure of disease, called the DAS28. The DAS28 score takes into account the number of tender and swollen joints and the level of inflammation in the body. It also includes a subjective, patient-reported measure based on how well the patient is feeling.

The team found that subjective measures of response were more likely to be influenced by psychological factors such as mood or beliefs about their illness and the therapies used.

“This may seem obvious but has not been reported before and is important because without treating the depression, the patient’s DAS28 score might not improve as much as it should on a biological drug, and doctors may assume the drug is ineffective,” explained Dr Lis Cordingley, a health psychologist who was the lead author on the paper.

Professor Barton added, “This is the first study of its kind in patients with high levels of active disease, and suggests that routinely assessing a patient’s moods and beliefs - separate to their physical state - would be useful in guiding patient management. As rheumatologists we need to be aware that depression may occur more commonly in patients with severe rheumatoid arthritis than we had realised.”

Arthritis drug tocilizumab ‘effective when administered subcutaneously’

Scientists at Osaka University in Japan have conducted a phase 3 trial to see if giving tocilizumab (RoActemra) via an injection rather than via an infusion, which is the way in which it is currently administered, is as effective when given by injection and that the safety profile remains the same.

In this study, patients were randomly selected to receive injections of tocilizumab alone every two weeks or an intravenous infusion every four weeks. The aim of the study was to prove that both options were similarly effective in reducing disease activity. Data from the trial revealed that response rates between the two therapies were broadly comparable and that the rates of adverse events and serious adverse events were also shown to be similar.

The study suggests that in future tocilizumab may be offered in an injectable form which will be more convenient for the patient and less expensive to administer.

Tocilizumab is a commonly prescribed biologic therapy in the UK. It is usually given every 4 weeks by infusion. Currently this drug is only prescribed to people who meet the NICE criteria, after the failure of standard disease modifying drugs. To read more about this drug, visit the NRAS website or contact us on 0845 458 3969 to request more information.

Low versus high dose rituximab for rheumatoid arthritis

A new study carried out by a Brazilian team at the Hospital Nossa Senhora da Conceicao in Porto Alegre, aimed to assess the benefits of prescribing a lower rituximab dose than is currently the case. At the moment an infusion of 1,000mg of rituximab is given to patients initially and then a second infusion of 1,000mg two weeks later. It had been suggested that reducing this regimen to a pair of 500 mg doses a fortnight apart might also be effective, but the existing evidence was inconsistent and contradictory.

The researchers reviewed existing published literature to find examples of randomised controlled trials and cohort studies which compared low and high-dose rituximab in order to evaluate how this affected the safety and efficacy of the drug. In total, they assessed six controlled trials and two cohort studies, and included data from four trials in their analysis.

The results of this analysis showed that there were no significant differences in the efficacy or rate of adverse events or serious adverse events between those in the low and high dose rituximab groups. The results were also corroborated following a separate analysis of two additional randomised controlled trials and a separate meta-analysis of the two cohort studies.

The researchers concluded that low dose rituximab was as effective as standard dose and that perhaps a further study should look at a one infusion regime.



A week in the life of...

...a Consultant Paediatric Rheumatologist

Dr Gavin Cleary, Consultant Paediatric Rheumatologist, Alder Hey Children's Hospital NHS Foundation Trust, Liverpool



From left to right: Mr Ian Roberts - Physiotherapy Extended Scope Practitioner, Professor Michael Beresford, Dr Liza McCann, Dr Gavin Cleary, Dr Clare Pain, Dr Eileen Baidam, Jane Kelly - Rheumatology Nurse Specialist, Alder Hey Children's Hospital, Liverpool

I trained as both a general paediatrician and a paediatric rheumatologist, and although my work now is predominantly in rheumatology my training as a children's doctor first and foremost remains fundamental to my role. I value working as part of a team and I am so fortunate to work alongside 4 other consultants, 2 specialist nurses, 4 physiotherapists and also a growing research team. Our department of paediatric rheumatology is embedded within a large Children's Hospital and we frequently interact with many other departments, perhaps to help establish a correct diagnosis to deliver the care and treatment our patients require.

I see patients in many different settings in the hospital including in-patients, day cases and the out-patient clinic. It is a privilege to work with patients and families as I do. Working with children keeps you very humble as they are so observant – a young patient reminded me in clinic last week, by turning to his mother and informing her in a very matter of fact way that "Mummy, Dr Cleary hasn't got much hair has he!"

Away from direct patient care I enjoy research work, teaching medical students and doctors in training, often trying to emphasise the significance of conditions such as juvenile idiopathic arthritis (JIA), hoping that they will recognise the signs and symptoms in the future. I have recently stepped down after 4 years as Chair of the Board of the British Society for Paediatric and Adolescent Rheumatology (BSPAR). I really enjoyed this role which included working with NRAS on some very important projects, and whilst I am trying to keep active within BSPAR it is time for others to take the lead role just now!

1. Monday

I try to be at my desk by 8.30am each day as this is a good time to plan the day ahead and catch up on emails. After a research meeting at 9am, we have a new patient clinic that I share with my consultant colleagues. If I'm not in clinic there are patients to see on our research ward prior to their treatment.

A major development in our service over recent years has been to appoint and train a physiotherapy extended scope practitioner to administer intra-articular steroid injections for patients with JIA, a role previously always done by a doctor. Many younger patients will require a short general anaesthetic in order for this procedure to be done, and we have a session in the operating theatre that has specialised x-ray equipment on a Monday afternoon. Although I do not do as many of these procedures as I used to I still like to attend some of the theatre sessions and keep my skills up.

2. Tuesday

We run a "service" rota between my consultant colleagues and myself meaning each week one of us takes the lead role for looking after in patients under our team. At our Tuesday "hand-over" we begin with a detailed discussion followed by ward round. We also try to use this as an opportunity to help train our junior doctors, sometimes quizzing them under exam conditions about the management of our patients. Usually, when on service I do a daily ward round for the rest of the week.

We have our main weekly team multi-disciplinary meeting at lunch time where we can share progress and management of our patients and also have an educational session. We may be joined by others from the hospital, perhaps if we are working to develop a new post, or to look at how we will work in our new Children's Hospital which is being built and due to open in 2015.

On the first Tuesday afternoon of each month we sit with the day ward team and review the notes of our patients who come for regular treatment. When we started this meeting 10 years ago we had a small number of patients' notes to review but now the size of the department has grown so much this meeting can take several hours.

3. Wednesday

I alternate a weekly joint clinic with ophthalmology colleagues for patients with uveitis, or complex rheumatology conditions such as lupus, vasculitis, dermatomyositis and scleroderma. We can be joined in these clinics by colleagues from the renal, dermatology and immunology teams which I always find very interesting and educational.

After clinic we try to find a few minutes to eat lunch as a team in the canteen, prior to our weekly meeting with the radiologists. This is such an important meeting where we can review all the x-rays and scans from our patients taken both at Alder Hey and also those sent over electronically from other hospitals.

If I'm "on service" it is then off to the wards!

4. Thursday

I'm in out-patients again in the morning, this time for a "general" rheumatology clinic. Here I will see patients with JIA, and also non-inflammatory conditions such as chronic musculoskeletal pain syndromes. Sometimes I see patients for whom I can simply provide reassurance that there is no serious cause for concern such as normal levels of hypermobility in very young children, or a walking pattern that will correct itself naturally over time. I really enjoy the variety of work in rheumatology, and also the fact there are now so many treatments available we can usually control conditions such as JIA before any damage has occurred. However, we must never become complacent, and strive to ensure we reach rapid and accurate diagnoses by educating GPs, junior doctors and colleagues in other specialities to recognise conditions

like JIA quickly and refer to specialist teams like ours so we can begin effective treatment. We also must ensure patients have access to trials of new treatments, and work with those involved in basic scientific research so we can eventually understand better the causes of the diseases we look after.

5. Friday

We have a hospital educational meeting 9-10am, followed by another general rheumatology clinic. After a bite to eat it is either back to the wards to make sure we have plans for the weekend if any patient has to stay in the hospital, prior to finishing dictating letters and arranging investigations for patients seen in clinic. I always try to ensure this is done by the end of Friday, because come Monday morning we are straight into another busy week...

Out of hours

I am occasionally required to visit the hospital at weekends or evenings if the condition of one of my patients changes. I am also called at times by colleagues such as those on our intensive care unit to give my opinion regarding a new patient.

If not covering the service, family weekends are busy with our 3 growing children, all very involved with different sports and activities. I am a keen but very amateur chef and enjoy nothing more than trying to cook something new at the weekend for family and friends – I just hope they enjoy it too!



The Cleary family

Group News Spring 2014

November 2013 saw the launch of the Thanet NRAS group hosted by Gill, Kim and Daniela. This meeting attracted 80 people on the night, in addition to 5 healthcare professionals. Dr Jassim and Dr DeLord from Queen Elizabeth the Queen Mother Hospital in Margate gave informative presentations which generated lots of questions.

As a result of the meeting, 9 people came forward to coordinate the new group. Their first meeting was held at the beginning of March with a good turnout, including newcomers who had not been able to attend the launch. The group has also been really lucky to be chosen as one of the local charities being supported by the Isle of Thanet Sunrise Rotary Club 'Big Knit' fundraising event in March. Congratulations to this new group – we have high hopes for your success!

Gill and Kim have been busy planning for 2014. The first new group this year will have been launched in Colchester on 27th March, with special guest speaker NRAS Medical Advisor, Dr Richard Watts. Other confirmed group launches are:

- The relaunch of the Great Yarmouth group on 23rd April at James Paget Hospital
- New group in Banbury, Oxfordshire on 21st May being supported by a very keen group of volunteers
- New group in Gloucester planned for lift off on 18th June – they have the privilege of launching during RA Awareness week!
- New group in Caerphilly (South Wales) planned for 15th September, with the support of Dr Madeline Piper who helped us launch the successful Bath NRAS group back in 2012.

There are meetings planned for other potential group launches taking place

over the year, so watch this space!

Congratulations to Annette from the West Dorset group who recently wrote to her local supermarkets for support and received a positive response with generous donations that will cover the costs of refreshments for the year! This is just a small example of how NRAS groups can be supported by local businesses in many ways. If you would like to talk to someone about how to engage with businesses in your area contact Kim or Gill at volunteers@nras.org.uk who will be happy to help!

For the latest information on group meetings, events and launches of our new groups please visit our website www.nras.org.uk/groups



The launch of the Thanet NRAS Group was a great success

NRAS Members show their commitment once more

The NRAS roadshows are held in various parts of the country to give Members the opportunity to come together to learn more about the work of their society, and in particular how they can get actively involved in representing NRAS and people living with RA in a wide variety of ways. Following the success of last year's 4 training days the Volunteer Network team have once more put together a varied interactive day of workshops and presentations to be delivered in four towns across the UK. NRAS Members have shown their outstanding commitment to being active members of their society and turned out in sizeable numbers.



Sharing ideas at the Elstree Roadshow

If you live in the North or Midlands it's not too late to catch a roadshow - there are two more planned for this year in Leamington Spa on 14th May and in York on 25th June. To attend please email volunteers@nras.org.uk or call Gill or Kim on 0845 458 3969.

We are told no one goes away uninspired or disappointed.

"It was great to meet other people with RA and to be able to exchange ideas about our diets and lifestyles. It was also fantastic to meet members of the NRAS team who were brilliant on the day!"

NRAS Members help shape future awareness and treatment

Seven NRAS Members attended a focus group at Guy's Hospital, London in January hosted by Dr James Galloway Clinical Lecturer and Honorary Consultant Rheumatologist, to gather patient input into a poster awareness campaign on the importance of vaccinations when living with rheumatoid arthritis. Everyone spoke candidly, and the facilitators found the discussion illuminating, especially on the topic of accessing the flu vaccine. There were many mixed experiences from those that have had to demand quite forcibly to obtain their flu vaccine, to those who got regular reminders from their GP surgeries.

NRAS has an excellent and growing reputation for working with external stakeholders on a wide range of projects from focus groups, like the one mentioned here, to industry and health care professional education days, media stories,

local service redesign and patient panels, and research steering committees. NRAS can only do this because of you, NRAS Members, who are willing to share your personal experiences of living with RA for the benefit of improving future care and developments of new initiatives that will in the long run benefit all those whose lives are touched by RA.

We salute and thank each and every NRAS Member for making NRAS known as the patient organisation that has a "can do, will do" approach to working with all in the rheumatology community.

The best way to be kept informed of future opportunities is by ensuring NRAS has your most up to date email address so you receive the regular e-bulletins and notices of opportunities that may interest you. If your details have changed do let us know to ensure you don't miss out.

Looking after your feet is no mean feat!

The podiatry department of East Dorset Trust, led by Robert Field, has proven that educating people living with RA about the importance of foot health care and podiatry services can ensure that people are kept mobile and pain free for as long as possible. By running education sessions for East Dorset patients the podiatry team has managed to improve the lives of many by ensuring a better understanding of foot health. NRAS was so impressed by this initiative that we worked with Robert to secure funding to be able to film the education sessions, therefore enabling people across the UK to benefit from the information covered in these sessions.

In March, NRAS members volunteered to be part of the filmed sessions and these will soon be available as part of the NRAS foot health section on our new website. Thank you to NRAS Members Julie Dickins, Roger Bishop, Helen Chambers, Kate Viner, Maarten Smid, Sue Hanmore and Joan Holt for giving up their day to be part of this filmed education day and a special thank you to Robert Field and his team for helping us to share this best practice with a much wider audience in this way.



Watch out for the new NRAS website to see these and other new informative videos.

EULAR Autumn Conference for PARE

Grand Hotel, Reykjavik 15th–17th November 2013 'Healthy Ageing with a rheumatic or musculoskeletal disease (RMD)'

By Donna Saunders, NRAS Member

Attending a conference in Iceland to represent rheumatoid patients from the UK was an exciting yet scary experience. I must admit I that I had heard of EULAR but I was not entirely sure of who they are and what they do, so I needed to do a bit of online reading before packing my suitcase! I was very impressed with what I discovered. The European League against Rheumatism (EULAR) represents the patient, healthcare professionals and scientific societies of rheumatology of all the European nations. Its aim is to stimulate, promote and support the research, prevention, treatment and rehabilitation of rheumatic diseases.

One of the priorities of EULAR is to strengthen the relationship of patient member organisations across Europe. Within EULAR, national organisations PARE (People with Arthritis/Rheumatism in Europe) are brought together once a year for an educational and networking conference.

Travelling to Iceland on my own was a very daunting experience, but I have to say that EULAR helped to ease this! Everything was very well organised. I was very relieved to see a lady holding up a EULAR sign as I walked through arrivals. I didn't feel quite so alone anymore, even if she was only the taxi driver!

Iceland certainly lived up to its name. It was cold! Snow had fallen the day before but was then being washed away by icy rain. Equally, the hotel was aptly named. It was grand indeed!

The speed networking ice breaker session that evening was an interesting experience. I don't think I have ever been in a room with so many people from so many different countries. The one thing that struck me was how everyone spoke such clear English. I felt quite ashamed at my lack of a second language.

The conference was attended by approx 120 delegates, representing over 30 countries. We all gathered together for the opening presentation on the Friday morning. We were welcomed by Maurizio Cutolo, President of EULAR, and Marios Kouloumas, vice president of EULAR, representing PARE. There was also a welcome speech by Dora Ingvadottir, President of Gigtarfelag Iceland and the former president of Iceland, Vigdis Finnbogadottir.

There were further speeches from Anna Lilja Gunnarsdottir of the Icelandic Ministry of Welfare and Stefan Olafsson, a professor of Sociology at the University of Iceland.

The conference consisted of a choice of workshops covering topics related to the theme of healthy ageing. I opted to take part in the following:

- Creating opportunities for healthy lifestyles
- Capacity building - working with volunteers
- Developing networks for young people with rheumatic and musculoskeletal diseases
- Developing and delivering self management courses.

During each interactive workshop I met some incredible people who are involved in patient groups. We all shared the same passion, that we want to help others to help themselves.

At the end of the conference each workshop facilitator presented an evaluation of what had been discussed and had to summarise it to three key words. The words **education** and **empowerment** were repeatedly mentioned. This highlights the importance of educating yourself and others through raising awareness and self management programmes.

As part of the conference we were asked to present a poster representing the organisation that we volunteer for. So, NRAS sent an informative giant poster off to Reykjavik to join me. I felt so nervous about doing this but I actually loved it! I got such a buzz from chatting to people

about NRAS and what amazing work they do. I think my enthusiasm must have shone through because the next evening at the Gala Dinner I won first prize for the Best Poster Campaign presented! I was so excited. It had already been such a wonderful evening with a swim in the wonderful Blue Lagoon whilst the snow fell, that this was simply the icing on the cake.

I felt such a mixture of emotions over that weekend from nerves to elation that I was totally exhausted by the end of it, but I have to say I really enjoyed myself and am thankful that I was given the opportunity to attend. I made some new friends and laughed lots as well as learning more about rheumatic and musculoskeletal diseases.

Talking to other organisations made me realise how NRAS are streets ahead of some countries. They tick all the boxes - they have the amazing staff, the informative website, the publications, the keen members and volunteers and their fingers in many pies, yet they still keep growing! I am proud to be a part of it.



Donna at the EULAR Conference

Rheumatoid Arthritis Awareness Week 2014

– Let's be vocal and make RA visible!

The countdown to RA Awareness Week 2014 has begun! This is our second awareness week campaign and we need you to help us raise the profile of RA as much as you can to change the public perception of this condition. The week will take place from 16th–22nd June so get this date in your diaries!

Invisible disease

In your magazine you will all find one of our brand new posters which promote this year's RA Awareness Week, the theme of which is 'Invisible Disease'. After surveying our members we settled on the theme of invisibility, pulled together your experiences and ideas about how you have felt invisible with RA or times where people haven't understood the condition, and came up with three poster concepts.

Get vocal to make RA visible

NRAS Members Angie, Carla and Jake kindly volunteered to model for us and we hope the situations are a good representation of how difficult it is for those around to understand the invisible symptoms of pain and fatigue when you are just doing very 'normal' things in your day to day lives. Now we need your help to get these posters in to your local community and start to spread the word about the campaign. We are asking you to find a place for your poster in the local community whether it's your GP surgery, pharmacy, community centre, shopping centre or anywhere it will be seen by lots of people (don't forget to ask permission and if going to your local surgery request a GP pack at media@nras.org.uk to give to them too). We'll be asking our regional NRAS groups once more to do as much as they can to get people talking about RA, so do keep an eye out for any activities that may be taking place near you!

Get social to make RA visible

There are plenty of things that you can be doing to help support us during the week. The easiest way you can help is to spread the word online and join the conversation on Facebook and Twitter, using the hash tag **#LookDeeper**. By getting vocal we can make RA visible!



NRAS RA Awareness Week poster campaign

Social media is a simple and effective way of raising awareness and spreading the message far and wide so please do get involved leading up to, and during, the week!

To get you started, request an RA Awareness Week pack at media@nras.org.uk, which includes all the information you will need to hold an awareness stand in your local area, including the posters, an information booklet, a RAmbles walk poster, a tea party leaflet, and a Managing Well publication.

Organise an event

A simple, fun and successful way to raise both awareness and funds during the week is by hosting an NRAS tea party. Just by inviting your friends, colleagues, or whoever you choose to have tea with you, you will be making a difference to those people who need our support. The tea party can be as creative as you wish – why not have a themed party or get everyone to wear fancy dress! Or perhaps you prefer the more traditional afternoon tea with friends? Whatever your theme we're here to support you and make sure that you remind your guests it's all for a good cause! You can register and request a tea

party pack on our website www.nras.org.uk/teaparty or by calling the fundraising team.

Take part in our research

To coincide with the launch of this year's RA Awareness Week and the theme of 'The Invisible Disease', NRAS is conducting a new survey of people with RA around the UK to explore the detailed impacts of chronic fatigue – one of the RA symptoms that is least well understood by the public and not visible. We hope the new research will capture some hard hitting facts about how chronic fatigue impacts the lives of people with RA that we can use to raise awareness with the public. If you would like to participate in the research then please complete the online survey, which can be found at: <https://www.surveymonkey.com/s/chronic-fatigue>. The closing date for responses is midnight on Sunday 18th May. All the information collected will be aggregated and made anonymous and the results of survey will be drawn together into a new report. For further information about the research please contact campaigns@nras.org.uk.

RA Awareness Week Walk – The RAmbles!

We are asking you to get involved in this year's key RA Week event – The RAmbles – and take part to help us to raise the profile of this invisible disease. The walk will be on Saturday 21st June in the beautiful grounds of Spetchley Park in Worcester.



There are three routes, one around the gardens (suitable for wheelchairs), and a one mile and a 5 mile walk – you choose which one you would like to take part in. Entry is £10 (whichever distance you take on), children under 13 are free. You will also get a free goody bag and an NRAS t-shirt to wear on the day!

If Worcester is too far for you to travel why not organise your own RAmbles? Get a group of family and friends together, choose your venue and date and start raising funds. The fundraising team are happy to help so you won't be alone! Or you might like to take part in an organised walk, a great one to join is



The Red Kite Ramble, which takes place in the beautiful Chiltern countryside. There are a number of walks like this one around the country just waiting for you to sign up!

For more information on our RAmbles, or if you would like help organising/finding your own walk, please contact Val at val@nras.org.uk or call on 01628 50154.

Help us to make this year's awareness week another great success!



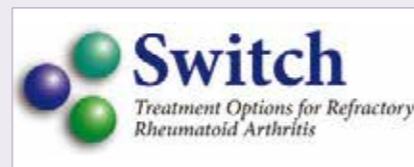
SWITCH - pioneering trial for rheumatoid arthritis sufferers

A new drug trial has been launched in a number of NHS hospitals across the UK for patients whose rheumatoid arthritis symptoms are not improving with their current treatment.

The National Institute for Health Research, Health Technology Assessment (NIHR HTA) is funding the SWITCH trial, led centrally by consultant rheumatologist, Dr Maya H Buch at Leeds Institute of Rheumatic & Musculoskeletal Medicine (LIRMM), University of Leeds and the Leeds Biomedical Research Unit (LMBRU), Chapel Allerton Hospital and the Leeds Institute of Clinical Trials Research (LICTR) at the University of Leeds. The NIHR HTA funds social care and public health research within the NHS that is essential for improving care in public, health and personal social services.

The SWITCH trial is aimed at patients on a current anti-TNF drug, which works by binding to the 'tumour necrosis factor', a molecule that leads to inflammation in joints in RA and associated symptoms.

Although several treatment options are available at this stage, current National Institute for Health and Care Excellence (NICE) guidelines recommend that patients who do not respond to their first anti-TNF drug should be treated with an alternative biologic drug called rituximab, although some patients may benefit from one of the alternative options available.



Dr Buch explains, "The SWITCH trial will compare rituximab with another licensed drug called abatacept, as well as a number of alternative anti-TNF drugs. All of these therapies have shown evidence of clinical success in the treatment of rheumatoid arthritis following failure of an initial anti-TNF, but this is the first head to head comparison to date."

For more information about the trial and a list of participating hospitals, please visit www.ctru.leeds.ac.uk/switch.

NRAS and Birmingham approach to engaging with South Asian community

By Kanta Kumar, NIHR Clinical Doctoral Research Fellow (Rheumatology)

The National Rheumatoid Arthritis Society is a strong champion of integrating with local communities to raise awareness about RA. Recent research has highlighted that many people with a new onset of RA delay in seeking medical help for prolonged periods and that delays are particularly long in people from a South Asian background. In Kanta Kumar's PhD work, she found that patients of South Asian origin did not view RA to be a serious disease and had inaccurate views about medicines used to treat RA.

With this background, NRAS and Birmingham University have created the 'Rheumatoid Arthritis: Apne Jung' (Our fight against RA) project. Through this, for the first time NRAS has actively engaged with the South Asian community during 2013. This project is led by Kanta Kumar (Research Fellow – Rheumatology, University of Birmingham) who is an Allied Health Professional advisor to NRAS. Together with NRAS staff Lorraine Tanner, (Helpline Manager), and Oliver Hoare, (Fundraising Manager), Kanta organised stands to raise awareness, and presentations on RA and NRAS services at a Hindu temple and at an Asian

charity event. Through these events considerable interest was generated about inflammatory arthritis, particularly RA, with participants finding the educational literature that was provided useful and informative.

Future initiatives of the 'Rheumatoid Arthritis: Apne Jung' project will include:

DELIVERING education for maintaining healthy joints through material which is culturally sensitive and holistic

EDUCATING the community about risk factors for arthritis and creating interest around lifestyle changes such as smoking.

INVOLVING Indian Pharmacists in project 'Rheumatoid Arthritis: Apne Jung'.

'Rheumatoid Arthritis: Apne Jung' is an excellent example of how partnerships amongst communities, healthcare providers and academics, can work together to effectively tackle RA awareness. This model can be incorporated and used for South Asian communities nationwide. If you are interested, please contact NRAS for further information.



NRAS innovation to raise awareness of Rheumatoid Arthritis amongst the South Asian Community

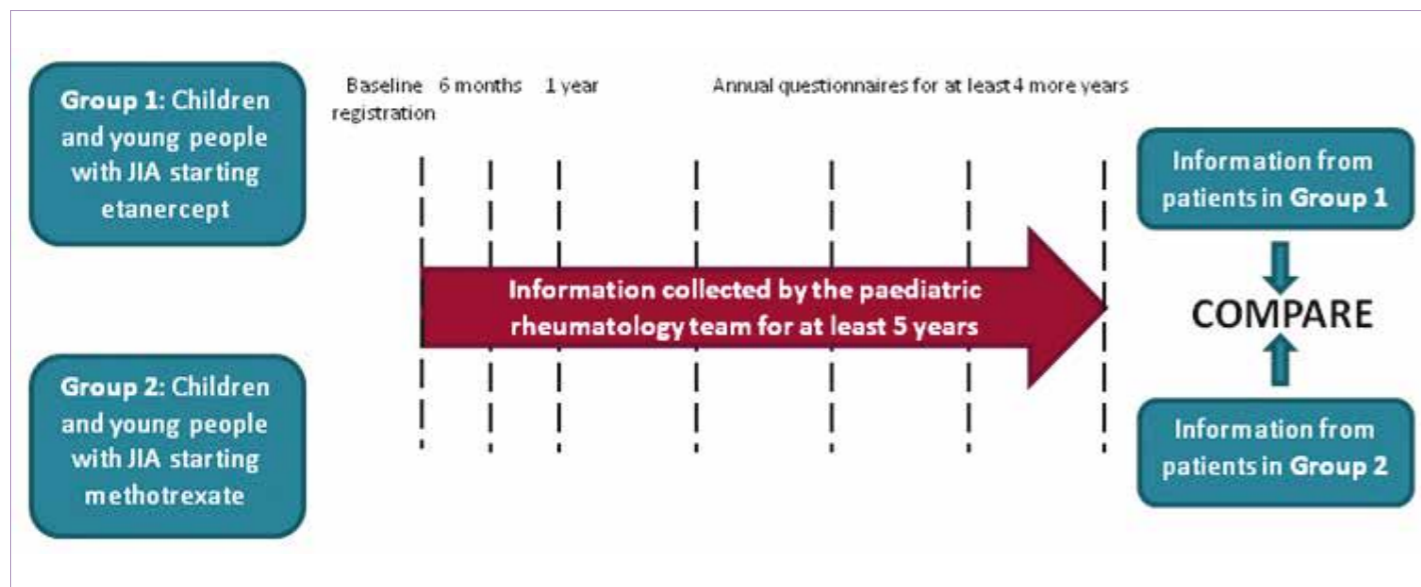


Kanta Kumar, Clinical Research Fellow (R) talking to an attendee

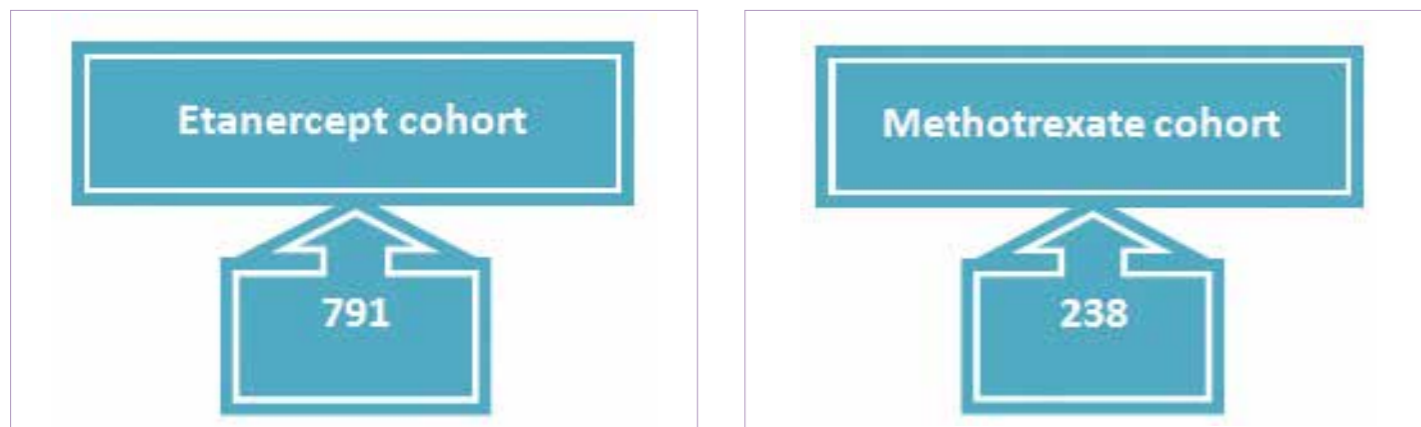
British Society for Paediatric and Adolescent Rheumatology Etanercept Cohort Study

The BSPAR ECS is what is known as a long-term prospective observational cohort study. This means that we recruit two similar groups (or 'cohorts') of patients – one group of children and young people who have been diagnosed with Juvenile Idiopathic arthritis (JIA) and are starting treatment with etanercept and the other group children and young people who have JIA starting treatment with methotrexate.

Both groups are followed up over time and the results from each group are compared to study and compare the long-term safety and effectiveness of these drugs. We are different from a clinical trial, as we do not influence the treatment the children receive, but rather watch or observe what happens when they take the treatment that their doctor prescribes them.



The first participant was recruited in 2003 and since then 1029 participants have been recruited.



With the data BSPAR ECS are collecting, we hope to look into the safety and benefits of using etanercept in children with JIA. The analysis team are currently looking at the rates of infection and other illnesses between the two groups in the study, and also at the growth and height of children in the study compared to the general population.

If you are a healthcare professional involved in recruitment and data collection

Thank you for your support of the study so far. We are continuing to recruit into both the etanercept and methotrexate cohorts of the BSPAR ECS and eligibility criteria are outlined below.

	Biologic Cohort	Methotrexate Cohort
Recruitment target	Participants with JIA who have newly started etanercept	Participants with JIA who have newly started methotrexate
Participant eligibility	<ul style="list-style-type: none"> • Diagnosis of JIA • Informed consent within six months of the first ever dose of etanercept • Can have received previous biologic therapies 	<ul style="list-style-type: none"> • Diagnosis of JIA • Informed consent within six months of the first ever dose of methotrexate • Must be biologic naïve

We request that we receive consent and registration forms within 6 months of patients starting their new therapy. This is to ensure that the data we collect reflects the entire period of time on these drugs and that dates of follow-up closely reflect the time since the treatment was started.

If your department is not involved in the study but would like to be, please contact the study coordinator, Emily Sutton, using the contact details below.

If you are a participant or parent of a participant enrolled on the study

Thank you so much for being a part of the BSPAR ECS. There have been a couple of changes to the study in the last year about which we would like to update you.

- The coordination of the study has moved from the University of Birmingham to the University of Manchester
- We would now like to ask you to provide a small blood sample, which will be taken at a time when blood is also needed for routine purposes, during a regular hospital visit. If you do not need a blood sample for routine clinical purposes, you may be asked to provide a saliva sample, using a "spit pot". If you joined the study before December 2012, you will be asked if you would like to sign a form saying you are happy to provide a blood sample at one of your usual hospital visits.

Meet the team:



Chief Investigator,
Dr Kimme Hyrich

Study Coordinator,
Dr Emily Sutton

Research Assistant,
Rebecca Davies

If you have any questions about the study please get in touch – we will be happy to help!

Email: emily.sutton@manchester.ac.uk | Tel: 0161 3061916 | Fax: 0161 2751640

Simple Tasks Campaign

The British Society of Rheumatology's (BSR) Simple Tasks Campaign will once again be promoted during 2014 and supported by NRAS. BSR will be highlighting the campaign to coincide with various awareness days, including our own RA Awareness Week.

Simple Tasks is a public awareness campaign designed to tell policymakers, general practitioners/healthcare commissioners and the wider public about the value of rheumatology services. The key objectives of the campaign are:

- To raise the profile of rheumatology in the UK and highlight how even the most simple tasks, such as using a fork, can be difficult for those with a rheumatological condition
- To increase the understanding of the work of rheumatologists and allied health professionals
- To emphasise the window of opportunity for preventing pain and disability in autoimmune and inflammatory arthritis

In May there is International Day of the Nurse, and BSR is asking all patients to talk about how their rheumatology nurse has helped them so if you have a story to tell please email tracey@nras.org.uk and I will forward any received to BSR for them to collate and publish. This is a great way of raising awareness of RA, how it affects your everyday life and the 'simple tasks' that we all take for granted, and is also a good opportunity to tell people about a nurse that has really helped you and been there when you needed them.

Visit www.rheumatology.org.uk/patient_information/simple_tasks for more information on the campaign, follow it on Twitter at @RheumatologyUK #SimpleTasksUK or visit the Facebook page at facebook.com/rheumUK

What Diet to Recommend to Patients with Rheumatoid Arthritis?

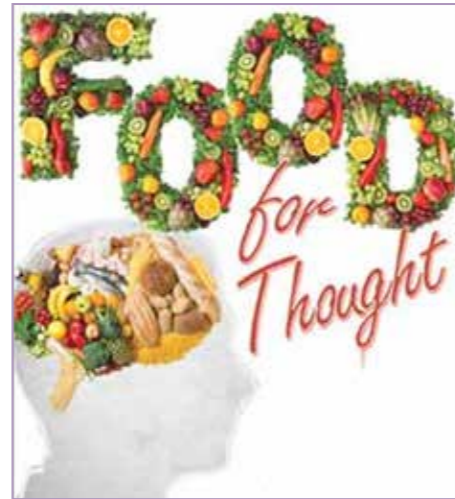
The following is a summary of a useful article written by Vanessa Caceres, freelance medical writer in Bradenton, Florida. The article is aimed at healthcare professionals advising RA patients about diet, but has good information which may be of interest to healthcare professionals and patients alike.

The authors acknowledge that:

- There are no clear cut answers on which diet is most helpful to patients with RA, however, when treating someone with RA it is important to consider food choices along with medication, exercise, and other factors.
- There are some drawbacks with using diet as a way to help RA symptoms:
 - there's limited scientific proof regarding the effectiveness of a dietary approach aimed to help RA
 - a dietary approach can be hard to follow in the long term
- Although there may not be one, be all, end all dietary approach to help those with RA beyond a well balanced diet, there are still some reasons why the diet discussion might be an important one to broach with patients.
- Even if the jury's still out on the ideal RA diet, excess body weight, cardiovascular disease and osteoporosis can be more common in RA patients, so these conditions alone are enough reason to advocate a balanced diet.

These foods will help provide patients with vitamins A, C and E, which can be important in targeting systemic inflammation.

The Mediterranean style diet, as described above, is accepted as not just helpful for inflammation, but also for heart disease. Researchers found that a Mediterranean eating plan and fasting followed by a vegetarian eating plan seemed to improve pain when compared with an ordinary diet. They also point out that there were no effects on physical function, stiffness, or other important outcomes.



The article also adds that evidence for the benefits of a gluten free diet as it relates to RA is not that strong. Although it's anecdotal evidence, this may prove to be helpful to a number of RA patients who are sensitive to gluten. Using an elimination trial approach (experimenting with cutting foods out of your diet) with gluten, dairy, beef or alcohol can be helpful for certain patients if they are willing to give it a try. However, the article suggests that every patient is different and this doesn't provide blanket recommendations for everyone with RA. The article also discusses the value

of omega-3 supplements and the use of CherryFlex, a fruit supplement that contains antioxidants and anthocyanins.

A study published last year in the journal Nutrition with 37 RA patients found that intake of omega-3 acids seemed to affect disease activity and have beneficial effects on RA by decreasing inflammation.

Omega-3 supplements may also enable someone with RA to use fewer anti-inflammatory medications.

All of the emphasis on diet doesn't mean one should ignore medications. The article suggests that a balanced approach is best and that medical treatment is needed to help control symptoms and pain and help prevent the disease from progressing. However, maintaining the body through physical activity and diet is also important and combining all these elements gives the best outcome.

RA Diet Myths

These foods are frequently cited as natural treatments for RA or foods for patients to avoid, although there is no research demonstrating their effectiveness in reducing RA symptoms.

Eat

- Raw food diet
- Cider vinegar
- Gin-soaked raisins
- Gelatin

Avoid

- Nightshade vegetables (tomatoes, potatoes, peppers etc.)
- Dairy products
- High-acid foods
- Citrus fruits

Source: Arthritis Foundation

My Story... by Carrie Thompson

I am Carrie, a 21 year old music student from Swansea, currently living and studying in London. Like any normal 21 year old girl, I love spending time with friends and family, shopping and of course, studying to achieve the career I want.

However, what most people don't see is that I suffer with several long term chronic illnesses. I have rheumatoid arthritis, a genetic condition of the connective tissues and collagen called Ehlers-Danlos Syndrome, Postural Orthostatic Tachycardia Syndrome and Polycystic Ovarian Syndrome.

I can remember from about aged six, and at that time I was a keen little ballerina, suffering from what doctors called 'growing pains', especially in my ankles and knees.

I was told to give up ballet and rest if it hurt but I was assured that I would grow out of it. I never did. Fast forward

twelve years, I was head girl at my boarding music school in Manchester, in my A-level year and about to start my music college auditions. It was almost as if it happened overnight. I woke up one morning in agony, unable to move my hands because they were so stiff and the fatigue was unbearable. I put it all down to stress and rested up and the next day the symptoms seemed to have disappeared. Over the coming months, this pattern of symptoms continued to the point that by the time I returned home for my Christmas holidays, I could hardly dress myself. My parents were concerned by my symptoms and sent me to be seen by the doctor who carried out blood tests to check for Rheumatoid Factor, erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP). My bloods showed negative for rheumatoid factor but elevated CRP and ESR. From this point it took three months for me to be given a diagnosis of Rheumatoid Arthritis. By diagnosis point, I could not carry out even very simple tasks like dressing, eating or walking unaided

and depended on my parents' help day and night. I was finally admitted into hospital, wheelchair bound and requiring morphine for pain relief where I spent the next 9 days. My CRP had reached 135 and I had also developed a plural effusion in my lungs. Despite this, it felt like a relief to me and my family to get a diagnosis so I could finally start to receive some treatment.

After three intravenous doses of steroid to help bring the inflammation down, I

was started on the drug Methotrexate and then Hydroxychloroquine, but after side effects like severe sickness, chronic fatigue and losing a lot of my hair without

much effect on the pain and state of my joints, I was taken off and moved onto infusions of a different biologic treatment called Tocilizumab and this drug change has given me a lot of my life back.

Having rheumatoid arthritis can be challenging and a hard diagnosis to come to terms with. The pain and fatigue is often debilitating and can dramatically change how you live your life. The hardest thing for me has been the stigma attached to having arthritis at a young age. Too often I hear the phrase 'But you are too young to have arthritis'. People are not aware that you can get rheumatoid arthritis at any age from 16 and

there are about 12,000 children under the age of 16 with Juvenile Idiopathic Arthritis. I want to spread awareness of inflammatory arthritis and also raise money. In August 2013, I swam the Great London Swim and raised over £1600. I am determined not to let my arthritis get in the way of living my life!



What to Advise Patients Regarding Diet

So, with all the conflicting evidence, what's the best thing to advise RA patients regarding diet? The article recommends the following:

- To eat a balanced diet - plenty of fruit and vegetables and whole grains
- To get enough protein from lean meat but not go overboard
- To aim for fish more often than other kinds of protein
- To also include almonds and other nuts, which provide healthy fats

A link to the full article can be found in the Healthcare Professional area of the NRAS website. Further information on diet can also be found in the lifestyle section of the NRAS website.

Scottish Ambassadors

– Making Friends and Influencing People!
By Sheila Macleod, NRAS Scottish Ambassador



And progress so far? We've had three very productive and encouraging meetings – two at the Western General in Edinburgh and one with the Glasgow Managed Clinical Network (MCN). Borders is scheduled for April and a clutch of meetings, including several in the West of Scotland, Aberdeen, Inverness, Tayside and Fife following soon after.

And what, realistically, do we hope to achieve? Well, on present evidence, we can expect to see a very significant take-up of our pack of information collated for newly diagnosed patients, very possibly increased levels of healthcare professional membership of NRAS, opportunities for representation on service-user liaison groups with scope to help shape provision for people with RA and, without doubt, heightened goodwill and a sharper profile for NRAS and the valuable work it does.

Clearly, there is still a way to go; we have a heavy schedule of meetings and follow up including evaluation, delivering on the undertakings we make and then building on the connections for the benefit of NRAS, healthcare teams and people across the country affected by RA.



Western General Hospital

The Scottish Ambassador Network has launched a project to build stronger working links with the health system through a systematic programme of visits to rheumatology teams across the country. As well as developing better understanding between NRAS and RA health professionals, we hope to encourage teams to use us as a resource – offering NRAS's excellent, patient-focused publications, access to NRAS initiatives like self-management training, and also the experience we can bring in the form of the patient perspective. And naturally we mean to 'get a feel' for the quality of service provision around the country!

We prepared the ground by running the idea past the Scottish Society of Rheumatology, taking on their comments, mapping out the sort of dialogue we want to have with teams, drafting ourselves a visit 'brief', running a pilot visit and then writing to clinical leads to request and arrange meetings.

NRAS continues to campaign

NRAS has continued to campaign in Scotland where the Scottish Campaigns Network has now grown in number to 14 ambassadors. New recruits include:

- John Paton
- Matilda Tumim
- Valerie Thrush-Denning
- Sheila Terry

Scottish Ambassadors have continued their programme of visits to rheumatology units in Scotland where they have been meeting with healthcare professionals to raise awareness of NRAS, build contacts and improve the range of information given to newly diagnosed patients. One of the latest visits was to Western General Hospital in Edinburgh, which resulted in a request for 100 patient information packs.



Alistair Carmichael

Our new Government Affairs Officer, Laura Wetherly, has been working with Ambassadors to revise and update the charity's first ever Scottish Public Affairs Strategy and a number of ambassadors have been busy meeting local politicians.

New Scottish Ambassador, Matilda Tumim, met with Alistair Carmichael, her constituency MP for Orkney and Shetland, to talk about challenges

around RA services and her experience of living with the disease.

Fellow Scottish Ambassador, Sheila MacLeod, participated in a round-table discussion on 'Maintaining the drive for innovation in rheumatoid arthritis treatment' which involved Margaret McCulloch MSP and Rhoda Grant MSP, Shadow Minister for Wellbeing. In February, several Scottish Ambassadors attended Arthritis Care's annual Professionals' Lecture in the Scottish Parliament.



Margaret McCulloch MSP

NRAS is also pleased to announce that Sheila MacLeod has accepted the invitation to become the first ever Chair of the Scottish Campaigns Network. Sheila was nominated by NRAS staff in recognition of the important role she has played in running the Cross Party Group on Musculoskeletal Conditions in the Scottish Parliament and her ongoing support for the charity.

In related news, the Cross Party Group for Musculoskeletal Conditions has undergone a period of transition. After the sad passing of Helen Eadie MSP, who co-founded the Group, Margaret McCulloch MSP has very kindly provided secretariat assistance to help ensure its work programme can continue.

The Wrexham NRAS Group

The Wrexham NRAS group was launched on 16th October 2013 at a well attended information evening hosted by Clare Jacklin, NRAS Director of External Affairs. With the full support of Wrexham Maelor Hospital, the successful event attracted 8 people to volunteer their time to coordinating regular group meetings. Here are some of their stories and why they want to be involved in the new group.



Wrexham Maelor Hospital

My name is Susan Dunbar and I am a retired NVQ assessor living in Connahs Quay. I wanted to join the local NRAS group to try and be helpful to other people who also have RA - I am a very positive person and did not know anyone else with RA, although I was diagnosed about 15 years ago. There are great benefits to being part of a group which understands the difficulties of RA as we can be more helpful to everyone and show we are not alone. This will help us move forward more positively and look forward to all the activities and help that we can bring to each other for a much brighter future together.



Wendy

Hi my name is Wendy and I have had RA now for almost 3 years. The medication is helping but I'm not quite there yet. I think it is a really good idea to have an NRAS group, so that people with the

disease know that there is somewhere they can go to meet others and get more information and help that will make it easier to live with RA, and know that they are not alone, which I think is very important especially if you have just been diagnosed with RA.



Bev

My name is Bev Buckley, and I was diagnosed with RA in 2009. We moved to Wales in 2008 and, having retired from my full time job, I started looking for something part time. I began working at the new M&S store at Eagles Meadow, and I thoroughly enjoyed it. After a busy Christmas period, I began to experience terrible pain and swelling in my wrists and shoulders, but put it down to RSI. The pain then moved to my knees and eventually we found out that I had RA. I battled on for some months, but eventually after a lot of effort on both sides, I gave up work. I felt very angry that this had happened to me, and very alone. Then I joined NRAS and began to realise that I wasn't alone at all. I spoke to a lovely lady on the helpline about injecting my Enbrel and that was so helpful. Good though that was, I do feel that face to face contact is better, so I was keen to have a group here in Wrexham, and I hope we will be very successful.



Lyn

I'm Lynn from Chester - I think by setting up a group in North Wales/Chester area it would greatly offer support to newly diagnosed and existing sufferers of RA. I was diagnosed with RA four and a half years ago and felt dreadful and quite isolated. Even though I have a fabulous family and a lovely circle of friends the condition is often misunderstood. I would like to offer support to help raise awareness.

I now take methotrexate and folic acid which luckily agreed with me, and although I still face struggles at times with few adjustments it enables me to lead a very full lifestyle. I am able to remain working full time and enjoying hobbies which include Pilates, bellydance, line dancing and burlesque which include doing shows to raise money for charities. All this is time consuming but enjoyable and helps me to remain positive and healthy.



Alun

I'm Alun - a sixty-something, pedantic, stereotyped, engineering type! These days I would much prefer to chill out and have some fun.

Originally from Wrexham, I have lived and worked throughout the UK, but have now come home to Wales to prepare for the next life phase, i.e., being old and grumpy. (I have previously been young and grumpy). I was informed I had RA some 14 years ago while working in the north of Scotland.

In support of my ailment, the Wrexham hospital team continue to make quite an impression on me, and I thought that being part of, and sharing ideas with, a like-minded group of people with similar experiences of this debilitating disease, would allow me to get involved, offer some thoughts of my own and maybe have some fun at the same time. So far so good!



Sian

I'm Sian - I was diagnosed with RA when I was 17, which (and a squirm a bit when I say this) was 16 years ago. I received excellent clinical care but I struggled to find someone to talk to about what life was and would be like living with RA, what support was available, how to navigate the healthcare system and discover ways in which I could help myself. This is where access to the voice of experience, people who had been in my position and knew the options I didn't, really would have helped me.

This is why I wanted to get involved in running a group in the Wrexham area. It's set up to be a great source of information, learning and support to all of us - RA suffers and those whose lives are affected by RA. To feel in the company of someone who understands at the moment you really need it is priceless - and if I can learn more about my condition and how I can help myself to boot, then I can take back a little bit of control over my life and living with RA becomes a positive experience!

Campaigning update

With the recent expansion of the government affairs team, NRAS has been able to undertake more campaigning work in Wales. The new Welsh Campaigns Network will be launched in late Spring, and we have been busy conducting telephone interviews with prospective Welsh Ambassadors. At the time of writing, NRAS has also just secured a meeting with David Rees AM, Chair of the Health and Social Care Committee, to update him about challenges being faced by RA patients in Wales.



David Rees AM

Dear Helpline...

I applied for the Personal Independence Payment (PIP) benefit and sent my forms off several weeks ago and still haven't been given an appointment for my assessments. Are other people experiencing these delays?

Unfortunately, this problem does seem to be fairly widespread. In talking to people on the helpline we are hearing increasingly about the length of time they have to wait for their assessments and the frustration and difficulty that this causes.

The Department for Work and Pensions (DWP), which process these benefits, sets out timescales and estimated figures for the number of claims it hoped to be able to process and some recent figures have suggested that this is falling far short in a number of areas.

A recent report produced by the National Audit Office (NAO) suggested that while the expected period for non-terminally ill claimants to receive a decision was 74 days (around 10.5 weeks), in reality the waiting time was 107 days (around 15 weeks).

Other figures in the report suggested that the DWP was falling short on the number of claims it had expected to process.

For example, the report suggested that by 25th October last year, 166 000 people had started new claims, yet the department had only assessed 16% of the cases it had expected to. The number of claims outstanding by 25th October 2013 was 92,000, which was much higher than the 32,000 outstanding claims the DWP had anticipated having at this time.

In short, it would seem that these delays will be almost inevitable for the immediate future, but we will keep you updated as to any changes. If you are experiencing financial difficulties as a result of these delays then you could contact one of the following organisations for help:

- The Money Advice Service www.moneyadvice.org.uk/en
- Citizen Advice (has a range of very helpful factsheets) www.citizensadvice.org.uk
- Turn2 Us www.turn2us.org.uk

The NRAS Government Affairs Team has been continuing to meet with both the Department for Work and Pensions and assessment providers to make them aware of the problems being faced by our members and work to improve the process for claimants. Additionally, we have contributed to, and reviewed, PIP training materials to help improve assessor's knowledge of rheumatoid arthritis.

The full NAO report can be found on the NAO website www.nao.org.uk in the 'reports by sector' section, under 'Welfare and benefits'.

NRAS has a guide to claiming PIP for anyone looking to start a claim and this can be ordered or downloaded from the 'Publications' section of our website.

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

What do my blood tests mean? How do I know if the results of my blood test are considered high?

On the helpline, we are often asked to comment on a blood test result and asked if this or that figure is 'high' or 'low', but unfortunately this is a question that can only really be answered by your own healthcare team (whether by the GP or rheumatology team). This is partly because the ranges can differ between laboratories and partly because what is considered high or low for one person may not be the case for another. Some tests need to take factors such as age, lifestyle and medical history into account. Monitoring your own blood tests over a period of time will start to give you an idea of what's considered high or low for you.

You will probably all be very familiar with erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) as these are regularly used to help monitor your disease. ESR and CRP are often referred to as inflammatory markers and are used to measure your levels of inflammation to give an indication of how active your disease is and how well the medication is working for you (though other factors, including your symptoms, will also be taken into account).

Some rheumatology teams will actively encourage patients to track their blood test results and may even supply you with a booklet to fill in with these results.

If this has not been suggested to you and you would be interested in monitoring these results, perhaps ask your rheumatology team if they have a booklet for this or if they could maybe help you to create your own in a notepad, monitoring some of the key blood tests.

The interpretation of any clinical laboratory test involves comparing the patient's results with the test's "reference range". You can read more about reference ranges on Lab tests Online www.labtestsonline.org.uk.

Further information on blood tests is available on the NRAS website

NEWS & EVENTS

Spread the Word!

Do you keep your magazine or pass it on? If you would like free copies of previous magazines for friends, colleagues, reception areas or clinics, please do let us know and we would be happy to send them to you. Call the office on 0845 458 3969 or email membership@nras.org.uk.

One simple way that you can help raise awareness of RA and the support NRAS can give is by inviting us along to your next clinic session or hospital information day, or perhaps there is an opportunity to have a stand in the foyer area at your local hospital?

We can give you a selection of publications, past copies of the magazine, information on NRAS and how we can help, as well as ways to help us. Please get in touch with Emma at emma@nras.org.uk or call us to discuss.

New NRAS website!

Keep your eyes peeled for the new NRAS website which, at the time of writing, we hope to launch in April! This site has been developed to help improve user experience on the site with a more simple navigation structure, improved search facility and more interactive resources through increased use of video and visual content. It will also host an integrated shop and interactive map.

Potential new natural therapy for RA

Researchers at Guy's Hospital in London are currently running a clinical trial for a potential new natural therapy for RA. If successful, then the two year trial will show that infusions of binding immunoglobulin protein (BiP) will enable the body's own immune system to help protect it against rheumatoid arthritis.

Men and women who meet the following criteria may be eligible to take part in the trial:

- Is your rheumatoid arthritis active?
- Have you failed at least one DMARD drug?
- Have you not taken a Biologic drug for 3 months or Rituximab for 6 months?
- Live within reasonable commuting distance of Guy's Hospital?

If you would like further information about the trial, please contact Professor Gabriel Panayi, Professor Emeritus of Rheumatology at King's College London, via email, at biptrial@kcl.ac.uk.

RA Awareness Cards

Don't forget that we have RA awareness cards available to help you explain to people what RA is and how it affects those who live with it. The cards, which are the same size as a credit card, can be given to anyone who wants to know more about the disease and can be ordered individually or in handy boxes of 100. All Members receive a small quantity with their membership packs when they join, however you can order more by emailing membership@nras.org.uk or call Emma or Gail in the Membership team who will happily send some to you.

NRAS wins the Waitrose Community Matters Scheme in Maidenhead

NRAS was lucky enough to be the winning charity supported by the Waitrose Community Matters Scheme, run in our local Maidenhead branch during January. We are delighted to have won the £500 grant and can't thank Waitrose, their customers and our local community supporters enough for choosing us.

Caution over advertised 'arthritis' products

Earlier this year, one of our Members made us aware of a product they had seen advertised which appeared to be making unsubstantiated claims about its effectiveness in treating both rheumatoid arthritis and osteoarthritis.

We thought that this might therefore be a good opportunity for us to remind Members to be wary of such products, and to always check with your rheumatology team, GP or pharmacist before purchasing or taking any arthritis products you see advertised. Even if the product is marketed as being 'natural' it could still interfere with your standard medication. Some of these products can also be very expensive, so if there is not good evidence of their effectiveness this should also be taken into account.

The organisation 'Sense About Science' have a useful booklet on this, called 'I've got nothing to lose by trying it' www.senseaboutscience.org

Sorry we missed you!

Here is the photo that was unfortunately omitted from the last edition of the Magazine in the HealthCare Champion winners article.

Ailsa Bosworth CEO, Hannah Duggins, Linda Longmore and Angela Lawrence from Chesterfield Royal Hospital, Theresa May MP



New and useful links

www.centerwatch.com

CenterWatch was the first internet site to publish detailed information about active clinical trials that could be accessed by patients and their advocates. Today, it has one of the largest online clinical trial databases actively seeking patients.

Methotrexate and Pregnancy - What Arthritis Patients Should Know

www.arthritis.about.com/b/2014/02/25/methotrexate-and-pregnancy-what-arthritis-patients-should-know.htm

NRAS Roadshows

2 down and 2 to go! There is still time to sign up to attend one of the NRAS roadshows by emailing volunteers@nras.org.uk or calling Kim or Gill on 0845 458 3969.

Two successful days have already been held this year in North London and Bristol so it is now time to head further north. The NRAS roadshow days give people the opportunity to meet others with RA while learning how to support and be involved in many aspects of the work of your society.

14th May - Woodland Grange,
Leamington Spa

25th June - Marriott, York

Places are limited so sign up today to join us for an informative, interesting and stimulating day.

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

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

giftaid it

Tweets



NRAS @NRAS_UK · Feb 4

Just realised we reached 4000 members on our @HealthUnlocked #RA Community over the last few days! Join us there at healthunlocked.com/nras

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Natalie James @nataliecjames · Jan 31

Preparing for my first appointment with my specialist on Monday, thanks to @NRAS_UK for all the help and guidance #grateful #IIBeatRA

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Laura Mitchell @LauraAMitchell · Jan 29

This rain is making training tough! Any kind souls looking to support @NRAS_UK +me in @LondonMarathon, here's the link: uk.virginmoneygiving.com/LauraMitchell10

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Ben2Ben @Ben2BenUK · Jan 23

I'm walking from the top of Ben Nevis to the top of Ben Macdui (over 100miles) and other events throughout the year for @NRAS_UK

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Charity Ecosystem @CharityEco · Jan 20

Thank you for the clothes donation for @NRAS_UK. It has help to send an information pack to someone diagnosed with rheumatoid arthritis.

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Neil Graham @nrg1664 · Jan 20

In September, I'm attempting to walk 100km in 24hrs to raise funds for @NRAS_UK & I would love your support justgiving.com/nrg1664 #jja #RA

View details

Reply Retweet Favorite More



NRAS @NRAS_UK · Jan 20

In 2013 @Helpline_NRAS received 2507 communications from people with #RA. Find out more about the service at nras.org.uk/help_for_you/h...

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Please Remember NRAS in your Will

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

A Gift in Your Will Supports Our Future



nras
National Rheumatoid
Arthritis Society

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