



nras

National Rheumatoid
Arthritis Society

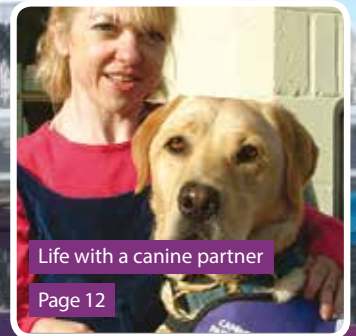
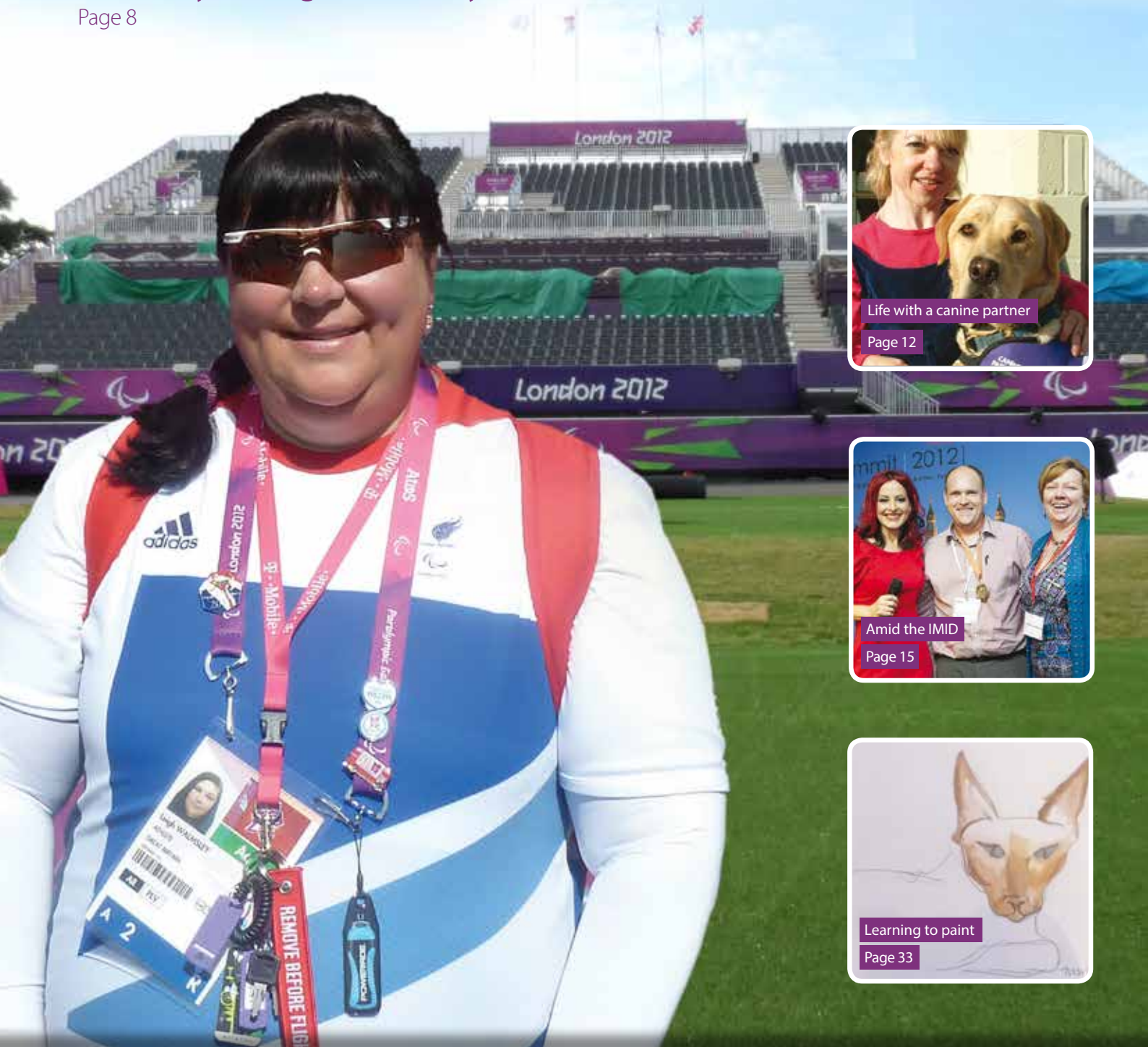
NRAS Magazine

Winter 2012

I'm a Paralympian!

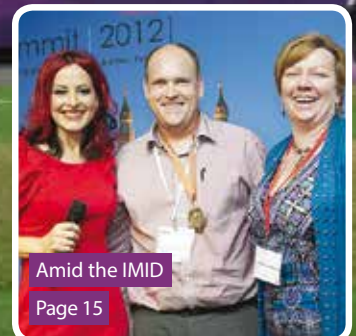
The story of Leigh Walmsley

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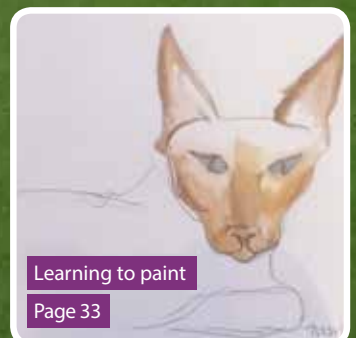
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Dear Members

As we begin a new year and I reflect on the activities and achievements in 2012, I think this was one of the busiest years in recent memory for NRAS. Things simply did not stop or slow down during the year at all. Even in July and August, traditionally less busy months as many are on holiday, we were going like a steam train! One of the reasons we have been so busy is down to the new NHS reforms and consequent changes to the health landscape in England which have gathered pace during the year in the build up to their implementation by April 2013 when GP commissioning comes in. Looking back, here are just some of the highlights of 2012.



January 2012

NRAS was joint organiser of a patient programme for 25 RA patients from across Europe which ran in parallel with the 2nd Excellence in Rheumatology conference held in Madrid. Three of our volunteers attended representing England, Scotland and Wales and we invited Arthritis Care to send a representative from Northern Ireland.

February 2012

We obtained the necessary funding to enable our current assessment project of JIA Services across the UK to go ahead with the support of the British Society for Paediatric and Adolescent Rheumatology. This project will report in mid 2013.

We made a joint submission with the British Society for Rheumatology and the Primary Care Rheumatology Society to the Quality and Outcomes Framework which resulted in QOF Indicators for RA for the first time for GPs (yet to be ratified and confirmed by the BMA/NHS at the time of going to print).

We held a briefing meeting in the Welsh Assembly for Assembly Members, patients and health professionals which has led to the possibility of a one day inquiry into RA in Wales scheduled for early 2013.

March 2012

The first Chief Executives' meeting was held by EULAR/PARE in Brussels for the larger patient organisations in Europe. NRAS is now on the Task Force to organise the agenda for the next meeting in April 2013 as EULAR has agreed to fund this annual meeting going forward.

April 2012

Dr Martin Lee left London to kayak round Britain to raise awareness of RA and funds for NRAS. This amazing journey took nearly four months and Martin raised over £32,000 for NRAS. An amazing achievement!

We exhibited at the British Society for Rheumatology annual conference in Glasgow which some of our Scottish Ambassadors attended. We launched our major new publication for 2012 – *Family Matters* – that looked at the impact of RA on the whole family.

May 2012

I attended OMERACT in the US, for the first time. The acronym stands for 'Outcome Measures in Rheumatology'. It organises consensus conferences about research and outcome measures in a two-yearly cycle and each conference is held in a different continent. I attended as a patient research partner, as part of an international group researching worker productivity measures.



June 2012

We attended EULAR in Berlin where we gave an oral presentation on *Family Matters*, presented at an international press conference for Novartis on 'Living with RA' and attended a press conference as a panel member reporting on a survey of NRAS members as part of a European project in collaboration with MSD Global.

We held our annual Coordinators' Conference in Maidenhead, attended by NRAS coordinators from across the UK to enjoy two days of educational sessions and peer to peer networking.

July 2012

I presented at a major education day held by Arthritis Research UK to review Patient Reported Outcome Measures in Musculoskeletal Disease.

I started work as a key member of Commissioning for Quality in RA Group on a new Patient Experience Measure for use in Rheumatology, with a view to submitting an abstract in November for presentation at BSR in 2013.

August 2012



I attended the first meeting of the Topic Expert Group appointed by NICE to develop a Quality Standard in RA. This work will run through to mid 2013 when the Standard will be launched. Commissioners will be taking Quality Standards into consideration when commissioning rheumatology services locally. The Standard will be based around NICE Guidelines.

NRAS joined with the British Society for Rheumatology and Arthritis Care to form the Rheumatology Commissioning Support Alliance (RCSA). The RCSA has been formed to provide advice and support to the new GP Commissioning Groups and Commissioning Support Groups in regard to the commissioning of rheumatology services.

September 2012



We held an open meeting at Bath with the team from The Royal National Hospital for Rheumatic Diseases with a view to launching a new NRAS group. This was successful and their first meeting will be in early 2013. Our group in Haverfordwest, Wales, held an open meeting at which an Assembly Member spoke movingly about her mother and sister, both of whom have RA.

I attended the British Society for Paediatric and Adolescent Rheumatology annual conference in Edinburgh.

October 2012



We held our first Members' Day in Taplow which was attended by over 100 members, friends, supporters and medical advisors. Professor Peter Taylor gave a wonderful keynote presentation and we enjoyed a lively panel discussion with different representatives of the multidisciplinary team.

We launched our Responsibility Deal for World Arthritis Day. To read the deal and pledge your support (it's still gathering signatures!) see our website.

November 2012



As members of the Arthritis and Musculoskeletal Alliance, November was a busy month with policy meetings and the annual ARMA lecture, which was given by Martin McShane, Director, Domain 2, National Commissioning Board on 'Improving the quality of life for people with long term conditions'.

December 2012



We launched our report into comorbidities in RA at a breakfast briefing in Westminster, attended by MPs, health professionals and NRAS staff. To read the report, please go to the campaigning section on our website.

We held our annual Christmas Carol Concert in Maidenhead which was supported by our founding patron, The Rt Hon Theresa May. This invariably marks the start of Christmas for the NRAS staff and this year's concert was very well attended and we had a wonderful programme of singing and reading.

There are lots of projects and activities left out of the above list as there is a limit to how much I can mention with space limitation, but all in all, it was a good year and I'd like to thank the NRAS team for all their hard work and dedication, our NRAS members for their enthusiastic support and for completing so many surveys (much needed!) which help to improve the understanding of life with RA, our Medical Advisors for their unstinting help and advocacy and to all our friends and supporters wherever you are!

May 2013 be a peaceful and kind year to you all.

Ailsa



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Farewell to Peter

Peter Rogers, who has been our Financial Controller and Company Secretary at NRAS since 2004, retired at the end of December. Peter has been a key member of the team, joining the charity when it had just four staff and helping us through managing the growth and development of NRAS to the charity we know today. He is going to enjoy an extended holiday to Sri Lanka with his wife Christine before returning to spend time with his four grandchildren.

Peter is replaced by Narinder Bains, who will be joining us in January and we welcome her to the team.



▲ Peter Rogers

Jill Thain

We were very sad to learn of Jill Thain's death this summer. Jill was coordinator of the NRAS group in Greenock and a great supporter of our work. This is a tribute to her, written by her husband, Bernard.

Jill passed away on Saturday 1st September and the packed room at her funeral on Friday 7th September was testimony to Jill's vibrant character, openness, honesty and the generosity she showed to all her friends and family.

Jill's drive, determination, direction, enthusiasm and lust for life spilled out in every direction. When she wasn't running a restaurant, she was gardening, playing bridge, going to book club, organising rheumatoid arthritis support group meetings, tweaking PA systems, and going off to visit her children in far corners of the world.

In her latter years, Jill's rheumatoid arthritis got significantly worse. However, her extraordinary courage and fortitude did not let her illness constrain her or define her unnecessarily. It certainly didn't stop her feistiness! She had a boisterous, deeply affectionate, one-up-manship, exuberance and a strong sense of self with a true talent to tenaciously hold to an argument or a point of view. Jill stood up for what she believed was right.

In August, despite having the restrictions of a wheelchair and oxygen, she was sitting on the beach on the Mull of Kintyre watching her grandchildren



▲ Jill Thain

play, and me fish (of course!) In the last few weeks of her life, Jill knew she didn't have long left, and didn't want to carry on with the pain and the breathlessness that frustrated her. Jill was ready, and she approached this with her usual practicality and courage.

Jill was always striving for the greater good of others. She lived life to the full. She was extraordinarily courageous. She has departed leaving very special memories with all of those who have had the privilege of knowing her.

Meet the team...by the team

Jamie on Lorraine...

Lorraine is the Helpline Manager and works closely with Sarah and Victoria to answer queries from NRAS members and the general public. Lorraine has a scrupulous eye for detail and when she is not answering calls, Lorraine can usually be found diligently reading through and updating our many NRAS publications. A long standing member of the NRAS team, Lorraine is kind-hearted, readily approachable and, above all, good fun to be around! No NRAS Christmas Carol Concert would be complete without Lorraine's angelic warbling, throwing herself into carol renditions with great gusto!



Val on Emma...

Emma has been a part of the membership team since March of this year and is now an established member of the office. She has brought lots of new ideas to the department and has more planned for the future! Her enthusiasm for her role is obvious with our Members at the heart of all she does. Emma has thrown herself wholeheartedly into the NRAS way, having recently joined some of the team taking part in the 'NRAS panto'. She played Prince Charming in the story of Cinderella and helped the team to win first prize – oh no she didn't – oh yes she did!

Emma is a welcome asset to the NRAS team, it's as if she has always been with us!

Benefits of Tai Chi for Rheumatoid Arthritis

By Hilary Goldson of Arthritis Matters, Reading

An arthritis charity in Reading, Arthritis Matters, has been running Tai Chi classes for members for several years, and the popularity of these classes has demonstrated that participants experience real benefit from this form of exercise in many different ways.

What is Tai Chi?

Tai Chi is an ancient Chinese exercise system for the body, mind and spirit. Tai means big or great, Chi means ultimate energy, so therefore it is all about generating and feeling energy through graceful movement.

Tai Chi and arthritis

There is a growing amount of evidence through studies, newspaper articles and personal stories of how helpful Tai Chi exercises are for keeping our bodies flexible, strong and supple. The gentle, slow movements allow the joints to be moved with awareness so that one can stop if there is discomfort or pain.

can be done standing or seated. In our classes, usual Tai Chi moves have been adapted as necessary to suit individual needs, and members have reported:

- Increases in leg strength so they can stand longer
- Increase in flexibility so that ordinary jobs are less of a problem
- Greater confidence to try things they have previously been concerned would aggravate their arthritis

太極



◀ Tai Chi balance exercise showing how Tai Chi improves balance

Tai Chi Qigong ▶



These include circling joints, stretching muscles and weight bearing. By respecting limitations and relaxing into the movements a greater range can be found. This careful use of movement encourages the use of joints without causing undue discomfort or wear and tear, because the exercises are all low impact.

Exercise, generally, helps the body's strength and resilience, so exercising with Tai Chi combines the benefits of exercise with relaxation. Most exercises are done while continually moving and

Feedback from participants

"It has helped to strengthen my legs after recent knee replacement surgery, and helps with my coordination and balance."

"My balance is so much better – I can now try on clothes in a changing room without needing to sit down."

"I feel warm and relaxed after a lesson, and my body feels it has had a gentle work-out."

"My joints feel more supple and I find it relaxing. I thoroughly enjoy it and would come every day!"

Independent Age



www.independentage.org

Independent Age is a registered charity providing information, advice and support for thousands of older people throughout the UK. The following gives you an idea of how they can help.

- A confidential advice and information service offers expert and personalised support by phone and email to about 3,500 older people, their families and carers each year;
- A further 40,000 people receive information from the website, including free information guides and factsheets to download about care and support;
- 6,000 members of Independent Age, vulnerable older people on low incomes, get long term practical, financial and befriending support, including visits from the team of trained volunteers.
- Policy and advocacy work increases awareness and influences decision makers.

Tom Hardwick contacted the advice service after seeing an article in the newspaper about what the charity does. He had paid thousands of pounds over a number of years to keep his wife, Edna, in a care home close by. The home meets her care needs and he had not minded paying the extra money at all but realised from what he had read that the local authority should maybe have been making a larger contribution to the care home fees.

An advice worker helped Tom develop and implement a strategy to make a retrospective challenge against his local authority. This took a number of telephone conversations and correspondence between them, including reference to the relevant guidance and Local Government Ombudsman cases. Initially, the local authority was not prepared to reconsider its position but, when the advice worker helped Tom draft a letter to them about judicial review, the local authority agreed to repay the £24,000 Tom had paid as top ups, to increase the standard rate for Edna's care home fees from that

point going forward and to repay the legal fees that Tom had incurred during the process. Three months after Tom first contacted the charity, he received full reimbursement from his local authority.

Tom wrote to Independent Age to say

"....thank you for your help in achieving success in this case. Its greatest effect is that my wife (who is physically frail but fully compos mentis) is now in better health than she has been since she entered her care home nearly five years ago because she now knows that her future is secure."

Most people get lonely from time to time but if you are older, and particularly if you are living alone, loneliness can sometimes become a regular feature of life. One in ten older people say they are often or always lonely. It can be worse if you are unwell, have moved or have recently lost a partner or friend. Independent Age volunteers are friendly, caring people who have

an interest in people's lives. They visit older people who have become members of Independent Age on a regular basis, or as needed, for a chat and a cup of tea or to help the older person develop confidence to get out and about a bit more, according to what the older person wants. It tries to match a volunteer to the person they visit, so that each visit is a source of satisfaction and enjoyment for both.

Mary is visited by Jean every month and said:

"Jean said, if you need me anytime, just give me a ring. I know you're independent but if you do need any help, or you need to talk about anything, don't hesitate to give me a call. She's very good."



Help is entirely free and goes on for as long as it is needed. There are 1,500 volunteers all around the UK, chosen carefully and they go through all the checks you'd expect. Volunteers are supported by a team of paid staff locally and at head office, working for a national charity that has been running for nearly 150 years.

Independent Age wants to ensure that more people are aware of their services so they reach more people in need of them. Information and advice frequently does not reach those who need it most nor when they most need it. You, or somebody you know, may benefit from becoming a member of Independent Age or may not know where to start with a particular care and support issue, such as choosing and paying for care or dealing with increasing health needs. If so, please do contact Independent Age on **0845 262 1863**.

(The names in this article have been changed and the real photographs of the people involved have not been used to respect confidentiality.)



Changes to Blue Badge Scheme for disabled parking?

As of April 2012 the Government announced the most comprehensive changes to the Blue Badge Scheme for 40 years. We have recently had a number of calls on the helpline about changes that have been made to the assessment process for the Blue Badge Scheme, and so have looked into this further.

The Blue Badge Scheme applies to those with a permanent disability and severe mobility problems. There are a number of eligibility criteria, some automatically entitle you to a Blue Badge and some criteria are more discretionary. The automatic criteria would include a person who is registered blind or in receipt of the Disability Living Allowance Higher Rate Mobility Component. These automatic criteria have not been affected by the April 2012 changes. The discretionary criteria would only be met if an individual can prove they have a permanent and substantial disability which means they cannot walk, or

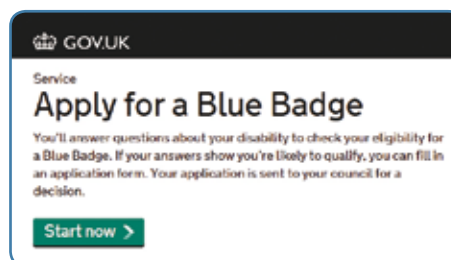


which makes walking very difficult. The April 2012 changes have occurred in the way mobility assessments are carried out to attain if someone meets this discretionary criterion. For those people who do not automatically qualify for a badge, independent mobility assessments are usually required, which have previously been carried out by an applicant's GP. Under the new Scheme these assessments will now be undertaken by independent medical professionals (who are not involved in the care of the applicant) with expertise in mobility, for example an occupational therapist.

This change will affect new applicants to the scheme and those applying for a renewal of their Blue Badge where the automatic criteria have not been met



and so further evidence is required to confirm that the discretionary criterion has been met. Further evidence will now be gathered in the form of the independent medical assessment, and information regarding the applicant's conditions and treatments may also still be gathered from the applicant's GP or other medical professionals involved in their care.



On the Government website www.gov.uk there is a 'Blue Badge Eligibility tool' where you can find out if you are likely to be eligible for the scheme. On entering the information for an individual that did not meet any of the automatic criteria, but had

substantial difficulty walking the tool suggested:

"The applicant may be eligible for a Blue Badge, but their eligibility will need to be assessed by their local authority. This may mean that they ask them to attend a mobility assessment."

As the mobility assessments are carried out locally it would therefore be best to contact your local authority with specific questions, the details of which can be found on the Government website www.gov.uk/blue-badge-scheme-information-council

You can also contact the Blue Badge Initial Enquiry Support Service on

0844 463 0213 (England)

0844 463 0214 (Scotland)

0844 463 0215 (Wales)

or by email

bluebadge@northgate-is.com

I'm a Paralympian!

By Leigh Walmsley

Leigh is 43 years old and a dual citizen (US/UK). Having been born with club feet, which were rectified with a Dennis Browne bar, she was involved in a cycling accident in 1980 which caused a severe comminuted ankle fracture and meant having surgery to fuse bones and repair muscle, ligament and tendon damage. In 1999, at the age of 30, she was diagnosed with RA with inflammation in her hands, wrists, elbows, shoulders, neck, spine, hips, knees, ankles and feet and takes sulfasalazine and methotrexate to control the disease. She took up archery in 2006 and, after a succession of illnesses and injuries, took part in her first full season in 2008.



▲ Leigh Walmsley

This is the story of her paralympic journey...

"If you had asked me a year ago if I would be competing at the Paralympic Games, the answer would have been "I hope so, but I doubt it." Fast forward a year and I'm now a Paralympian. Even thinking about it takes my breath away.

My first steps on the Paralympic path started back in 2009, but the Games were not on my mind then. I simply wanted to find my way in to the national para-archery squad. I attended a T1D, classified, but nothing further happened, so just continued my archery. I applied to the UK Sport Talent 2012 programme for para-archery, and made my way through several tryouts and on to the programme which meant training camps every two weeks for six months. Sadly, although the only woman on the programme, I wasn't brought in to squad, but continued with my archery. In June 2011, I attended the BWAA IUnernational and not only qualified third, but won the bronze medal as a British independent against international archers. THEN I got noticed and was invited to represent

GB in the Czech Republic where I won a team gold, and was brought in to the squad in September 2011.

A lot changed. I started using a stool in February 2012 to help my

"I have a great rheumatology team that looks after me very well... In January I started shooting from a stool, which has helped my balance... I can do more shooting if I do little and often, warm up and stretch".

balance. I changed arrows. I changed my technique. It seemed to help as I finished second in both selection shoots and was chosen for the team. After that, it was head down time. Between May and August was a whirlwind – lots of practice, competitions, meetings, launches, interviews. Wonderful and frightening.

All the competitions, meetings and advice in the world cannot prepare you for the Paralympics. The holding

camp at Bath University was a good preparation buffer, but when the bus pulled into the Paralympic village, you knew it was something special and we were treated as stars from start to finish. Just about everything was geared towards the athletes and making our Paralympic stay amazing. The Gamesmakers, volunteers and staff were fantastic and couldn't do enough for us. The Village was the way the world should be – everyone happy, saying hello, everything clean and efficiently run.

Beyond the niceties was the reason for being there – the archery. Considering this was my first major international competition, I was pleased with my individual performance. As archers, we don't shoot in front of crowds, so we had two choices – soak it all in or be terrified. Having been part of the Opening Ceremony only two days previously and feeling like rock stars at a sell out concert, shooting 70m in front of family and friends seemed relaxing. My adrenalin was pumping, despite feeling externally calm, but I took strength from family and friends cheering me on, and won my first match. It was like going on an exhilarating ride that you couldn't wait to go on again, and luckily I got to go on it again. Unfortunately, my next opponent who went on to win bronze, took me out. If I had to lose to someone, it would be her, as she is a

fantastic archer and a sweetheart. After she won her medal, we shared a long hug and some tears. Her coach, who speaks only a little English said it was a victory for Europe. Judging by the strength of her hug, it certainly felt that way.

Following the Games, we had the amazing experience of the Closing Ceremony and even more exhilarating and emotional, the Athletes Parade. The outpouring from the public was amazing and had me smiling and in tears throughout the entire day. I had never felt more special or admired and certainly wished everyone who made my Games so wonderful had been up on the float with me.

Once we packed up our kit, loaded the buses and returned to our homes, it wasn't long before normality returned despite trying to ride the Paralympic wave as long as possible. Sadly for some of us, the wave came crashing down only weeks after the Games ended. This is the side of sport many people don't see, but nevertheless is part of elite sport. While there are always changes after a Games, we did not expect the damage to be so severe. Just over half of our squad were let go, many of them past and present Paralympians. The good thing about archery is that we are all members of archery clubs and we can still be competitive in the sport. The hope is that by being competitive, we can keep our dreams for Rio 2016 alive."

Leigh says, 'I have a great rheumatology team that looks after me very well. In January I started shooting from a stool, which has helped my balance. I can do more shooting if I do little and often, warm up and stretch. Most importantly I listen to my body. There is no point in trying to shoot when I'm having a flare or aching, as I won't shoot to my best and it will not only hurt but get me down. It's quality rather than quantity. As archery is a mental game, I can visualise or work on my own psychology if I'm not able to shoot.'

Having RA also means adapting certain aspects of my archery, like using a stool, wearing supportive shoes and orthotics, wrist supports, etc, as well as techniques such as hand position and anchor. Paralympic archery is virtually the same as Olympic, what adapts is the archer, not the support.'



▲ Leigh preparing to shoot



Changes to healthcare

– what it means for GPs and patients

By Dr Ruth Burnett, local GP and Medical Director of MSK care in Buckinghamshire

As we move towards clinically led commissioning, there is a lot of uncertainty amongst the general public about what this means, what this involves and how it will affect people. These concerns are understandably particularly high amongst people with chronic health conditions who require regular access to both primary and secondary healthcare, and who may have concerns that their care will suffer as a result.

Clinically led commissioning for England - What does it mean?

Previously GP practices, hospitals, mental health services and community services in England have been commissioned by Primary Care Trusts (PCTs). Each geographical area had its own PCT and was responsible for setting its own targets and spending its own budget. The budget was set by the local Strategic Health Authority (SHA) and Department of Health.



Download this report from www.dh.gov.uk and search liberating the NHS

In July 2010 the Government published the White Paper 'Equity and Excellence: Liberating the NHS'. This set out its long term vision for the NHS with the key principles of change being the abolition of PCTs and SHAs and

their responsibility for commissioning, planning, designing and paying for health services. The main aim of the changes was to put patients at the heart of the NHS with greater emphasis on outcomes for patients, rather than simply meeting targets. The hope is that this will be achieved by more independence for healthcare providers and reduced bureaucracy.

From 1st April 2013 PCTs will no longer exist and they will be replaced by Clinical Commissioning Groups (CCGs). This is not a sudden process, but a gradual changeover, with CCGs taking over by this date. Over the past year CCGs have become established, applied for authorisation and approval, and in many cases started to work as 'Pathfinder CCGs' which have been shadowing the outgoing PCT to ensure that changeover is as smooth and problem free as possible.

So what is a CCG? CCGs are groups of GPs and GP practices clustered geographically that agree to work together to commission local services. GPs already play a key part in coordinating patient care and acting as advocates for their patients, and they will now have more responsibility, but therefore control, over how local budgets are used for their healthcare communities, and also financial accountability for the consequences of their decisions. This whole process aims to shift decision making as close as possible to patients. As well as carrying the responsibility for planning, designing and paying for the local NHS services, GPs and other involved



clinicians and healthcare professionals involved in the CCG would also be responsible for engaging with local people to ensure that the services they are paying for meet the needs of you, the patients. A new consumer body called HealthWatch England will be set up. Local HealthWatch bodies will replace the current Local Involvement Networks (LINks). They will promote public engagement in the NHS, comment on changes to local services, act as advocates for complaints, and deliver advice across health and social care. One of the proposals in the Health and Social Care Act 2012 is that each local authority will have a statutory duty to set up a Local Healthwatch in its area.

What will all this mean for patients?

Hopefully patients will only notice an improvement in care, driven primarily by the fact that each CCG is able to commission services and budgets to best suit its particular population. A CCG in an inner city area may have different priorities from a rural CCG for instance. Similarly, the ethnic or socioeconomic factors within a CCG region may alter the priorities that the CCG feel will maximally benefit the majority of its patients. CCGs will work with patients and healthcare professionals, and in partnership with local communities and local authorities, they will have at least one registered nurse and a doctor who is a secondary care specialist on their governing body in addition to the involved GPs.

Previously GPs and practices have

had varying levels of involvement in the development of services and commissioning process, but with the change to CCGs each practice will have to have quite a significant involvement. Generally each practice will have one GP who is more heavily involved than the others, and if this GP is your usual healthcare provider then you may notice that they are not available for as many clinical sessions as they were previously.

Challenges for GPs

Over the past few years there has been a general move to shift management of chronic diseases, and acute care where possible, out from secondary care providers and into the community. It is generally accepted that this is of benefit to all concerned – hospitals are increasingly stretched for capacity, and patients usually find it easier and preferable to visit their GP who knows them and their care needs very well, than to visit busy hospital outpatient departments. With this occurring over a significant number of disease areas (such as diabetes, COPD, heart disease) it has increased the workload in general practice significantly. As was noted by some members during the NRAS Members Day Q&A session in October, this can mean that at times GPs appear to be struggling under an increased workload, working longer hours and spending a significant amount of time with paperwork and targets. While this is true, it also gives us a greater overall view of a patient's care and enables us to act as the central hub of care for a patient with a long term medical condition.

GP practices have had to strive to achieve QOF (Quality and Outcome Framework) targets (a financial incentive scheme for GPs, negotiated on an annual basis, which incentivises activity that meets national health priorities) for a significant number of years now, which are generally accepted to improve healthcare provision for patients who fall within the disease areas involved. As was discussed at the NRAS Members Day, there is a move for rheumatoid arthritis to become a new QOF area and this will hopefully help RA to become a priority. It would mean that for the first time GPs will be commissioned to create a register of RA patients, conduct regular reviews for cardiovascular and osteoporotic risk and try to ensure that care for RA patients is optimal.

The changes within primary care commissioning have also resulted in the introduction of Quality Performance indicators which are also targets that each practice and each locality has to strive to achieve. Unlike QOF, these are driven more by the priorities of each locality and CCG, and practices have the ability to set these individually and in discussion with the other practices in their locality. This ensures that the targets are optimised for their patient population and will help to ensure that they increase efficiency in areas of excess spending for a region (for instance, emergency admissions, patients turning up to A&E for assessment when they could be seen by their GP or out of hours service) and that savings achieved can then be put towards improving care in areas that are of benefit to the particular patient population of that area.

How can I become involved and help myself and the areas of greatest importance to me?

The benefit to patients of the way in which healthcare management is changing is not simply that your GPs, the healthcare providers who know you best, are more heavily involved in how healthcare is managed within a region. There are ever increasing opportunities for you, the patients, to become involved and to help us to shape local and national healthcare targets to best benefit you and the other patients in your region.

These include:

- Taking part in a working group
- Attending occasional focus groups or workshops
- Working alongside us on projects
- Responding to questionnaires
- Commenting on consultation documents
- Taking part in discussion forums
- Commenting on our public leaflets
- Taking part in national surveys
- Attending a public consultation
- Attending public board meetings



If you search for your local CCG online, or ask your GP practice for details, there are ways in which you can get involved both with your GP practice, your locality commissioning group, or the CCG overseeing the region. We need patients with balanced views who can put their own personal health problems to one side but bring experience of negotiating the healthcare system to bear, an interest in helping develop services, and a willingness to take part in healthcare input to help us best develop services to help you.

Life with a Canine Partner

By Jenny Moir, Head of Public Relations, Canine Partners

Lorraine Harrison, 46, from Plymouth in Devon was diagnosed with rheumatoid arthritis when she was 18. She is married to a Naval Officer in the Submarine Service who is sometimes away from home for long periods, and she has a young daughter, Abbie, to look after. She was unable to get dressed or undressed by herself, and many other simple tasks became a real struggle. However, help came from an unexpected source... in the shape of a golden retriever called Moray.

Moray is an assistance dog trained by the charity Canine Partners, and he has transformed Lorraine's life. "Since having Moray," she says, "life has become much more fulfilled. Without Moray, my little girl Abbie would have had to step in as a young carer and coping would have been very difficult indeed. A canine partner has ensured that I can retain my independence which is very important to me.



▲ Lorraine and her canine partner Moray

"Moray is able to do a multitude of tasks that many people take for granted: he draws the bedroom curtains, fills/empties the washing machine and he is especially good at changing the bedding as I don't have the strength to do this on my own. On one occasion I fell in the kitchen and Moray did exactly as he was trained and went to fetch the telephone for me to call for help.

"When we are out shopping he not only gets tins and other items off the shelves



for me, but also puts them in the basket. Then at the checkout he will unzip my handbag, and get my purse out ready for the cashier. When we return home he is ready and waiting to start unpacking the bags. He will then open the fridge, drawers and cupboards for me."

Canine Partners trains around 55 dogs a year to help people like Lorraine lead a more independent life. There is a waiting list of two years, as more and more people with disabilities apply for one of these very special canine carers. The Charity receives no government funding, and relies on the generosity of individuals, organisations and businesses to support their work. It takes between 18 months and two years to train a canine partner.

Lorraine's husband, Mark, is also grateful for Moray's help. He says: "From my perspective, Moray has given me absolute peace of mind which is fantastic. Having him at home has allowed me to continue to serve with the Armed Forces."

Caroline Jephcott, 35, from Gloucester is a young mum with a toddler who also has reason to be grateful to Canine Partners, as she and her family rely on the help of Labrador, Yasmin. She explains: "Yasmin is a big help with the baby, fetching nappies and baby clothes for me. She follows him about and lies down in front of him to divert his path

from stairs or the television. She also tidies up his toys at the end of the day, something that would take me two hours using a helping hand but takes her one minute!



▲ Caroline Jephcott and her canine partner Yasmin

"I am totally wheelchair bound at the moment and cannot even walk to an object two steps away. Not only is Yasmin acting as supernanny chasing my son about where I can't, but she also busies herself helping me get up and down from the floor so I can try to play with my son. She is an assistance dog whom I could not be without, but she is also our dog who makes us very happy and is part of the family"

If you think you might benefit from having a canine partner, then please call
01730 716043
or visit
www.caninepartners.org.uk

Amid the IMID!

By Clare Jacklin

So what is IMID? Immune Mediated Inflammatory Disease. Each year a summit of patient groups from across the globe is held at a different European city. 2012 was London's opportunity to play host and how appropriate as it had been such a great year for the UK, and London in particular. The patient groups from the host nation form a committee to plan, organise, facilitate and host the Summit. It was my pleasure to represent NRAS on this committee with my counterparts from Crohn's and Colitis UK, Psoriasis Association, NASS (National Ankylosing Spondylitis Society) and ARMA.

We all worked hard at ensuring that the theme "A Bigger Voice for a Better Future" resonated throughout the entire two day conference via the presentations, guest speakers and workshops. The aim of the Summit was to share expertise and experiences of the different groups from across these disease areas around the topics of public awareness, utilising social media, common issues facing people living with these autoimmune conditions and collaborative working where appropriate.

119 people from 22 countries attended the Summit, held at the Thistle Hotel,



▲ Clare appearing from the video booth

Marble Arch with delegates from as far away as New Zealand, Russia, Canada and Australia descending on the capital. I was honoured to do my impersonation of Boris/Seb in welcoming everyone to London at the opening of the Summit and then bringing the proceedings to a close at the end of two incredibly busy and productive days.

There were two key highlights of the event for me. The first was the incredibly informative Plenary Session "The Science behind the IMIDs" facilitated by Professor Dennis McGonagle of the Leeds Institute of Molecular Medicine. Professor McGonagle

was joined by a prestigious panel of experts, Dr Stuart Bloom, Consultant Gastroenterologist; Dr Catherine Swales, Consultant Rheumatologist; Dr Andrew Keats, Consultant Rheumatologist; and Dr Anthony Bewley, Consultant Dermatologist.

The other was the inspirational speaker on the second day, Carrie Grant of Fame Academy and The One Show fame. Carrie gave us an incredible insight into her life living with an autoimmune condition and is an ambassador for Crohn's and Colitis UK. She illustrated the theme perfectly by explaining how when voices join together the message is louder and clearer and leading the entire delegation in a harmonised version of Let it Be. Paul McCartney eat your heart out! It demonstrated for even those with limited understanding of English, how even though we all represented different aspects of Immune Mediated Inflammatory Diseases and may be singing different words the overall message is the same and we can join together in getting the message of the need for early diagnosis out to the public and truly make a difference.



There was a poster competition that the various patient groups entered with the aim of raising awareness of the similarities and links between these inflammatory diseases and I am delighted that our very own PR and Press Officer – Andrew Scott – won bronze medal for his poster (above).



▲ IMID organisers

We captured the international flavour of the Summit by having a video booth (cunningly disguised as an iconic British red telephone box) where delegates were encouraged to share an initiative or successful campaign that they had introduced in their countries. A short podcast is available on the NRAS website www.nras.org.uk/IMID and is well worth a visit.

It was an honour to represent NRAS and people with RA at this prestigious event and one thing I really did take from meeting other patient organisations from across the globe was that, as bad as we may think we have it here in the UK in terms of access to services or treatments, there are so many other countries far worse off than us. So thank heavens for the NHS and the fabulous rheumatology teams across the UK that are working so hard to help people with RA.

IMID is funded by an Educational Grant from Abbott



▲ Carrie Grant (left) with Andrew Scott (centre) and Clare Jacklin (right) at the poster award presentation

Hair loss and RA medications

I am about to start taking methotrexate and am very concerned that hair loss is listed as a potential side effect. Why does this happen, will I lose all of my hair and will this be a permanent thing? Many people worry about this potential side effect of methotrexate which is completely understandable as our hair can be an integral part of our appearance and self image. It may first be helpful to understand the normal cycle of hair growth.

Each hair follicle produces a number of hairs during a lifetime. There are three phases in the normal hair cycle. Anagen (or growth) phase on the scalp lasts 3-5 years and the hair grows at approximately 1 cm per month. This is followed by the catagen phase, and finally the telogen (or dormant) phase where the hair remains in the follicle but does not grow. At the end of the telogen phase the follicle starts to produce a new hair which pushes out the old hair, in humans this happens at a rate of around 50-100 hairs per day.

The hair loss experienced as a result of some RA medications is known as anagen effluvium, where hair is lost excessively in the anagen phase, and is a result of exposure to drugs or chemicals. The drugs that can cause hair loss target all rapidly dividing cells, which includes cell produced by the hair follicles. This type of hair loss is usually noticeable to the individual within days to weeks of starting the treatment, but hair loss experienced by those on MTX for RA is uncommon (approximately 3%) and if it does happen is usually slight. In addition, hair growth usually returns to normal on stopping treatment. If you do feel your hair loss is becoming more than very slight you should discuss this with your rheumatology team.

Tips for looking after your hair

- Use only gentle hair products, such as mild or baby shampoo
- Brush your hair gently, perhaps using a soft brush or wide-toothed comb
- Try not to blow dry or straighten your hair too often (this can over dry the hair and make it break), and maybe think about using a heat protecting spray when you do
- Avoid wearing hair in a tight band, and avoid sleeping in hair rollers as this can damage and break your hair
- A poor diet, stress and alcohol can make the condition of your hair worse so eat as well as you can (with plenty of fruit and vegetables), drink alcohol in moderation and avoid stress, if possible, to keep your hair in good condition
- Gently massaging the scalp may improve the blood supply to the hair follicles
- Avoid perming your hair and try to use tints or dyes made of natural colourants or vegetable-based dyes
- Consider keeping your hair in a shorter style to make it look thicker

References available on request

I am going on holiday to a warm climate but have been told that my skin might be more sensitive to the sun. Is this because of the rheumatoid arthritis or the medication?

Does this mean that I will have to avoid the sun altogether?

Rheumatoid arthritis is not, by itself, a condition that would make you more sensitive to the sun, but a number of medications are considered photosensitive to one degree or another (including some anti inflammatories as well as DMARDs). you should certainly take sensible precautions in the sun, but you should not need to avoid the sun altogether (and sunshine is our main source of vitamin D, which is essential for healthy bones).

Photosensitive reactions to medication can be classified into two categories. The first of these, phototoxicity, is the more common. This is where ultraviolet (UV) light from the sun activates the photosensitising drug, and damage is done to the skin, often resulting in an intense sunburn with peeling skin. The less common but more serious form of photosensitivity is a photoallergic reaction, where the UV light reacts with the drug, causing a response from the immune system. This can cause solar hives to appear on the skin, but these outbreaks usually disappear once the medication is stopped.

The following advice from the NHS website on how to be 'SunSmart' can help you to stay safe in the sun, especially if you are at a higher risk of sunburn due to photosensitive medication:

Spend time in the shade between 11am and 3pm

Make sure you never burn

Aim to cover up with a t-shirt, hat and sunglasses

Remember to take extra care with children

Then use factor 15+ sunscreen

Remember, you can burn just as easily in your garden as you can on a beach, but hopefully these simple rules will help to prevent that from happening wherever you spend your summer.

Should I inform the DVLA that I have been diagnosed with RA?



The law requires you to inform the DVLA (Driver and Vehicle Licensing Agency) if you have any physical disability or medical condition which is, or may become, likely to affect your fitness as a driver (unless you do not expect it to last more than three months). Of course, everyone is affected by their RA very differently so telling the DVLA will be a personal decision and will depend on whether your RA specifically affects your driving.

If you use any special controls for driving you must inform the DVLA of this. However, if you are involved in an accident and your health is believed to be a contributing factor you may be prosecuted if you have not informed the DVLA about your medical condition. In addition, in this event, your car insurance may be invalid so you should also be sure to inform your insurance company of any condition disclosed to the DVLA.

To inform the DVLA of a medical condition you will need to fill in a medical questionnaire (G1) which allows you to include specific details about your condition or disability. The questionnaire will also ask you to give consent for a DVLA medical adviser to request medical information from your doctor. If the DVLA does require further information they may then contact your GP or consultant, arrange for an assessment with a locally appointed medical officer, or ask you to undergo an eyesight or driving test. If the DVLA is able to make

a decision based on the information you have provided in the questionnaire alone they will aim to respond to you within 30 days but if they require any further information it may take up to 90 days for a decision to be made.

The decisions that can be taken once you have informed the DVLA are:

- you may be able to retain your licence or be issued with a new driving licence
- you may be issued with a driving licence for a specific time period (1, 2 or 3 years) if the medical adviser decides that a review of your medical fitness is required in the future
- you may be issued a driving licence which indicates that special controls need to be fitted to the vehicle you drive to enable you to overcome the effects of a physical disability

- DVLA will tell you to stop driving if medical enquiries confirm that you are not fit to drive until your condition improves

If your driving licence is revoked or refused by the medical adviser at DVLA you will be:

- provided with a medical explanation of why this decision was taken (wherever possible the DVLA will advise you when you can re-apply for your licence)
- sent a notice that explains your right of appeal to a Magistrates' Court if you live in England or Wales, or to a Sheriff Court if you live in Scotland

For more information about informing the DVLA, or to download a medical questionnaire (G1), you can visit www.gov.uk or contact the DVLA directly by calling DVLA Drivers Medical Enquiries - Tel: **0300 790 6806**

Who is the best consultant in my area?

This is a question we get asked a lot on the helpline, and unfortunately it's not something on which we are able to advise people. There are many different criteria that would determine a 'good' consultant, and these criteria will often differ from patient to patient, depending on aspects such as how well controlled their disease is and how much information they want about their condition and treatments. Some people will make their decision based on the size of hospital/rheumatology department, or will pick university hospitals or hospitals associated with research.

However, we do recognise that it is important for patients to have access to information on the consultants in their area, so the following is a website that we have found, to help you with making the decision on which consultant to see:

The website is called Dr Foster and the web address is www.drfoosterhealth.co.uk Here you can click on 'consultant guide' and select the following.

Hospital type: Select 'any,' 'NHS' or 'private'

Body area/category: Leave blank

Condition or procedure: Rheumatoid arthritis

Specialty: Rheumatology

Postcode: Type in your postcode

Distance: Select the distance you would be willing to travel

This will bring up the consultant rheumatologists in your area, but you could also use the search engine to find a surgeon or other specialist. The level of detail that you will get on the consultants in your area will vary depending on how much information they have supplied to the website, but in some cases might include areas of specialty to the consultant. For example, a rheumatologist may list rheumatoid arthritis as a specialty, or another condition that you may have, such as osteoporosis or vasculitis.

Campaigning - Update

NRAS continues to be involved in discussions about the health reforms in England. In September we attended a Department of Health strategic partner working day on the future of the NHS Constitution, with the Chair of the NHS Future Forum, Dr Steve Field and the following month, Graeme Johnston, Chair of our Board of Trustees, gave oral evidence to an All Party Parliamentary Group for Patient Involvement inquiry into the impact of the NHS Constitution in primary care. Separately, NRAS also took part in a Department of Health Homecare Medicines working group, which drafted a new patient charter setting out the rights and responsibilities of patients who receive homecare medicines.

Another important strand of the health reforms that NRAS has been involved in relates to commissioning. Several meetings and telephone calls have taken place with partner organisations of the Rheumatology Commissioning Support Alliance, which is a pilot project that has received a grant from the Department of Health to improve commissioning for rheumatology. The pilot will develop an online database to support commissioners of rheumatology services and work with a Clinical Commissioning Group over 12 months to test the new database and advise on the redesign of a local service. Recent activity has focussed on developing a specification for the database with an information technology company and finalising the organisational structure. Separately, NRAS also took part in a commissioning event in September hosted by Northwick Park Hospital about the future of rheumatology services in Brent.

Ailsa also took part in two meetings of the new NICE Topic Expert Group on the RA quality standard, which is expected to report by mid 2013. The 150 quality standards being developed will be key documents underpinning the new NHS quality framework in England. NRAS has pushed hard at these meetings for the inclusion of holistic annual reviews and the promotion of treat to target strategies.



At the beginning of August, NICE announced that it had recommended the inclusion of a number of new RA indicators in the Quality and Outcomes Framework (QOF), the voluntary financial incentives framework for GPs. The new indicators would incentivise GPs to create a register of RA patients and undertake monitoring of RA patients for cardiovascular and osteoporotic risk. At the time of writing, the British Medical Association and NHS Employers are still negotiating over whether they will become a part of the QOF in 2013/14.



Chair of the NHS Future Forum,
Dr Steve Field

The British Society for Rheumatology and Arthritis Research UK (with some input from NRAS) has also been working with the Department of Health to develop a proposed tariff for early inflammatory arthritis. Under the proposal, service providers (such as hospitals) would be financially rewarded for making rapid assessment and giving appropriate treatment to people referred with suspected early inflammatory arthritis. The proposal aims to increase the number of people with early inflammatory arthritis who begin treatment within six weeks of GP referral and receive appropriate follow up care. The tariff has been shortlisted for possible implementation in 2013/14.

The Welfare Reforms also continue to progress and NRAS was invited

to take part in an Evidenced Based Review organised by the Department for Work and Pensions to examine and make recommendations about the descriptors used in the new Work Capability Assessment (WCA) in relation to people with fluctuating conditions. Unfortunately, after a number of weeks of engagement we came to the conclusion that the process was flawed and so decided to withdraw. However, NRAS was subsequently approached for advice on the redesign of one of the indicators relating to manual dexterity



NRAS's Chief Medical Adviser, Professor David Scott

and we contributed some thoughts about how this could be improved. NRAS's Chief Medical Adviser, Professor David Scott, has also been nominated to comment on a forthcoming revised Medical Protocol on RA, which Atos gives to its all its assessors who administer the WCA. Meanwhile, NRAS made a submission to the Year 3 Harrington Review which is monitoring the implementation of the WCA, and to keep NRAS members up to date with all the welfare reforms, Jamie presented to the NRAS Maidstone and Worcester groups. Separately, NRAS was asked to comment on a forthcoming report by the 2020 Health think tank on work schemes for people on long term sick leave in the devolved nations.

NRAS has recently been involved in a number of developments relating to the approval of NHS treatments. In September, the charity made a written submission relating to the scoping exercise for the new NICE Multi

Technology Appraisal on RA drugs and also attended a scoping workshop to discuss issues relating to the sequencing of RA drugs and Disease Activity Score access thresholds. NRAS advocated for the new appraisal to review the existing approach to sequencing and for the DAS thresholds to be lowered. Separately, NRAS also responded to a National Voices member survey on NICE approved therapies.

Work has also progressed in Scotland and NRAS, with the Scottish Public Health Network having published a major new report in September looking at gaps in the service in Scotland and making recommendations to assist NHS Boards to plan and develop future services. NRAS then undertook a campaign planning session with the Scottish Ambassadors in early October, where they received presentations from The Scottish Inflammatory Diseases and Rheumatology Industry Group and the Scottish Medicines Consortium about the drug development process and opportunities for patient involvement. In the same month, NRAS attended the SNP Annual Conference in Perth with two Ambassadors and met with



The new Cabinet Secretary for Health, Alex Neil MSP

four MSPs including the new Cabinet Secretary for Health, Alex Neil MSP. Jamie also attended a roundtable discussion on the future of RA services in Scotland, hosted by Jackie Baillie MSP, and Scottish Ambassador, Sheila McLeod, and continued to provide the secretariat for the Scottish Parliament's Cross Party Group on Arthritis and

Musculoskeletal Diseases, which met to discuss juvenile idiopathic arthritis.

In Wales, at an NRAS Information day at Haverford West in September, Jamie presented to NRAS members and the public on the challenges facing rheumatoid arthritis services in Wales.



Angela Burns AM

The audience was then addressed by Angela Burns AM, who spoke about her own family's experience of the disease and offered to help the charity with its campaigning efforts in the National Assembly for Wales. In a separate development, the charity has just commenced its search for ten NRAS members with the disease to become Welsh Ambassadors in Wales, to replicate the initiative we launched in Scotland earlier in 2012, and undertake direct advocacy with policymakers.



Welsh Assembly

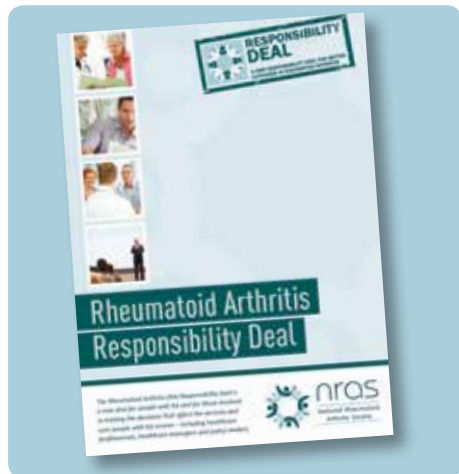
If you are interested in getting involved in this new initiative, which will include dedicated training, please get in touch with Jamie at jamie@nras.org.uk

Launch of the Rheumatoid Arthritis Responsibility Deal

To coincide with World Arthritis Day on the 12th October 2012, we launched a new Responsibility Deal to demonstrate how people with RA and those involved in making the decisions that affect their care and services – including healthcare professionals, healthcare managers and policymakers – can work together to make a real difference to clinical outcomes across the UK.



The Responsibility Deal was the result of an online consultation exercise that NRAS held earlier in 2012, inviting comments from everyone with an interest and connection to the disease. The charity received a great reaction with nearly seven hundred submissions in total from NRAS members, other supporters, and stakeholders from across the rheumatology community. We then summarised this information into a series of eight practical pledges targeted at four key audiences and set out the underlying policy context.



The vision behind the document is a longer term campaign to help raise awareness of RA and to try to get more of our members and the general public involved in campaigning for the cause. To facilitate this, we focused the launch around the power of social media and online campaigning with a new e-petition on our website to enable people to pledge their support. We also collaborated with major political blogs Left Foot Forward, Lib Dem Voice and PoliticsHome to post opinion pieces that linked the Deal to current challenges facing the NHS, with other pieces also published in health publications Nursing Standard and GP Magazine.

Patient pledges

- I pledge to become more knowledgeable about RA and take greater responsibility for managing my disease
- I pledge to work closely with my healthcare professionals to ensure that I can lead a better quality of life

Healthcare professional pledges

- I pledge to continue to improve my knowledge about RA to optimise the experience of the RA patient's journey through healthcare services
- I pledge to understand my RA patients and their individual needs, so that I can support them to help them manage their condition more effectively

NHS service manager pledges

- I pledge to help improve the capacity and ability of rheumatology healthcare professionals to offer and deliver evidence based, high quality care to their RA patients
- I pledge to look at new ways to better meet the needs of RA patients

Policymaker pledges

- I pledge to increase my understanding of RA and to raise its profile amongst other policymakers
- I pledge to help develop policy that will raise the standards of care and quality of life for people with RA

Anyone can demonstrate their support and we encourage everyone with a connection to the disease to do so. It's easy to sign up – if you have access to the internet, then simply log on to www.nras.org.uk/responsibilitydeal and follow the links at the bottom of the page.

Signing up is an indication of your willingness to help NRAS work together with the entire rheumatology

community to raise awareness and understanding of RA, improve access to services and medicines, empower people to self manage their condition more effectively, and, ultimately, lead to a better quality of life for all people with the disease. We will report to NRAS Members about the campaign's progress in future editions of the magazine.

A journey without fear

by Katy Evans

Two tiny black dots on the tip of my index finger. That's all there was to see. In the cold my fingers and toes would turn completely white and the pain was excruciating. The first GP I saw seemed mostly disinterested in my fingers and spent the majority of his time with me berating me for my weight. He sent me for blood tests, which came back "all clear", and that was that.

Then my right arm wouldn't straighten. Odd, but not yet painful. I kept my hands in gloves at all times, watching the tiny black dots slowly growing in size. The second GP I saw waffled about Reynaud's, printed some sheets from Google for me, and sent me away saying "well, if this has all come on so quickly, maybe it will all go away again just as quickly."

Within seven days my left arm wouldn't straighten, it was agony to raise my arms to brush my hair, my wrist screamed at me when I changed gear in the car, my hands throbbed constantly, a feeling like boiling oil was being poured through my veins. I couldn't get in and out of the bath by myself, the strength in my arms and legs had totally vanished and such a simple act as bathing myself reduced me to tears. I didn't sleep at night, kept awake by the terrible pain, and barely made it through my working days.

Finally, GP number three recognised there was something seriously wrong. He made a tentative diagnosis of RA and Reynaud's, but admitted that the NHS waiting list to see a consultant was long and recommended that I see a consultant privately. Thankfully it didn't come to that as the GP managed to contact the rheumatologist directly, who squeezed me into his lunch break. I will be forever grateful for the kindness and reactivity of these doctors, without whom my suffering would have been seriously prolonged.

The next few months were some of the hardest months I think I have ever faced in my whole life. I was diagnosed with rheumatoid arthritis, given heavy doses of steroids as well as a week's in-patient IV treatment for the supposed Reynaud's that was affecting my hands and feet. By this point two fingers on my right hand had large black areas of ischemia. I had ring block anaesthetic injections while in hospital which dulled the pain slightly, but still there wasn't an explanation of what I was experiencing.

A specialist in a nearby town took interest in my case, and I then spent another ten days as an in-patient. I cannot fault the care I received in the NHS at this stage. I was tested thoroughly – two MRI scans, a heart echo scan, a CT scan, x-rays, electrical nerve testing – you name it, I had it! The final verdict was rheumatoid arthritis with associated Digital Vasculitis.

I felt lost and helpless. My relationship with my partner had only recently ended, and being quite a distance from my family he was the one person I could call upon for support and assistance, which he gave me unquestioningly and I could probably never thank him enough for that. I was hearing terrifying things every day and



▲ Katy Evans

coming to terms with the fact that I had an incurable, chronic disease. My consultants assured me I would go on to lead a normal life, that once the treatments started to work I would be able to manage my disease. I didn't believe them. I was convinced that I would be suffering this level of pain and discomfort for the rest of my life.

I was taking a huge number of medications, many of which I knew I would continue to take for the foreseeable future. Taking methotrexate meant that conceiving a baby would need to be carefully planned and preceded by six months free of the drug. Even worse, one of the possible treatments suggested by the second specialist, and thankfully rejected, had a high risk of causing infertility. My life, my freedom, my faith and trust in my body was gone. I was only 27.

That was eighteen months ago. I kept taking the medications, had a second

spell in hospital for the IV treatment I had received before, and finally the blackened scabs were gone from my fingers leaving almost no visible trace (my right index finger is infinitesimally shorter than my left... but only I would ever know!)

With the unerring love and support of my family and friends, I got through those first few months of agony and fear and I survived! There are days when I ache, there are days when I'm so tired I can barely move, there are days when parts of me hurt like hell – but these days are thankfully in the minority. I am getting used to the fact that I need a bit more time in the mornings – no longer can I leap from bed ten minutes before having to leave the house! I have adapted to type without the use of my right index finger – it was too painful for a long time, and now it feels normal to not use it. I can brush my hair, I can take a bath, I can walk to the shops, I can go to the gym and to the swimming pool, and almost all of the time I can go to work every day and lead a totally normal life, just like I was promised all those months ago.

Remembering those first few months now, it feels as though they must have happened to someone else. I forget that it was me who went through that experience. But here I am today, stronger and more prepared to deal with the daily challenges that I face, as a result of the hurdles I have already managed to overcome.

I know it's a long journey; ultimately it's a journey that I will be on for the rest of my life. But it's a journey that no longer fills me with fear. I wish I could go back and tell my newly diagnosed self that the consultants were right – I can fight this and win, and keep on winning a little bit more every day.

Read about Katy's fantastic fundraising efforts in the fundraising section of the Magazine

New year, new challenges!

With Christmas becoming a distant memory it's time to look forward to what 2013 has to offer. Now is the ideal time to take on a new challenge in aid of NRAS!

We started planning our events programme in August 2012, and have hopefully found a few different challenges for people to sign up to this year, along with our old favourites. For the first time we have included a sailing challenge, not a cruise but a tough round-the-clock challenge in all weathers, working as a team, sleeping and working in shifts. This is a great challenge to take on if you want to achieve something totally different.

If sailing isn't your cup of tea, why not hold an NRAS Tea Party? These can be held any time during the year and we can provide you with a tea party fundraising pack which includes ideas on where and when to hold your party, posters and invitations to send to your friends.

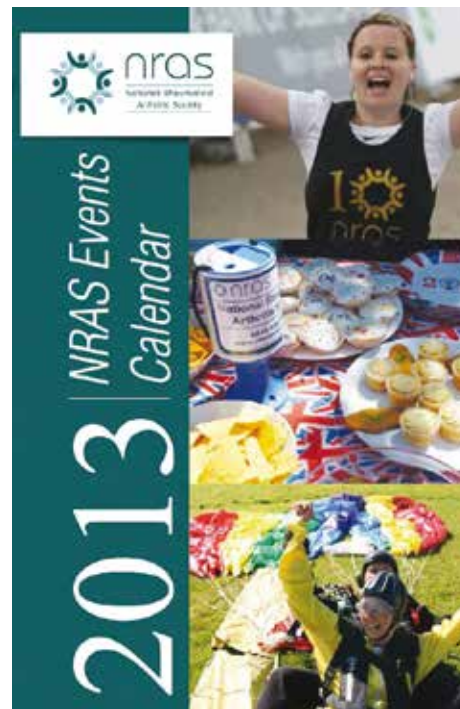
We also have places in the Great North and South Runs and the Royal Parks Half Marathon so if 2013 is the year you are

Now is the ideal time to take on a new challenge in aid of NRAS!

going to take on a half marathon now is the time to get in touch! Or perhaps you might like to throw yourself out of a plane at 13,000 feet – we can arrange this for you too!

Please remember if the right challenge for you isn't included in our events programme, get in touch and tell us what you would like to do, we are always happy to help.

For information on any of our events/challenges or to discuss a challenge of your own please contact Val at val@nras.org.uk or call on **01628 501547** or visit our website at www.nras.org.uk/events



Nominate NRAS as JustGiving Charity of the Year

Nominations for the JustGiving Awards 2013 have opened and we would love you to nominate NRAS as Charity of the Year.

Our supporters were fantastic during 2012. More of you than ever set up JustGiving pages and raised money for NRAS with 105 fundraising pages being created and 1,944 donations being made resulting in a total of £44,425 being donated to NRAS. We would like to ask for your help again by asking you to nominate NRAS for this award in 2013.

The award celebrates the achievements of fundraisers and charities who have raised so much money for good causes through JustGiving in the past year.

The nominations close on the 1st February, 10 charities will be shortlisted

in total and will be announced at the end of February. The charity with the highest votes will win the JustGiving Charity of the Year.

It's very easy to nominate, simply visit www.justgivingawards.com, choose the Charity of the Year category and fill in the online form.

This is our chance to get public recognition for our supporters and volunteers who worked so hard for us during the year.

Please help us to do this by voting for NRAS!

Visit www.justgivingawards.com



JustGiving
**Awards
2013**

The Great North runners do it again

On a wet and windy September morning 22 NRAS runners set off to complete the iconic Great North Run in Newcastle. Among the team was member, Helly Berger, who was pushed round the course in her 'chariot' by a team of four including Chris Deighton, BSR President. A regular runner for NRAS, James Randle, who chooses a different outfit to wear each year, ran dressed as a Dalek and was also joined by our newest member of staff, Andrew Scott. To date £7,642 has been raised from all their great efforts, thank you all so much.



◀ James Randle (the Dalek!), Paul Johnson, Ryan Smith and Andrew Scott from NRAS



◀ (L-R) Chris Deighton, Suzanne Murphy, Helly in her chariot and Liz Buckley



Royal Parks Half Marathon

14 runners took part in this year's Royal Parks Half Marathon, 11 of whom were from NOW Magazine who chose to support NRAS in their fundraising efforts this year. The magazine also carried an article on RA to raise awareness of the disease. A total of £4,260 has been raised and a big thank you to all those who took part.

◀ The NOW Magazine team

Running in Reading

A team from Bristol Myers Squibb who were planning to run in the NRAS 10K in July, ran in the Reading 10K in September. The NRAS run had to be cancelled due to bad weather.

The team of 5 – Subash, Maria, Andy, Helen and Krishna – all survived the run and raised £1,253 for NRAS. Thank you!

If you would like to reserve a place in any of the runs for 2013 please register your interest with Val at val@nras.org.uk – you will get a stylish NRAS t-shirt or running vest to wear on the day to show your support, personalised with your name. We can help with setting up an online fundraising page, send you a sponsorship form and be there on the day to cheer you on.



▶ (L-R) Krishna, Helen, Subash, Maria and Andy

NRAS Tea Party

Many thanks to all those who held tea parties during the year to raise awareness of RA and to help raise funds for our work. There was some impressive baking being done!

We are continuing with our tea party fundraiser for this year and hope that you will join us in organising a tea party at some time during the year. It's a good reason to get together with friends, family or colleagues and a good excuse to eat some yummy cake. You could theme your party for the time of year, hold it to mark a special occasion such as a birthday, or anniversary, or make it a big party by holding it at your school, in your local community centre or at work!

How about...

- An Easter party with simnel cake, easter egg cupcakes and an egg hunt
- A banish the winter blues party with feel good cake
- A spring party with pretty cupcakes and a flower theme
- A traditional party with a choice of tea, scones, fairy cakes and fruit cake

To download your free Tea Party fundraising pack visit www.nras.org.uk or call the fundraising team on **01628 501547** and we will post one to you. **Happy baking!**



Cox Green Townswomen's Guild

For the second year running, the Cox Green Townswomen's Guild of Maidenhead chose NRAS as their Charity of the Year. They have been busy raising funds for NRAS in so many ways in 2012 by putting on lunches, tea parties and cheese & wine evenings, craft selling, jewellery recycling, holding jumble sales and having stands at a combined charity fair and gardening show. They are also taking part in the Maidenhead Swimathon early in 2013.

In 2011 the Guild raised a massive £1,116 for NRAS and a huge thank you goes to all the Cox Green ladies for their hard work. We are looking forward to seeing what has been raised in 2012!

If you are involved in a group in your community and would like to support NRAS by doing some fundraising or choosing us as your Charity of the Year, please contact Oliver Hoare on **0845 458 3969** or email **oliver@nras.org.uk** to find out more.



▲ Members of the Cox Green Townswomen's Guild

Katy swims for NRAS

A member, Katy Evans, who was so inspired by Leigh Walmsley and her achievement in being part of the Paralympic archery team that competed this year, decided to set herself the challenge of swimming a mile (64 lengths of a 25m pool) in her local swimming pool.

Katy was diagnosed with RA 18 months ago at the age of 27, and had watched Leigh, who has RA, compete at the Paralympics (see Leigh's story in this Magazine). Katy said 'I have been slowly building up to being able to complete the distance with the aim of making as much money as possible to support NRAS and raise awareness and understanding of the disease and through the training get fitter and healthier and manage to reach the biggest physical challenge I have ever set myself.'

She completed the challenge in October, with her Mum, Dad and sister Helen swimming with her and raised an incredible £1,232. What a fantastic achievement and well done Katy for achieving your goal.



◀ Katy (right) and her sister, Helen, after completing the swim

Rotary Golf Day Cheque Presentation

On the 19th September, Oli attended the cheque presentation evening of the Wollaton Park Rotary Club, who you may remember held their annual charity golf day on 8th August in aid of NRAS. We were presented with a cheque for £4,000, which is a fantastic achievement, and can't thank the club enough for their hard work and generosity. Along with monies and sponsorship on the day a total of £6,255 was raised.

Mike Lucas, President of Wollaton Park Rotary Club, chose to support NRAS because his wife, Daphne, lives with rheumatoid arthritis and has benefitted from our support services.

If you have a rotary club in your area or you are involved with your local golf club or sports club, why not see if they are willing to support NRAS?



▲ Oli (left) accepting the cheque from Malcolm Whitt of Wollaton Park Rotary Club

Christmas Concert

The annual NRAS Christmas Concert was held on December 7th with performances by St Nicholas' C of E Combined School Choir, Voices Anon and All Saints Community Choir. The Ronettes - Ailsa, Lorraine and one of our Trustees, Wendy - also performed along with tenor William Branston. We were delighted to have our founder patron, The Rt Hon Theresa May MP, with us on the evening who gave a reading.



The Knit Factor

We launched our new initiative, The Knit Factor, to coincide with National Knitting Week in September and have been delighted with the fantastic response we have received from our Members, volunteers and supporters. The initiative is being supported by the UK Handknitting Association and Aneeta Patel, the author of *Knitty Gritty* and www.knittingsos.co.uk.

You have all been sending in your knitted creations which are being listed on eBay and sold to raise funds for NRAS. We have received hats, scarves, jumpers, blankets and Christmas decorations and are amazed at all the talent with knitting needles that is out there! NRAS staff have been taking up the challenge too, which for most of us as very much novice knitters has definitely been a challenge but great fun!

Knitting can be very good for those with RA as it is a gentle but effective way of keeping your hand joints moving and hopefully a way of being able to join in with a fundraising activity and support NRAS. Here are some tips which may help:

- Pace yourself and knit for short periods of time to avoid your hands stiffening and becoming painful
- Use plastic or bamboo knitting needles as these are gentler on your fingers and 'warmer' to the touch
- The larger the needles and the thicker the wool the faster your masterpiece will grow, so if you are impatient this is the one for you!

In Maidenhead Library a local knitting group, Knit & Natter, meets every Wednesday afternoon. The group started off as a library knitting group in May 2011 and still meet in the library every week.

The group are very grateful to Maidenhead Library for allowing them to use a corner of the library every week to catch up on what has been happening during the weekend whilst at the same time knitting lots of lovely garments!

Maureen Richardson, one of the group, said "Maidenhead Knit & Natter are always happy to support local causes and help where they can." They have been very generous in donating a number of different knitted items for the NRAS Knit Factor which are being auctioned on eBay in aid of NRAS, from little booties to matinee jackets! So far they have raised £20.95 for NRAS.

Keep up the good work ladies!

Do keep knitting and sending us your finished articles to list for sale. Or alternatively, why not get a group of friends, colleagues, neighbours together and organise your own sale or all get together and knit squares to make into a blanket... the possibilities are endless!

Visit www.nras.org.uk/knitfactor to download your free How to Knit guide and a pattern for baby booties to get you started, kindly supplied by Aneeta Patel. You can also call **0845 4583969** to order a hard copy. Visit www.ukhandknitting.com for more ideas and to look at their 'Knitting for Therapy' pages where you can share your experience of knitting and read others too.



▲ Tracey, NRAS Director of Operations, modelling a scarf knitted for knit factor



▲ A collection of the items for sale on eBay



▲ Irene Woodiwiss and her granddaughter Charlotte displaying all their knitted items



▲ Members of the Knit and Natter group at Maidenhead Library

Good sleep hygiene may improve pain in inflammatory arthritis

How to manage sleep problems is a common question to the NRAS helpline and we therefore felt that this study and the Sleep Hygiene leaflet, which was produced as result of this work, may be of interest to you.



The researchers in Swindon looked at factors affecting sleep not related to mood and disease activity. Participants in the study were asked to complete an anonymous questionnaire which included questions on sleep, asking about sleep interruption, sleep quality, effect of daytime sleepiness on concentration, mental and physical function, sleep posture, sleep aiding medications, caffeine and alcohol intake. Of 1,331 patients invited, 605 replied of whom 402 were female, 381 of whom had a diagnosis of RA. The results showed that 89% of patients reported interrupted sleep, compared with 41% in a general population. 53% reported daytime sleepiness affecting concentration, mental function and physical function. 28% of patients reported poor concentration on a daily basis and this group in particular reported a higher level of poor sleep posture. Overall 24% reported poor sleep posture. 89% drank caffeinated drinks, on average 4.7 cups daily.

9% drank no caffeinated drinks. The average alcohol intake was 1.7 units weekly, with 4% regularly drinking alcohol to fall asleep. The study confirms the importance of sleep issues in inflammatory arthritis patients with half of the patients reporting daytime sleepiness affecting mental function, physical function and concentration. The study also suggests that factors such as sleep posture and mood, caffeine and alcohol intake, and bladder dysfunction may also affect sleep quality. The recommendation is therefore that these factors should be addressed in routine consultations, to aim to improve sleep quality which may in turn reduce the need for a change in DMARD medication, and importantly improve patient quality of life.

Copies of the Sleep Hygiene leaflet can be found in the publication and resources area of the NRAS website or by calling NRAS on **0845 458 3969**.

The US Food and Drug Administration (FDA) approves a new rheumatoid arthritis drug

The FDA, the US agency responsible for ensuring the safety and desired effect of new drug treatments, has approved XELJANZ® (tofacitinib citrate), a new drug for the treatment of adults with moderately to severely active rheumatoid arthritis. It has been approved for those who have had an inadequate response or cannot tolerate methotrexate. XELJANZ may be used alone or in combination with methotrexate or other non-biologic disease modifying antirheumatic drugs (DMARDs) such as leflunomide, sulfasalazine or hydroxychloroquine.

The drug is the first to have been approved for the treatment of RA from a new class of medicines known as Janus kinase (JAK) inhibitors. It is the first new oral DMARD for RA in more than ten years. XELJANZ is specifically designed to inhibit the JAK pathways, which play an important role in the inflammation involved in RA.

At the moment we do not know when this drug may become available for use in the UK but NRAS will bring you an update when this information is issued.

Moderate consumption of alcohol is associated with reduced risk of rheumatoid arthritis in women

This Swedish population based study evaluated the association between long term alcohol consumption and the incidence of RA in women, looking at both the amount of alcohol and specific types of alcoholic drink consumed.

The researchers reported that drinking three glasses of alcohol weekly is associated with a decreased risk of developing RA. After adjusting for factors such as age, smoking, and dietary habits, researchers found that women who reported drinking more than three glasses of alcohol per week in both 1987 and 1997 had a 52% reduced risk for RA compared with never drinkers at both assessments. One standard glass of alcohol was

defined as approximately 500 ml of beer, 150 ml of wine, or 50 ml of spirit. The reduced risk was similar for all three types of alcoholic drink.

Higher amounts of drinking could not be evaluated in the study since Swedish women drink relatively little alcohol. It is important therefore not to assume that higher levels of alcohol consumption would have the same protective effect.

It should also be noted that, whilst long term moderate consumption of alcohol may reduce the risk of developing RA, it is known that alcohol is related to a higher risk of breast cancer for women. Recommendations regarding cancer prevention say that it should be a maximum of one glass a day which is in line with the study's conclusion on RA.

In an article on this topic which appears on the Arthritis Research UK website, Professor Alan Silman, Medical Director of Arthritis Research UK, agreed that the study should not be regarded as a directive to binge drink. He stated:

"It's important to stress that the paper isn't saying that excessive amounts of alcohol are good for you. And it must be remembered that drinking alcohol in excess can be especially dangerous in rheumatoid arthritis patients who are taking some anti-rheumatoid drugs that may cause liver damage, and anti-inflammatory painkillers which can lead to gastro-intestinal problems, which can be exacerbated by alcohol."

'My feet – visible, but ignored...'

A qualitative study of foot care for people with rheumatoid arthritis

This study set out to explore patients' experiences of foot problems associated with their RA. 22 patients, 16 women and six men all who had RA related foot problems and who had received some advice/treatment for these foot problems were recruited to help with this study. The study participants took part in a recorded focus group and the data was transcribed and analysed into themes which were identified as:

- **The significance of foot symptoms in relation to diagnosis of rheumatoid arthritis** – Many of the participants reported that they had experienced problems with their feet before a diagnosis of rheumatoid arthritis was made. Most reported that their feet were ignored by their general practitioners (GPs) even if they mentioned foot symptoms during a consultation.
- **Knowledge of and explanation about foot symptoms** – The participants reported that they had patchy knowledge of what causes the foot problems associated with rheumatoid arthritis. The majority expressed relief once they had acquired knowledge about their foot symptoms. However, the lack of timely 'information giving' by many practitioners resulted in them being left to work out for themselves what their foot problems were.
- **Assessing foot health interventions** – Some participants reported difficulty in getting foot care, with delays in being referred and getting an appointment. For some they felt that not enough attention was paid to their feet to a point where they felt they were ignored. Participants also stated that they felt that there appeared to be a reluctance to refer for foot surgery.
- **The effectiveness of foot health interventions** – Frequently, it was reported that the potential effectiveness of foot orthoses was limited by the footwear styles that the participants liked to wear. Some orthoses caused abnormal wear of their footwear necessitating new footwear or the orthoses to be discarded. However, when foot orthoses fitted into a variety of footwear styles, use was much better and foot symptoms improved. Current provision of therapeutic footwear for women was reported to limit the types of clothes that could be worn and they expressed that this made them feel less feminine. Most had accessed general foot care for nails, corns and callus. They valued this in respect of improvements in comfort. It was also acknowledged that the option for open access to podiatry was reassuring in that they could get immediate help when new problems arose.
- **Improvements to foot health interventions** – The majority expressed the opinion that GPs should have knowledge about rheumatoid arthritis and the significance of foot problems in its diagnosis. Once a diagnosis has been made then referral to podiatry services was considered to be essential for those with foot pain.

Finding footwear in which to accommodate both their feet and their foot orthoses was an issue for the majority. It was suggested that in an age of technological advances therapeutic footwear should be designed and manufactured in contemporary styles with improvements in fit. The need for a variety of therapeutic shoes for different functions was expressed.

This study has highlighted a wide gulf between what these participants need in relation to their foot symptoms and how in reality they are managed. It is a matter of concern that foot problems seem to be ignored as early detection of foot problems may aid the diagnosis of the RA and having effective foot health interventions is important in giving patients improved quality of life.

Are smoking and being overweight important predictors for developing RA?

A group of researchers from the Netherlands have conducted a study to try to determine if smoking and being overweight are important factors for developing RA in those whose blood contains RA specific autoantibodies.

55 people who were deemed at risk of developing RA because of the presence of these autoantibodies, and who had never shown any evidence of arthritis, were followed over time. The participants were assessed as being a never or ever smoker and having a normal BMI (body mass index) of less than 25 or overweight, ie a BMI of equal or greater than 25.

Results indicated that 15 participants (27%) had developed arthritis when they were followed up, on average at 13 months. The results also suggest that being overweight is a risk factor in its own right. The risk of developing arthritis in the group who were smokers and overweight increased to 60% after a follow up on average at 27 months.

This small scale study suggests that in those with the RA specific autoantibodies in their blood the importance of life style factors should be critically evaluated in clinical research aimed at disease prevention.

Review of the long term safety of rituximab in rheumatoid arthritis

A question frequently asked by callers to the helpline concerns the long term safety of drugs, especially so for the newer biologic treatments. A recent review of data collated over 9.5 years as part of a follow up of the global clinical trial programme has looked at the long term safety of rituximab in rheumatoid arthritis, focusing on the adverse side effects of interest to RA patients.

This analysis shows that rituximab remains generally well tolerated over time and multiple courses, and that the safety profile is consistent with the data that was published following its clinical trials. Overall, the findings indicate that there was no evidence of an increased safety risk or increased numbers of reports of any type of adverse events (AEs) including infections, cardiovascular events, malignancies or fatal AEs, in those who had been taking rituximab for up to 9.5 years.

Volunteers busier than ever!

We usually experience a quiet period during the summer months but oh no, not this year! There has been a noticeable increase in requests for volunteers to participate in an ever widening variety of projects and research. Here is just a snapshot of the sorts of things that volunteers have been doing on behalf of all those who live with RA.

- Focus group looking at what does remission mean to YOU. This was to formulate the basis of a survey that many of you will have taken part in by now to capture how remission is being talked about, if at all, with healthcare professionals and what is the outcome of aiming for remission for patients?
- Focus groups on what further support could be made available via a homecare delivery service and their nurses
- One young member, Louise McCulloch, had her bones scanned as part of an article in the Daily Mail to raise awareness of the connection between RA and osteoporosis
- 25 people participated in three focus groups exploring the impact of RA on emotions and relationships. I hope many of you will have taken part in the online survey as a result of these focus groups which in turn will help us produce an online resource and booklet that will aim to give information and support to patients and their healthcare professionals in addressing these sensitive issues
- Five NRAS Members joined other patients from Guy's hospital at a focus group co-facilitated by NRAS and a health psychologist, Anna Ferguson, looking at patients' attitudes to adherence to treatment and how that is communicated with healthcare professionals
- Jean Fisher and Jo Watkins attended a Quality, Innovation, Productivity and Prevention (QIPP) workshop in Sheffield. This is an NHS initiative which we'd urge others to participate in if invited to do so. It is important that the patient voice is heard at such discussions. See a synopsis of Jean's experience below
- Members volunteered to host an information table as part of the Burley Wharfedale Health & Wellbeing event - it is so important that we reach out as much as we can by participating in such events to raise awareness of RA and NRAS
- Group coordinators regularly host an information table at rheumatology clinics, most recently John Wright from the Solihull group did so and found the experience very worthwhile reaching people with RA that had never heard of NRAS or the group before

Ask yourself, would you like to help shape the future of rheumatology services or are you able to do your bit to raise awareness in your area of RA and NRAS? Whatever it is, big or small, we can all make a difference and we so appreciate all that NRAS Members and volunteers do. If there is a local event you would like to represent NRAS at please contact clare@nras.org.uk or call **0845 458 3969**.

The things WE do for NRAS

You may think that those of us at the NRAS office are always asking you to go the extra mile for us, and we truly appreciate all you do. But we too put ourselves out on a limb for NRAS and I thought I would share with you what some of us did recently to raise money for NRAS.



▲ Members of the NRAS cast performing at the Potty Panto

Potty Panto was a Maidenhead charity event which set the challenge for three local groups to write and perform a 25 minute pantomime with a maximum cast of ten people. I managed to persuade Lorraine (Helpline Manager), Ruth (Online and Social Media Coordinator), Emma (Membership Supervisor), Wendy Garwood (NRAS Trustee), Val's daughter Tory, as well as my own two children, Hannah and Paul, to join me in treading

the boards for NRAS. Our version of Cinderella was hysterically funny with Lorraine being the loveliest of good fairies, Wendy being the wickedest of wicked stepmothers and the less said the better about me as an ugly sister! The good news is that against stiff opposition from a local highly talented youth drama group, the NRAS theatrical team won, bringing back to the office a wonderful trophy and £250 for the NRAS coffers.



▲ (L-R) Emma, Ruth, Clare, and Lorraine showing off their first prize and cheque following the Potty Panto

If you would like to check out the shenanigans of the Potty Panto crew visit www.nras.org.uk/panto and if it makes you smile how about making a donation online?

4000th Member!

In late October, NRAS reached a major milestone when it welcomed its 4,000th Member, Sara Britton from Bristol. Sara, who was diagnosed in October 2011 said, "rheumatoid arthritis was a disease I knew nothing about and wrongly assumed that it only affected the elderly. NRAS taught me that it can affect anyone at any age, and it takes no prisoners. Being part of NRAS was a lifeline to a community who understood exactly how I was feeling at a time when I was confused and frustrated."

The 3,000th charity member was registered in 2010 and the team had been eagerly anticipating the latest landmark, which was celebrated in the best possible way – with a cake!

We are so very grateful to all of you, our Members, who through your support help the charity to go from strength to strength.

If you've been thinking about becoming a Member, why not make it your New Years' Resolution to join the NRAS family? **Visit www.nras.org.uk** then click on 'Join' for further information.

Gift Membership

If you're struggling to find the perfect gift for a loved one then why not give a gift that lasts all year? If you have a family member or friend who lives with rheumatoid arthritis, why not consider buying them gift Membership of NRAS? For just £25 for the whole year, they will receive all the benefits of Membership plus a gift card which has a space for a personal message from you. We can arrange for it to be sent straight to the recipient or we can send it to you so you can give it to them yourself.

Also, if you have RA yourself and are looking for a way in which your family or friends can support you, then why not suggest they buy you gift membership of NRAS as a present?

For those who wish to support our work, but do not have RA themselves, we also have Friends of NRAS – a loyal group of people who support us by giving a regular donation towards our work (either monthly or annually). Their support allows us to continue running our freephone helpline, helps us to set up new NRAS groups and allows us to continue sending publications free of charge. In return, Friends of NRAS are kept up to date with our work with quarterly newsletters and receive an NRAS lapel badge.

If you are interested in Gift Membership or want to become a Friend of NRAS then please visit our website and click on 'join'. Alternatively you can call us on **0845 458 3969** to pay over the phone, or complete the form included in this magazine.

Group News from across the UK

Jamie and Ailsa braved the M4 to head to our most westerly NRAS group in Havefordwest for their annual open day. Well done to Claire and Jean for organising another informative and stimulating day for patients from the area.

Happy 2nd Birthday to Blackpool NRAS group, BADRAGs, they had a great celebration in November.

Well done Ashford for holding their first meeting in November following the group's launch in July. The group leaders have now confirmed their dates for 2013 and have secured a venue for the year.

Two groups were launched in the autumn in Bath and Dorchester. Both groups have now got their group leaders in place and Bath's venue and dates have been set for the first half of 2013.

Group launches being planned for 2013 are Basingstoke, Cambridge, Cheltenham and Flintshire, so if you live in any of those areas and would like to get involved with getting the group established please email gill@nras.org.uk.

For up to date information on meeting dates, venues and speakers visit www.nras.org.uk/groups

QIPP Workshop in Sheffield

Jean Fisher and Jo Watkins attended the QIPP workshop in Sheffield to contribute to improving the quality of care for patients with inflammatory arthritis. Attendees, including consultants, nurses, managers, a GP and the president of the British Society of Rheumatology, were divided into groups to develop plans for future work on such things as initial referral, shared care in RA and rapid access issues.

"The main problem seems to be the lack of funds. Costing of 'patient pathways' needs to be reviewed as do other areas of the system. Jo and I felt our input was valued. It was reassuring to know that so many professionals are concerned about the welfare and care of people with RA and they are working hard to improve the situation." Jean Fisher

New look Volunteer Network Team

Kim Fitchett joined the volunteer network team in September to replace Sue who left in June and Gill Weedon joined our merry band in November. Many of our groups will have met Maimie Hume who has relocated to Cambridge due to family circumstances, so left us in September and is very much missed but we wish her well, and welcome Gill to the team.



▲ (L-R) Clare, Kim and Gill from the volunteer network team

Members' Day 2012

Nearly 100 Members, guests, NRAS Trustees and staff attended the first annual NRAS Members' Day on Thursday 11th October at Taplow Court, Maidenhead.

We were extremely pleased to welcome our guest speaker Professor Peter Taylor (Norman Collisson Professor of Musculoskeletal Sciences, University of Oxford) who gave an excellent presentation entitled "Translating clinical targets into realistic personalised goals for patients with both early and established RA".

After our afternoon tea and cake, kindly provided by the Homemade Cake Company in Maidenhead, we had a very interactive Q&A session with our multidisciplinary panel which was well received by all those who attended. Some of the questions that were asked, and the answers given, are available to read here.

We intend to make this a regular annual event and to move it around the country to ensure that all our Members, wherever they live, will find it as easy as possible to come along and enjoy the day.

A copy of Peter's presentation is available on our website as well as pictures taken on the day. The expert panel Q&A is also available in the Members area of our website so please do contact the Membership team via email membership@nras.org.uk or call us on **0845 458 3969** if you require a reminder of your login details or if you are interested in joining.

Tracey opening the afternoon's proceedings



Professor Peter Taylor presenting at the Members' Day



NRAS staff and members waving for World Arthritis Day



The multidisciplinary panel



Members' Tips

Arthritis Gloves

I have just started using these gloves. They provide warmth but still enable me to use the computer. The compression isn't so tight that it turns your hands into claws either!

www.imakproducts.com

From Angela in Newmarket



Window Cleaning Vacuum

I recently went to my daughter's house to see her demonstrate their new gadget - very impressed and I want one! It was very light to use and I have read a few reviews, all of them good. You even can use it for getting condensation off windows in the morning.

www.amazon.co.uk

From Paula in Nottinghamshire



Seat Belt Extension & Pads

A seatbelt extension makes seatbelts much easier to use and easier to handle. Sheepskin seatbelt pads take the pressure off sensitive bones making them a lot more comfortable to use.

www.amazon.co.uk

From Carolyn in Pembrokeshire



Plug Tugs

These Plug Tugs attach easily to ordinary electrical plugs and provide a secure loop that enables the user to grip them - they're so simple but makes it easier to pull plugs out of wall sockets.

www.completecareshop.co.uk

From Sylvia in Newton Abbott



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



Survey on social, emotional or psychological support for people living with inflammatory arthritis

Last autumn NRAS was pleased to support an important piece of research being conducted by the University of the West of England (UWE) and funded by Arthritis Research UK on social, emotional or psychological support for people living with inflammatory arthritis.

Surveys were sent by post to 1,200 NRAS Members in England, of which over 500 responded. UWE and NRAS were delighted with the number of responses received.

The snapshot below is based on the responses of around 90 NRAS participants, and is intended to give a flavour of some of the issues which are emerging. They are also based on the 'free text responses' which have been received so far.

General comments on the NRAS service

- Forum and blog are very helpful, one respondent called them 'a life saver'
- Provides empowerment and support to challenge GP/ rheumatology teams where appropriate
- Helpline is caring and supportive
- NRAS excels in educating the public and family about RA
- Website is great at providing answers
- The support is invaluable

Social/emotional support which respondents found helpful

- Support groups with other patients/people who understand
- OTs mentioned specifically as supportive and caring
- Family support very important
- Access to rheumatology nurse for advice when needed

Social/emotional support which respondents have found unhelpful

- Long times between appointments, leads to concern about contacting rheumy team with problems and feeling isolated
- Nurse/consultant/GP too busy to talk about emotional/ social issues – anxiety about raising them and being seen as a nuisance
- Emotional issues are asked about but not followed up
- GPs – lack of specialised knowledge and tendency to underestimate severity of pain/fatigue

Other issues

- 'You don't look ill' – invisible symptoms hard to explain to friends and family
- DLA and applying for benefits highlighted as emotionally upsetting by several respondents
- Fatigue – not the same as 'normal' tiredness and little understanding from friends/family

By participating in this confidential survey and sharing your experiences and views, you will be helping to develop useful support services for those living with inflammatory arthritis. The findings will be published in an academic journal and we look forward to reporting on them in due course.

Become a 'Friend of NRAS'

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

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

...follow the easy steps below

Step 1

Tell us about you



Title First Name

Surname

Address

Postcode

Tel No

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

Email

Step 2

Become a Friend



I would like to become a Friend of NRAS.

Annually: £25 £50 Other £ Monthly £

NRAS was recommended to me by:

Step 3

Pay by Direct Debit



Instruction to your Bank or Building Society

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

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

Service User No. NRAS Reference No.

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

Name(s) of Account Holder(s)

Bank/Building Society Account No. Branch Sort Code

Name and full postal address of your Bank or Building Society

To: The Manager Bank/Building Society

Address

Postcode

Reference

Signatures Date

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

Other ways to pay



There are two other ways to pay:

Cheque or postal order - Please make cheques payable to NRAS

Credit/Debit card - Please complete your card details below

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

Name on card

Card Number

Valid from / / Expiry date / /

CVC (Reverse of card)

Issue no. (Switch/Solo cards)

Amount £ Date / /

Signature

Step 4

Gift Aid it

giftaid it

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

YES/NO*

*Please delete as appropriate

Step 5

Simply post this form



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

National Rheumatoid Arthritis Society

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

Do you have rheumatoid arthritis?

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

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

call us or visit our website

0845 458 3969

www.nras.org.uk

To join and get your welcome pack

At our Members Day held at Taplow Court last October, we held a Q&A session with an expert panel made up of health professionals. Unfortunately, we did not have time to go through all of the questions that we had put forward for this session but we thought you might enjoy reading some of the answers given.

Q. Why is it that in some areas you get access to podiatry and in other areas it's patchy at best, non-existent at worst? Since being diagnosed with RA I have always had problems with my feet and yet rarely do I get a chance to see anyone qualified to do something about my problems.

A. Firstly, podiatry is accessible. Normally patients are referred on via GPs, or as in my case where I work as part of a multidisciplinary team within an acute site, they're referred on by a consultant. It's important that they are referred on fairly quickly because as far as podiatry is concerned it's important for us to maintain foot function, and reduce any foot pain that is associated with rheumatoid arthritis as it can manifest itself throughout the body.

In terms of accessibility, certainly in Berkshire, it is fairly easy for a GP to refer a patient to a community hospital where they will be seen and assessed by a podiatrist. They will assess their actual needs for having continued podiatric care, whether they could be encouraged in self care to maintain their own independence. If their feet are quite problematic and they do need regular care then there is no reason why they would not be taken on by a podiatry service. They would then be seen at regular intervals to address whatever foot problems they have. This care could include simple nail cutting because they are unable to hold their nail clippers or getting some sort of device specifically made for their feet or whether they've even got wound care associated with RA.

Arun Bhargava, Podiatrist at Heatherwood and Wexham Park Hospitals

Q. Is there a time period for the standard drugs such as methotrexate, sulphasalazine and hydroxychloroquine, would you suggest not taking them for longer than say ten years?

A. It's a long term disease so people will remain on these medications once they've started for a long period of time until they don't work, in which case you'd switch to something else. Obviously patients are worried about side effects and I think every drug will have a side effect. Interestingly enough, side effects tend to be worse when you first start the drug and your body either gets used to the drugs, or the drugs get used to you and the effects lessen over time. And we monitor patients through blood tests for instance and obviously if they get side effects they will let us know.

Patients will say 'can I stop my medication' and there is only a little bit of research on stopping drugs, most of the research that is done is on starting treatments. The only research on stopping drugs was on hydroxychloroquine (which is one of the milder drugs that we use) and what happens to those who stop taking it, and patients symptoms got worse. We are always worried about patients relapsing when they come off treatment as very often if you restart the drugs you may not get back to how good you were before. We only ever change a medicine if they are not doing well on it, if they are, then we leave well alone.

One of the reasons why we do regular blood tests, check joint scores and ask the patients how they are feeling is that unfortunately although we would love everybody to respond to these drugs, 1) patients don't always respond and 2) is they lose their response, for example with time the drugs become less and less effective and they have to switch.

Dr Christopher Kelsey, Consultant Rheumatologist at the Queen's Hospital in Romford and NRAS Medical Advisor



▲ Dr Christopher Kelsey

Q. The people at the hospital generally have long waiting lists but you don't know how long they are, so you phone up them to find out and they don't know, so then you phone your GP and they get annoyed because you keep bothering them and they want to see their patients. What do I do?

A. What we're designed to be almost is your advocate. We're meant to be your central point so yes, you might have RA but actually you can get other problems too. Our aim is to be the person who tries to coordinate their care but ideally not to be adding an extra step that makes more work for you and more work for them.

Obviously things differ in different counties but in Buckinghamshire we have an intermediary care service where I'm involved as Medical Director of MSK Care. This would be where, if necessary, I would normally take over from your GP in terms of organising the x-ray, I could then review the x-ray, I can review the MRI, I can liaise with podiatry or the specialists if I need to. Not every county has that in place and, as a GP as well, I know that it can feel like we're the messenger boy and the coordinator but it is designed really to ensure that we're there for you, with you at the centre. We try to be coordinator for all the aspects of your care that you need. It just seems maybe that, more recently, it has got a lot more complicated. Your GP is fundamental as they should be getting a

copy of your blood results, whether they're done by the hospital or done by us. This means that we know whether, because of your RA, something is a bigger risk factor for you than with somebody else who doesn't have RA.

There is an increasing move to bring things out to primary care because we know the demands on the hospital are huge, it's often easier for you to come to the GP rather than go to the hospital and this is true for a lot of conditions. Primary care is already dealing with a lot of things that used to be dealt with by secondary care. And yes at times, the demand for what we are trying to do and the number of hours in the day is more of a challenge than it was perhaps!

Dr Ruth Burnett, Local GP and Medical Director of MSK care in Buckinghamshire

Q. Is there any research being done into the cause of RA and are we anywhere nearer knowing what the reason is?

A. There has been a really big advance in this and what we've learnt is that the genes, the inheritance we have in our genetic code within cells is a major component. There's a major piece of, fairly recent, technology that is able to look for the associations between particular genes. We now have genes that code for 30,000 proteins in our body and they have identified 40 genes so far that have been identified as strongly linked to susceptibility to RA. These may have evolved because they gave us some advantage many generations ago, for instance protecting us against infectious agents, but now those infectious agents are not around and render some people more vulnerable to the effects of RA. There is one genetic association in particular that counts for about a quarter of the predisposition to rheumatoid. However, firstly I should hasten to add for any of you who have RA and are worried about whether your offspring will get it, even if you have identical twins, if one child gets it, there is still only a 10-15% chance of the other sibling having it. So it doesn't necessary run always true in the families.

So, there are genes that predispose and then there other factors, smoking being one of them. The way that was discovered was that in Sweden it was noticed that in the days of the great railways, when people were travelling across the country in steam trains, the firemen who shovelled the coal and were breathing in the smoke all the time, would often get RA. It happens that in Sweden this particular gene is in a higher proportion of the

population than it is in other countries. So this, plus smoking (and in this case it was inhaled coal smoke but it also works for cigarette smoke) triggers some abnormality in the immune system. Now, we also know a little bit about what that is and in some people it may well be a bug that causes gingivitis (or gum disease) and in generations gone by it was observed that patients had no teeth because they had terrible gum disease, they lost their teeth and then they developed RA afterwards. So, the picture's not complete but we're beginning to understand it's a combination of a genetic effect, plus some sort of environmental effect, of which smoking might be one factor but there may be others including stress, and then some infectious insult – it's a whole series of events and if they happen to coincide then RA results.

Professor Peter Taylor, Norman Collisson Professor of Musculoskeletal Sciences at the University of Oxford and NRAS Medical Advisor

Q. How critical is diet when using TNF inhibitors with methotrexate and do they affect the health of the gut and if so, how can one maintain a healthy gut?

A. Questions about diet are often raised, particularly in appointments with the nurse. It's something that we don't fully know the answer to but there's likely to not to be just one dietary rule that will suit everybody. What we do know is that having a healthy diet, following the general health promotional messages that come out to us (five fruit and veg a day, not eating too much red meat and having oily fish), it is these principles that should apply to us all, whether we have RA or not. There isn't anything specific that we would say for many of medications but there has been some work done with anti-TNFs that has suggested that certain food related bugs have caused some problems with skin infections in people who are on anti-TNF treatments. And so if you looked in information leaflets from Arthritis Research UK a couple of years back, it specifically went into the fact that you should probably avoid cheese with mould in or around it, that you should avoid feta or goat's cheese, raw egg and raw egg products. It has been taken out of the most recent leaflet but they have suggested good food hygiene principles should be applied and it gives a link to the healthy food website.

Diane Home, Consultant Nurse at West Middlesex University Hospital and NRAS Chief Nurse Advisor for England

British Society for Rheumatology Rheumatoid Arthritis Biologics Register

(BSRBR-RA) UK CRN ID: 7302

The BSRBR-RA is a unique collaboration between the University of Manchester, the British Society for Rheumatology and the pharmaceutical industry. We are proud to be the largest prospective register of rheumatology patients receiving anti-TNF α therapy in the world and with over 20,000 patients registered and we continue to grow.

To date, we have recruited over 20,000 participants on to the study, all of whom are still under follow up via their consultant rheumatologist unless withdrawn or passed away. Over 40 journal articles have been published on the data that has been collected since the start of the study. Articles can be downloaded from our website – details are at the bottom of the page.

If you are a health professional involved in recruitment and data collection...

Thank you for your support of the study so far. Your support over the last decade has been vital to the success of the register.

Registration guides and flowcharts can be found on our website, or please contact the office if you have any questions.

- The BSRBR-RA is adopted on to the UKCRN portfolio (ID: 7302) and accrual figures are uploaded every month on your behalf. All registrations (including the re-registration of participants already on the BSRBR who start tocilizumab or certolizumab) count in the UK CRN accrual uploads.
- We have been informed that some of our centres use the support available via the UK CRN to employ research nurses or data clerks to assist in the recruitment and follow up of participants. If you do not currently access any support via the UKCRN, there may be some funds available.

We would advise you contact your R&D department in the first instance.

We are continuing to recruit to the BSRBR-RA to study the safety of new biologic therapies. This includes any patient with RA starting tocilizumab, certolizumab and biologic-naïve patients starting etanercept, infliximab or adalimumab. We request that we receive consent and registration forms within 6 months of patients starting their new therapy.

If you are a participant enrolled on the study...

Firstly, thank you so much for being a part of the BSRBR-RA. The data you have provided us - both directly through your follow-up questionnaires and diaries, and also via your rheumatology consultant - have been so important in helping the researchers analyse the safety and effectiveness of biologic therapy compared to other treatments.

Some of our findings so far show that, although we found the risk of serious infections is low in patients on biologic therapy, we suggest it could be lowered further by following the advice issued by the Food Standards Agency (FSA) for all patients on treatments which affect the immune system. The FSA advise that certain types of food should be avoided such as: blue veined cheese, pâté, feta and goats cheese, and unpasteurised milk and ice cream.

Skin Infection Advice

We have also seen a number of skin infections in patients receiving biologic therapy so always seek early medical treatment if you are concerned.

We have an excellent record of participation, with patient follow up return rates staying at 70% or above, so a big thank you to all!

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



▲ The Rheumatoid Arthritis Biologic Register Team at the University of Manchester

This advice has now been incorporated into the Arthritis Research UK Biologic Patient Information Sheet as a direct result of your contribution to the BSRBR-RA

BSRBR-RA Biologic Studies Group
Arthritis Research UK
Epidemiology Unit
Unit 4 Rutherford House
Manchester Science Park
40 Pencroft Way
Manchester M15 6SZ

www.medicine.manchester.ac.uk/medicine/arc/bsrbr

T: 0161 275 1652 or 0161 275 7390

F: 0161 275 1640

E: biologics.register@manchester.ac.uk

Drug	Diagnosis	Biologic Naïve?	Other Details
CERTOLIZUMAB	RA	Can be first or second line therapy	Can be re-registered into this cohort if already on the BSRBR-RA and switch to certolizumab
TOCILIZUMAB	RA	Can be first or second line therapy	Can be re-registered into this cohort if already on the BSRBR-RA and switch to tocilizumab
ADALIMUMAB	RA	MUST be biologic naïve	Referred to as the 'Anti-TNF comparison cohort'
ETANERCEPT	RA	MUST be biologic naïve	
INFLIXIMAB	RA	MUST be biologic naïve	
ANAKINRA	All rheumatic diseases	Can be first or second line therapy	N/A
RITUXIMAB	Not recruiting	Not recruiting	Cohort closed 31/12/2011

▲ Rheumatoid Arthritis Biologic Register

The Artist

by Imogen Elliott

At the age of 15 I woke one morning to find my feet had seized up. The only way I could describe it at the time was that they felt broken. Within days my hands had locked. The doctors put it down to growing pains but my mother persisted and eventually I was diagnosed at 17 with rheumatoid arthritis. I was studying art at college at the time and was devastated. Since the age of eight all I ever wanted to be was an artist.

For two years I lived with constant pain in my hands. On occasions the pain was so severe that I could not even dress myself. Walking was so painful that I devised a way to walk on the outside of my feet almost balancing to elevate the pain. I lived on painkillers until the rheumatology consultant started me on methotrexate.

My mother requested acupuncture which I had every six weeks to relieve the pain naturally. This, for me, was this best form of pain relief but it was expensive. As my dose of methotrexate was increased I became anxious and confused, one of the side effects of the drug. The good thing about it though is that has prevented my bones from deforming.

In 2009 I moved to Cheltenham to study for a BA in Illustration at the University of Gloucestershire. I knew it was going to be tough but I could not give up on my dream.

The first year I was very ill as my immune system was low, another side effect of methotrexate. At times I would have an extreme flare up in both hands and feet and have to miss a class but I was determined and pushed myself to complete the three year course.



▲ Imogen on the opening night of her exhibition at Centre Arts in Cheltenham

The pain in my right hand prevented me from drawing most of the time but then I started to doodle with my left hand. I created a style using my left hand that has now become my own style. In September I had my first solo exhibition at a local gallery and my work was exhibited for a month. I continue to take commissions and sell my greetings cards.

Every month I still attend hospital for blood tests and continue to take my methotrexate but I won't let this hold me back from my dream.

▼ One of Imogen's latest pieces of artwork



In the next issue of the NRAS Magazine...

...what rheumatoid arthritis has taught me

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



▲ Su Nami

www.facebook.com/Su2Po

Christmas Cards

Many thanks to all those who have supported us by purchasing Christmas cards and merchandise this year. We have raised £1,991.50 from these sales which is much appreciated and this will go directly towards supporting all those who live with RA.



Get Social

If you want to keep up to date with rheumatoid arthritis news and what NRAS is getting up to, you can 'Like' our Facebook page and 'Follow' our Twitter account! You don't even have to join the sites to view our pages.

The NRAS Facebook page can be viewed at www.facebook.com/nationalrheumatoidarthritisociety

Our Twitter link is www.twitter.com/NRAS_UK or you can search our user name **@NRAS_UK**. The Membership team and Helpline team also tweet regularly, as do various members of the team.

If there's anything you would like to share that is related to NRAS or RA, you can always get in touch via the social media sites or email ruth@nras.org.uk



Look out for our new RA Awareness Cards

In the next few months we will be producing RA awareness cards which we will include with all new Membership packs and renewals to hopefully help you with explaining to people what RA is and how it affects those who live with it. The cards, which will be the same size as a credit card, can be given to anyone who wants to know more about the disease, or simply doesn't really understand how it affects you. If you would like a supply of the cards before your renewal is due please contact membership@nras.org.uk or call Emma or Gail in the Membership team who will happily send some to you.



An Apology

The article on the History of JIA which was featured in the Autumn issue of the Magazine was unfortunately not attributed to its author, Ann Hall. We apologise for this error.

UNWANTED CHRISTMAS PRESSIES...?

Need to get rid of those socks that Auntie gave you? Not another Christmas jumper from Granny... then sell them on eBay and raise funds for NRAS at the same time! Simply list the items you want to sell in the usual way and ask for the proceeds or part of the proceeds to go to NRAS, which is listed as a registered charity on eBay. It's a great way of getting rid of those unwanted gifts or just a good excuse to have a New Year clear out and declutter your life!



Foot Health

A new section on foot surgery has been added to the foot health area of the NRAS website. Do take a look and let us know what you think!



28 day prescribing could be costing the NHS more than it's saving

Pharmacy researchers investigating the Department of Health endorsed policy promoting shorter prescribing durations have found that across the board 28 day prescribing policies could be costing the NHS more than they save.



This research was conducted by Professor David Taylor at University College London, School of Pharmacy, and looked at prescribing trends for 11 medicines, including aspirin, during the period of 1998-2009. The study found that by sticking too rigidly to a 28 day prescribing regime, GPs were prescribing lower doses per prescription, which led to an extra 35 million items being dispensed in 2009, compared with 1998. This increase in the number of prescriptions has led to an estimated £150m a year extra being spent on dispensing fees.

Shorter prescription times had been introduced to try to tackle the problem of unused medicine in the NHS, and the extra cost still needs to be weighed against the possible benefits in patient compliance with taking their medication.

New Year Survey

Please watch out for a New Year Survey being sent out to all Members shortly. The survey is twofold – to be able to learn a bit more about you to ensure we can tailor the most relevant information to send and also to ask you if there are other contacts or avenues you may be able to introduce us to help broaden our supporter base. An example of this might be if you or a family member works for an organisation, they might be willing to put NRAS forward to be considered as its Charity of the Year or get together a team of staff to support NRAS by taking part in one of our events. It is essential for us, as a charity, that we explore all possible avenues of support if we are to secure the long term future of NRAS. To save costs, all those who are signed up to email will be sent a link to an online survey and those who are not will receive a survey in the post. Your opinions are important to us so please do help us by completing the survey when it arrives.



Thank you all in advance!

NRAS is seeking two new Trustees

We are looking for two new Trustees to join the NRAS Board of Directors in 2013. We would like to appoint a Treasurer to assist our Financial Controller with financial planning and a second Trustee with business/professional experience. As with most smaller charities, we would ideally like to find trustees who may have contacts and experience to bring which is so important in helping us take the charity to the next stage of its development.

The Board is responsible for the governance of the charity and overseeing its operation to ensure that we act prudently, within the legal framework and are making best use of the resources we have. Meetings take place four times a year, starting at 5pm, at the NRAS offices in Maidenhead.

If you know someone who you think may be interested in becoming involved, would have a real passion for what we do and the people we support and wants to contribute to the charity's development, we would love to hear from them. Please contact Ailsa at ailsa@nras.org.uk or call **01628 823524**. A full description of the role is available at www.nras.org.uk

Coming in next issue...

The next issue of the NRAS Magazine will be delivered at the end of April 2013. The Spring issue will contain articles on our new RA and Relationships guide which we are currently working on and will launch at the BSR Conference in Birmingham in April, an article on the Yellow Card system for adverse drug reaction reporting, an update on the conclusions of our JIA work as well as the usual news on what NRAS has been up to. If you would like us to include anything do let us know and don't forget to keep sending in your tips and hints for making life with RA more manageable, to andrew@nras.org.uk



Don't forget to follow us on
social media

too:

Join the NRAS Facebook page

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

& be part of the NRAS community

Follow us on Twitter

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

To see what is happening
on Helpline follow them

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

For up to date membership
information follow

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

twitter



NRAS website updates

There are some updated areas on the NRAS website so
do take a look at www.nras.org.uk

Disease Activity Score

(DAS)

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

Foot Health section

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

Publication Downloads

– all NRAS publications are
now downloadable from
the website



www.nras.org.uk

Please remember NRAS in your Will

A gift to NRAS in your Will is a way of continuing to support a cause which mattered to you during your lifetime. This year we have been very fortunate to receive gifts in Wills which have enabled us to start the evaluation project on JIA services in the UK and update the campaigning area of our website to allow Members to be more involved in issues which matter to them.

A Gift in Your Will Supports Our Future



Give as you live

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

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



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

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