



nras
National Rheumatoid
Arthritis Society

WINTER 2014
Magazine



P21
FEATURE
Biobank
Improving the health of
future generations

GENERAL ARTICLE

**WHAT DOES
REMISSION MEAN
TO YOU?**

In 2013 we conducted an online survey entitled 'What does remission mean to you?' p13

GENERAL ARTICLE

**FOLLOW ME FOLLOW
YOU GIVEAWAY**

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FUNDRAISING

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KILIMANJARO**

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Please read and feel free to share

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GET IN TOUCH

www.nras.org.uk
01628 823 524

Dear members...

As we draw towards the end of 2014 and I reflect on the last 12 months, it has been a challenging year for the charity in terms of fundraising. It's also been a challenging year for me personally as I have spent most of it battling with the consequences of uveitis which has already claimed most of the useful sight in my right eye, and earlier in the year started in my left eye.

This has led to many visits to London to my eye specialist, a lot of treatment and I am now starting on my fifth biologic in a hope that I can get systemic control of the uveitis. Dealing with pain and joint problems is bad enough, but being threatened with losing your sight is a whole different ball game and extremely scary. However, for the moment, as I write, I have no inflammation in my eyes, and my fervent hope for 2015 is that it stays that way!

However, back to the challenge of fundraising in the current climate and thinking about 2015. We need your help and as you think about the new year and what it will bring for you, if you or someone you know or love is affected by either RA or JIA, I hope that some of my suggestions below will inspire you to continue to support us next year. In spite of the increasing challenge in obtaining funding, we have achieved more for our beneficiaries in 2014 and reached more people with RA and JIA than ever before. Some of our key achievements in 2014 include:

- Launch of our new website
- Development and piloting of a new training programme for health professionals on how to support patients in regard to issues around emotions, relationships and sexuality

- Ran our second RA Awareness Week with increased media coverage and reach
- Launched NRAS groups in Chesterfield, Gwent, Colchester, East London, Gt Yarmouth, Banbury, Gloucester, Salford and Truro (phew!)
- Launched a new service for families and young people with JIA called JIA-at-NRAS
- Increased our events programme and introduced our own RAmble for RA during RA Awareness Week as an annual event
- Developed a new Tribute Fund, the NRAS Cherry Blossom Fund
- Grown our online community on HealthUnlocked to an amazing 6,000 members
- Set up a new commissioned services arm of the charity to deliver supported self-management services
- Published a major new report on fatigue
- Launched our new Welsh Campaigns Network



- Worked successfully with the musculoskeletal community to promote public awareness of RA which has culminated in Department of Health agreement to run a pilot in 2015
- Developed and validated a Patient Reported Experience Measure (PREM) as a leading member of the Commissioning for Quality in RA group (CQRA), which is incorporated into the national audit which rheumatology units are currently undertaking

However, doing all this requires increasing effort to raise funds to support our work. Next year we need to raise even more than we have this year in order to keep doing all the good things you tell us we are doing. So as we look forward to what I hope will be a happy, healthy and peaceful new year for you all, can I ask you to please think how you might be able to support us next year? If you feel up to an individual or team challenge, have a look at our new events programme (included within this magazine), there's more for everyone, including families, to take part in.

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If you or your family or friends work for a company which usually supports a 'charity of the year', please ask them if they would consider NRAS in 2015. If you know someone with RA, consider giving them a gift of 'NRAS membership' – many tell us that finding out about NRAS was the best thing they ever did for their RA! There are lots of different ways to support us to suit individual tastes and pockets and to find how you can help in 2015, please email fundraising@nras.org.uk or if you'd like to hold a fundraising event for us in 2015, however big or small, we'd love to support you to do that.

Meantime, my best wishes to you all for 2015.



Farewell to NRAS

Tracey, our Director of Development, is moving on to a new challenge and left NRAS at the end of November to join Sue Ryder as Head of Hospice Fundraising. Tracey said, 'I have loved my 6 years at NRAS and been so lucky to have worked with a great team of people whom I will miss enormously.'



I have been privileged to meet some amazing people who live with the daily burden of RA and been truly inspired by their motivation and determination to not let their disease rule their lives. The charity I joined in 2008 was very different from the NRAS we all know today and it has been fantastic to see the charity grow and develop to the very successful organisation it is today. What have been the highlights... there have been so many but I think the key ones are seeing the formation and launch of RA Awareness Week, seeing the fundraising team grow and our income streams develop, the successful implementation of RA Guidelines and seeing NRAS truly become the voice of RA and hold such an important role in the MSK arena. But there are so many more too! I will continue to watch and support NRAS and stay in touch with many of the great friends I have made. I am very much looking forward to the challenge of my new role but my new office just won't be the same without all that cake that seems to appear in the office on a daily basis! Thank you all for your support over the years!

NRAS Magazine

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Meet the Team...

Kim on Laura

Laura joined as the youngest member of the NRAS team back in January 2014. What I know about her is that she's always smiling and happy and despite having a long commute out from London, she walks into the office with a smile. Laura is always working really hard as Government Affairs Officer, and when she's not got her head down in the office, she's out representing NRAS at various meetings in London. Along with all of Laura's commitment to getting the voice of RA heard in the campaigning world, she also 'looks after' the NRAS Scottish Ambassadors.

I have great respect for Laura as I know she must have worked really hard to get to where she is today and be so successful in all the work she does for the charity.



Daniela on Mark

Mark is one of the newest members of our growing team, joining NRAS at the end of May 2014. He is the Trusts and Grants Fundraiser and sits within the noisy Fundraising team! I drive Mark to and from work on Fridays and it has been a great opportunity to find out more about his background. I learned that Mark taught English in China for two years! He loves travelling and backpacked around Australasia, South East Asia, China and parts of Europe. However, Mark has Juvenile Idiopathic Arthritis (JIA) and this resurfaced quite badly when he was in his last year of teaching. He returned home and is now on the right medication and feeling a lot better. Mark joined NRAS with the intention of a new challenge and to help make a difference to the lives of people with RA and JIA. He is even jumping out of a plane in a tandem skydive challenge for NRAS next year!

He is a real addition to the team and is one of the nicest guys I've had the pleasure of working with.



Get involved...

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



Membership

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



Fundraising

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



External Affairs

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

T: 01628 823524 www.nras.org.uk enquiries@nras.org.uk

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

NRAS involvement in commissioned musculoskeletal (MSK) services in England

Since the beginning of the new NHS England commissioning arrangements, under which the 211 Clinical Commissioning Groups (CCGs) have a major share of the responsibility for ensuring that the most cost effective services are provided to their respective populations, NRAS has been exploring ways in which the charity can influence the design and delivery of better rheumatology and primary care services for people with RA.

To date there have been a small number of competitive tenders for musculoskeletal (MSK) services and NRAS has been actively involved as bidding partner in four of these. The first, in Bedford, resulted in NRAS and Arthritis Care being part of the winning bid but both charities withdrew before any formal contract was signed, when it became apparent the funds being allocated to the self-management support we were due to provide were completely inadequate.

NRAS has also been involved in supporting three bids across the county of Sussex, two of which have been successful. We are now in the active

preparation phase, getting ready to start providing direct self-management support in central and east Sussex in the early part of 2015. The newly formed Sussex MSK Partnership, made up of a local social enterprise, a longstanding MSK/orthopaedic charity and two existing NHS Trusts, has taken the lead in the bidding process, and NRAS will in due course be a formal sub contractor. It is no exaggeration to say that the involvement of NRAS, and the expertise the charity brings to the proposed services, has been a significant factor in the Partnership's successful bids. Turning those bids into 'live' services will be a major challenge for all concerned, but the opportunities that exist to broaden

and improve what is offered to patients are obvious and very exciting. NRAS will also be working alongside a number of established voluntary organisations in the county, including Age UK and the Federation for Independent Living, which we hope will enable a more holistic package of support to be offered that embraces aspects of social care and other non medical advice.

Our e-newsletters will contain more details as things develop, not least because we anticipate a number of important volunteering opportunities to arise in the months ahead as we complete the planning and budgeting process with the MSK Partnership.

Fresh support for the newly diagnosed

A diagnosis of RA can be a frightening and bewildering experience for anyone, even if there might be a small element of relief in knowing definitely what is wrong.

We know well that the experience of such a diagnosis, including the approach and manner of the diagnosing clinician, can vary enormously. It is also clear that the type and degree of support provided to people following a diagnosis of RA can sometimes leave them feeling abandoned to their fate, with far more questions than answers.

As a response to this obvious need for something better, NRAS has developed and run the first successful pilot of a short workshop called 'New2RA', specifically to provide support to people within the first few months of being diagnosed.

Over a two hour period participants have a chance to share and reflect on the feelings and concerns that the diagnosis gave rise to, compare the National Institute for Health and Care Excellence (NICE) recommended pathway with their own (frequently very different) experiences, learn more about the importance of following the prescribed medication and some simple approaches to self-managing the condition, as well as having some time to chat with other participants and share personal stories. Everyone goes away with additional information on living with the disease and a clear sense of the many different ways NRAS can support them in future.

The feedback and reactions to this first pilot were extremely positive, which confirmed our own sense that in future this simple workshop could fill a significant gap in the support, both practical and psychological, offered to people newly diagnosed with RA. Our aim now is to refine the content on the basis of the feedback received, and then to seek the additional resources needed to provide the workshop in as many places as possible. We hope to be able to report further progress before too long.

Follow Me Follow You Giveaway – Laura E James

Mission Possible

Thank you to NRAS for inviting me back. Since my last visit when I related my story of living with RA and achieving my dream of becoming a published writer, my second contemporary romance novel, Follow Me, Follow You, book two in the Chesil Series, has been released.

Follow Me, Follow You is a family relationship story about recovery, healing, and reconnecting. The heroine, Victoria Noble, is desperate to bond with her four year old son, Seth, before the fragile link between them is completely destroyed. Realising it's down to her to change, Victoria makes it her mission to turn her and her son's lives around. Will she succeed, or is her target way beyond her reach?

As a person with RA, my missions and targets have to be realistic and achievable. I know my limits, and for the most part I respect them, but there are times when I'm compelled to break through – moments when I'm struck by the notion life is for living. Often the objective for the next few days is to rest and recuperate. Coffee and cake may form a substantial part of that plan – both realistic and achievable.

Those not-so-good days are the ones when as a family, we share in the gentle things in life; books, music, conversation, laughter and love. I don't deny it would be fantastic if I could gather up the buckets and spades and yomp down to the beach with my children and my husband, join in with the jumping on the trampoline, or dance in the kitchen with them from dusk until dawn, but for now that's not on the cards. I tend not to dwell on this, and focus on what I can, rather than what I can't, do, but it doesn't stop me hoping for the best possible outcome.

My Remission Mission, posted on the NRAS remission website, reads: *For me, remission means living my life to the max and doing all the daft, silly, funny, lovely little things with my family at any given moment.*

With the way research is advancing, I'm optimistic my Remission Mission statement will one day be achieved, as I hope yours will.

www.lauraejames.co.uk

To be in for a chance for winning a copy of Laura's new novel, please send your best tips and hints for people living with RA to media@nras.org.uk



Members Top Tips...

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

Making my experience so much easier

I recently went shopping at my local supermarket and signed up to the bar code scanner system that most supermarkets tend to have these days. They should really be promoting them for people with conditions like RA. It made my experience so much easier, with no queues and I could go at my own pace. I recommend it to everyone!

Anne Hitchings



Warm skin/muscle

I wish someone had told me that actually having a shower (or bath) and then using my Methotrexate and Enbrel pens was much more comfortable than on cool skin/muscle.

Connie Cluderay



The gadgets I can't manage without

The gadgets I cannot manage without include my Culinare One Touch can opener and jar opener. They really work! I pack them when I visit family so I can still get meals for grandchildren when required. Also, I use a light plastic jug to fill my kettle, it was only 30p, it is such a help.

When my hands were first troublesome and I went out for a meal, either I had to choose curry or rely on help to cut up my dinner. Now I ask for a steak knife, even for fish and chips. Restaurants do not seem to mind and it is great to be independent.

Elaine



Memory foam mattress

My memory foam mattress topper has transformed my life. I can now sleep so much better – much less pain and stiffness and I now sleep properly most nights. Don't worry about replacing your mattress – just get a topper from ebay – mine is three inches deep.

Dawn Ferris McColl



Share your ideas...

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

Government Affairs

We are pleased to report a major breakthrough, during the last quarter, in our quest to improve public awareness of RA. With the support of the National Clinical Director for Musculoskeletal Conditions, Professor Peter Kay, Public Health England has agreed to pilot a public awareness campaign on inflammatory arthritis in part of England.

Our CEO, Ailsa Bosworth, has been appointed to the topic expert group and has met with other stakeholders to finalise the details. The news follows a lengthy campaign by NRAS to persuade the Government to fund a national public awareness campaign, which led to the publication of our *Breaking Down Barriers* report in 2013.

In the build up to the 2015 General Election, NRAS has raised its profile with the main political parties. NRAS co-chaired an Association of the British Pharmaceutical Industry (ABPI) Patient Organisation Forum meeting with 44 organisations to discuss the health policy landscape with David Cameron's former Director of Policy, James O'Shaughnessy.



James O'Shaughnessy

We then published our 2015 General Election Manifesto, with 10 key 'asks' for the next Government. Most recently, NRAS's Head of Government Affairs, Jamie, attended a New Statesman round table with Labour's Shadow Minister for Care and Older People, Liz Kendall MP, and Sir John Oldham, author of Labour's Independent Commission on Whole-Person Care, to discuss the report's implications.

In respect of the Employment and Support Allowance (ESA), NRAS authored a major consultation response to Dr Paul Litchfield's final Independent Review on ESA. We also worked with new NRAS Medical Adviser, Sandi Derham, an Occupational Therapist Clinical Specialist



Liz Kendall MP

in Rheumatology at the Royal National Hospital for Rheumatic Diseases NHS Foundation Trust, to submit detailed comments about a training module for ESA assessors. NRAS Government Affairs Officer, Laura, has also been appointed Chair of the Disability Benefits Consortium's progressive conditions sub-group of charities and attended meetings with Sheila Gilmore MP and Department of Work and Pensions officials, James Bolton and Mark Wilson, to discuss collective concerns.



Dr Paul Litchfield



Sheila Gilmore MP

There has also been significant movement around the Personal Independence Payment (PIP) during the last quarter. Again, NRAS authored a major consultation response to Paul Gray's Independent Review on PIP and we also worked with NRAS's Chief Medical Adviser, Professor David G I Scott, to submit detailed comments about Capita's musculoskeletal training materials for PIP assessors. Most recently, NRAS also attended meetings with Motability to talk about the work they are doing to help disabled who lose access to their Motability vehicles as a result of the tougher higher rate mobility criteria within the PIP.

Following the introduction of the Care Act 2014 in May this year, further consultation has taken place around the legislation and NRAS submitted comments on the detailed regulations. Closely aligned to this, politicians have continued to discuss the future integration of health and social care. NRAS has undertaken little previous research into the social care experiences of our Members, and wishing to correct this situation, we held a focus group, collected case studies, undertook Freedom of Information Requests and brought this together to produce a new report, *Social Care and RA: The Social Care Experiences of People with Rheumatoid Arthritis*.

Elsewhere, NRAS submitted detailed comments to a new ABPI report on RA, which reviews implementation of the Best Practice Tariff on Early Inflammatory Arthritis and the coverage of the musculoskeletal conditions within local authorities' Joint Strategic Needs Assessment planning documents, and provided briefing to the National Clinical Director for Musculoskeletal Conditions about areas of collaboration with the National Institute for Health and Care Excellence (NICE) ahead of his meeting with NICE's Deputy Chief Executive, Professor Gillian Leng.

NRAS Manifesto for the 2015 General Election

*In the run up to the General Election, and beyond, we want to strike up a conversation with policymakers, our Members and the wider public about opportunities that exist to further improve RA services. To coincide with World Arthritis Day on 12 October 2014, we published *General Election 2015: 10 things the next Government can do to help people with rheumatoid arthritis to help inform discussions between the charity's supporters and policymakers.**

As health policy is a devolved matter, RA services are configured differently in England, Scotland, Wales and Northern Ireland. However, welfare policy is determined by the UK Parliament. In the context of the 2015 General Election, our manifesto therefore calls for a range of actions to be undertaken in relation to health policy in England, but two of the recommendations in the manifesto refer to welfare that affects everyone in the UK.

Our 10 calls for action are as follows:

1. Introduce a national public awareness campaign and double RA early diagnosis rates within five years
2. Devise a Clinical Commissioning Group Outcome Indicator for RA that is synchronous with the NICE RA Quality Standard
3. Create a template Commissioning for Quality & Innovation (CQUIN) payment for Inflammatory Arthritis
4. Review the Best Practice Tariff on Early Inflammatory Arthritis and make public reporting compulsory
5. Create a Strategic Clinical Network for Musculoskeletal (MSK) disorders
6. Develop a MSK core dataset for Joint Strategic Needs Assessments (JSNAs) and issue new guidance on coverage of MSK within JSNAs
7. Make access to self management support a fundamental 'right' within the NHS Constitution

8. Include RA within the list of medical exemptions to prescription charges
9. Publish progressive conditions' guidance for the Employment and Support Allowance to cover Support Group access and reduced reassessment for claimants
10. Change the Personal Independence Payment's unfair 20 metre rule back to 50 metres

Download the full manifesto at:
www.nras.org.uk/2015manifesto



NRAS Manifesto 2014

You can help us to spread our message by doing the following:

- Contact your local parliamentary candidates by downloading and sending off our template letter, which is available on the NRAS website (listed above)
- Attend constituency meetings with your local parliamentary candidates to discuss this manifesto and give them a print out of this document



- Get in touch with NRAS's government affairs team to notify us of any responses you receive from your local parliamentary candidates at campaigns@nras.org.uk
- Tweet your support online using the hashtag: #RA10things



Social Care & RA: Social care experiences of people with rheumatoid arthritis

Social care is legally defined as care, support and protection for all those in need or at risk due to illness, disability, poverty or old age. This includes all care and support whether provided by private companies, family, friends or local authorities.

In England there are considerable pressures on the current social care system. The sustainability of both the health and social care systems is questionable due to a number of factors:

- The proportion of the population over 65 is rising in line with the rising life expectancy
- The presence of long term conditions is more likely in those aged over 65
- The demand for social care services has increased and this trend is predicted to continue
- Local authority spending on social care has decreased by at least 20% since 2010



New social care research by NRAS

Little research has been conducted into the social care experiences of people with RA. We therefore wanted to answer fundamental questions about the types of services people with RA use, how frequently they require these services, their level of satisfaction and what types of changes are needed.

We conducted a literature review of the law, regulations and policy around social care. We then conducted interviews with four people with RA and sent out Freedom



of Information requests to 13 local authorities. We also held a focus group and designed, piloted and distributed an online survey to people with RA in England and their carers, which attracted 146 completed responses.

Our research generated five key recommendations to improve social care for people with RA:

1. Local government needs to collect more robust, condition specific data on social care to help identify best practice for people with long term conditions, such as RA. The majority of respondents did not receive appropriate information for their condition, so they could effectively plan ahead.
2. The 'duty of prevention' in the Care Act 2014 needs to be translated into earlier and more effective intervention. Many survey respondents did not receive social care to help prevent loss of independence and earnings and there is no clear way to currently enforce the duty in the Care Act 2014.
3. The duty in the Care Act 2014 to provide information and advice to all recipients of social care, irrespective of eligibility, needs to be fulfilled. Our literature review revealed that the duty to provide information has been present for a long time, but our survey results showed that currently information and advice on social care is not reaching people with RA.
4. The threshold to access social care, as outlined in the Care Act 2014, should be lowered to 'moderate needs'. Respondents with RA generally had moderate needs and therefore did not qualify for help. Our survey also revealed that people with RA have a great deal of unmet need and unsatisfactory care.
5. The proposed regulations under the Care Act 2014 need to be changed to require assessors to consider a 12 month period when assessing people with fluctuating conditions. Respondents with RA were dissatisfied with the current failure to properly consider fluctuation during these assessments.

Scotland campaigns update

The Scottish Government has taken the first concrete step towards responding to the Scottish Public Health Network's Needs Assessment on RA, first published in 2012. A meeting took place between Scottish Government officials, representatives from the Scottish Society for Rheumatology and leading charities (including NRAS) to discuss a possible quality improvement exercise around RA and inflammatory arthritis.

Chair of our Scottish Campaigns Network, Sheila MacLeod, attended a round table discussion in the Scottish Parliament, on behalf of NRAS, about 'maintaining the drive for innovation in rheumatoid arthritis treatment'. The event included a speech from the Labour Shadow Minister for Wellbeing, Rhoda Grant MSP, and was also attended by Nanette Milne MSP and Anne McTaggart MSP.



Rhoda Grant MSP

Working alongside Sheila, fellow Scottish Ambassador, Valerie Thrush-Denning, represented NRAS at a meeting of the Arthritis and Musculoskeletal Alliance and Mavis Graham undertook a site visit with Glasgow Southern General Hospital's rheumatology team to introduce the work of NRAS and discuss how NRAS can work with the team to further support newly diagnosed RA patients.



Southern General Hospital



The Scottish Parliament Building

During the last quarter our Head of Government Affairs, Jamie Hewitt, also delivered a presentation, at the Scottish parliament building, to the Cross Party Group on Arthritis and Musculoskeletal Conditions about the Scottish findings from our recent report, *A Focus on JIA* which highlighted the positive aspects of the service in Scotland, although there was still a need for further investment in staffing for paediatric rheumatology.

NRAS's government affairs team has also been working with Nanette Milne MSP and Margaret McCulloch MSP to table several written questions about aspects of Scottish policy. Through our questions we discovered that the Scottish Government has made no economic assessment of the impact of RA, it has no plans to formally publish the Scottish National Audit of Early Rheumatoid Arthritis (SNARE), and it has no plans to reprint the Recognise, Respond and Relieve public awareness flyer on RA.



Margaret McCulloch MSP

Finally, NRAS submitted comments to a consultation by the Scottish Medicines Consortium to appraise the use of two new biosimilars – Remsima and Inflectra - for use in the Scottish NHS. NRAS provided factual information based on issues outlined in a biosimilars position paper, previously published by NRAS.

Wales campaigns update

We are pleased to announce that Huw Roberts has been appointed as the Chair of the NRAS Welsh Campaigns Network to help drive forward the work of our Welsh Ambassadors.

One of Huw's first engagements in the new role was to attend a meeting with the Director of Arthritis Care in Wales, Mary Cowern, where he discussed the prospect of creating a new Cross Party Group on Inflammatory Arthritis in the Welsh Assembly.

NRAS took urgent action after learning that around 300 rheumatology patients at Withybush District General Hospital in Haverford West had started to be denied access to critical medicines because of a lack of resourcing within the hospital's rheumatology unit.

In response to the situation, NRAS issued a public statement, orchestrated an e-campaigning action that was completed over 100 times and alerted local politicians and the media. At the time of writing, Hywel Dda University Health Board has issued an apology and stated that the normal service would resume on 14 November, which NRAS will continue to monitor.

During the last quarter, NRAS's government affairs team also worked with Welsh Conservative Shadow

Health Minister, Darren Millar AM, to table several written questions in the Welsh Assembly about RA. Responding to the questions, the Minister said that the Welsh Government had no plans to make an assessment of the economic impact of RA in Wales, or to carry out a public awareness exercise on this condition and reconfirmed that an exercise is being undertaken with stakeholders to review the Service Commissioning Directives for Arthritis and Chronic Musculoskeletal conditions.



Huw Roberts



Mary Cowern



Darren Millar AM

NRAS Annual Conference 2014

In late September we held the 3rd NRAS Annual Conference, this year in West Yorkshire. It was an excellent day full of interesting presentations, opportunities to try Tai Chi and Pilates and time to socialise with others living with RA.

We were privileged to have Dr Maya Buch speak about clinical trials and the work she is involved in as a National Institute of Health Research (NIHR) Clinician Scientist. Dr Buch is also a Senior Lecturer at Leeds University and Honorary Consultant Rheumatologist at Chapel Allerton Hospital. Her colleague, Dr Ai Lyn Tan, attended the conference and gave an interesting talk on the importance of Early Arthritis Clinics and 'Treat to Target'.

We were also very grateful to our other presenters who enabled those attending to explore the benefits of exercise,

the power of food and nutrition, have taster sessions of Tai Chi and Pilates, learn about social media and how to cope with fatigue.

The feedback from those who attended has been excellent, with one delegate telling us, *"This is the first NRAS conference I have attended. I have found the experience very informative, having never knowingly met another person with RA before. This experience has probably been more beneficial to my ability to cope with RA than my GP or research can achieve."*



NRAS Annual Conference 2014

What does remission mean to you?

In 2013 we conducted an online survey entitled 'What does remission mean to you?' Our aim was to uncover the views and experiences of people living with RA, looking at the term 'remission', what remission means to people with RA and their understanding of DAS28 (Disease Activity Score 28). We were delighted that over 1,100 of you took part!

The key findings from the survey were:

- Half of the people surveyed had not discussed remission with their doctor or nurse
- Nine out of 10 were not aware what constitutes clinical remission
- Over 80% did not know their DAS28 score
- 86% of people with RA believe more education is needed for patients and 65% believe more education is needed for HCPs

We are committed to empowering those affected by RA, and improving awareness and understanding around disease management, and whilst clinical remission in RA may be achievable for some patients, all patients should aim to work with their clinicians to better define what remission means for them and set personal goals to achieve the lowest disease activity possible. Effective management can have both short and long term benefits in the future and help you to lead a better life with RA.

In October we were excited to further expand this campaign by launching the Remission Mission interactive photo wall, allowing you to share what remission means to you and raise awareness of the need for improved management of rheumatoid arthritis.

From something as simple as being able to brush your teeth, work full time or do the gardening, the word 'remission' truly means different things to each of you who live with RA, as well as your family, friends and the healthcare professionals who see you living with the disease.

Over 150 people have already uploaded their message to the site, including GP and TV Presenter, Dr Hilary Jones, who said,

REMISSION MISSION

"Remission means my patients being able to do all the things they want to do without their disease holding them back."

We'd love to get 1000 people to take part to spread the word about RA by sharing their messages, so please visit the Remission Mission at www.nras.org.uk/remissionmission and share your message and spread the word on social media too.



Remission Infographic



Remission Mission Homepage

Against all odds

So many of our fundraisers take part in personal challenges for us, even though they are living with RA and struggling on a daily basis, that doesn't deter them. Here are a few of their inspirational stories.

Adele Blackburn took part in the Liverpool to Leeds Canal Path Cycle challenge. Having been diagnosed with RA at 24 Adele felt her life was over. Once she was over the initial shock she made the decision to live life to the full and challenge herself. Her biggest challenge to date has been this cycle ride. Adele and her husband took part together, completing it over four days and loving every minute of it! She raised £157.50 for NRAS.



Adele at the finish line

Rebecca Studholme took part in the Three Peaks 26 mile walk. Rebecca was recently diagnosed with RA and knows what a crippling disease it can be. With the support of her mum and dad they took part in the challenge together and completed it in just under 11 hours! The support Rebecca received from family and friends was wonderful and they raised a fantastic £1,057 for NRAS.



Rebecca with her mum

Suzie Erwood took part in the Great Scottish Swim in Loch Lomond having been diagnosed with RA just over 2 years ago. At the time of diagnosis she was struggling to walk, couldn't drive and some days struggled to even get out of bed in the morning. Two years later it's a very different story, her mobility is very much improved. In August she took on the two mile open water swim in Loch Lomond which was covered by a Channel 4 documentary! Suzie has an amazing positive and inspiring attitude to life. She has found a renewed love in her swimming and is now training to become a swimming instructor. She raised £1,427 for NRAS.



Suzie Erwood

Christine Hosey took part in the Cornish Coastal Walk, Christine had always been very active, having taken on 100 mile treks across Tanzania in the past and loved it. However, four months ago she was hit by pain; she said, "I went from feeling a bit stiff one day to a week later being unable to even lift myself up in bed." Like so many people Christine thought arthritis was something only older people suffered with. Although Christine is now reliant on medication she was not going to let her RA deter her, even though the walk was going to be a huge challenge for her, both physically and mentally. With the support of a great network of friends she completed the walk in three hours. She said, "The biggest thing for me was I felt as though I had my life back for a short time, I never thought I would be able to complete the walk, it has lifted my

self confidence immensely – I cried the first happy tears I have in a long time." Christine raised £242 from her walk.



Christine Hosey

Alison Johnston took part in the Land's End to John O'Groats cycle ride. Five years ago Alison suffered a life threatening cycle accident, however this didn't stop her love of cycling and a year later she was once again up and cycling. During 2013 she was diagnosed with RA. Following some difficult months she found a treatment which allowed her to take up cycling again. In August she started her three week challenge from Land's End to John O'Groats, a gruelling 1,033 miles. Alison's son said, "To me my mum has been an inspiration and role model for showing her determination in getting back on her bike and proving what can be done if you want it enough." Alison raised £1,012 for NRAS.



Alison Johnston

Garry Cormack took part in the Ben2Ben Challenge, accompanied by his friend Kevin. He wanted to do a long walk for a charity in 2014 and spotted the East Highland Way which starts at Fort William and ends in Aviemore. As if this wasn't enough, he extended it to include the two highest peaks in Scotland, Ben Nevis and Ben Macdui, and so the 'Ben2Ben' challenge came to be! Garry raised an amazing £3,886 for NRAS and kept us all up to date with a fantastic blog (www.ben2ben.co.uk). The challenge culminated in 100 miles between the two peaks. Garry is now thinking about what challenge he might like to take on in 2015!



Garry Cormack

Eleanor Houlston took on the challenge of a two hour Zumbathon. Eleanor, one of our North East Group Coordinators, decided to put her new found passion for Zumba to great use, and with the help of the group organised a two hour Zumbathon in her local hall. Eleanor's instructor was a treasure and she and her colleagues gave up their free time to help run the fundraiser. Eleanor says, *'I am just so grateful that at my age and having RA I can do this, it puts a smile on my face. I am so fortunate to be in remission, it wasn't something I thought about when I was first diagnosed.'* The group raised £1,294 for NRAS.



Zumbathon

A huge thank you goes to all our fundraisers who constantly amaze us; your commitment to NRAS is second to none.

And it rained and rained and rained!

On a very wet August morning, five very brave souls took on the challenge of the RideLondon 100 cycle ride, London to Surrey and back again!

Martin, Darren, Rob, Jill and Chris had been listening to the weather reports all week - London was going to be hit by the tail end of Hurricane Bertha on Sunday. She didn't let us down as she arrived at around 9am, our poor cyclists would have been drier had they jumped into a swimming pool!

With torrential downpours it was difficult to see anything, let alone thousands of other cyclists. However, with the weather came great camaraderie amongst the cyclists who chatted as they braved the elements with the crowds offering encouragement along the route.

Suddenly the rained stopped, the sun came out and all was well again and our riders made it to the finish line with flying colours, all completing in excellent times. Rob said, *'Would I do it again? Definitely, why wouldn't I?'*

Our team raised a fantastic £5,235 between them. Thank you all for working so hard to raise funds for NRAS. Perhaps a swimming event next year?



Rob Butler after the race

Blackmoor Ladies Golfers chip in for NRAS

Over the last year we have been very kindly supported by Blackmoor Ladies' Captain, Jean Teuten, at Blackmoor Golf Club, Whitehill. Jean was absolutely thrilled at the amount of £2,550 raised by her Ladies' section with events throughout the year of coffee mornings, competitions, invitations, opens, raffles and donations and is so grateful to everyone who helped her reach this amazing amount.

Jean lives with RA and has a personal interest in wanting to raise funds and awareness for us, and particularly for her, the Basingstoke NRAS Group, which she attends.

We are thrilled at what Jean has achieved and want to express our sincere thanks to her, the Club and her ladies for their generous support over the last year. If you, or anyone you know, is taking the helm and becoming the captain of their club this year, why not consider supporting NRAS as your charity of the year? We can provide branded materials, attend events and come and speak to your members to tell them about the work we do. To discuss an opportunity, contact Oliver Hoare on oliver@nras.org.uk or call 01628 823 524.



Top: Blackmoor Golf Club

Bottom: Jean, Oli and Marion

Time to get dirty!

This year we have seen a massive increase in the number of people taking on 'Tough Mudder' style challenges.

In case you haven't ever heard of 'Tough Mudder', it's a monstrous 10-12 mile obstacle course designed to test all-round strength, stamina, teamwork and mental grit. Tough Mudder is probably one of the toughest events there is!

Becki Burrows took part in the North West Tough Mudder in September. Having been diagnosed with RA at 17 she spent several years and many hospital visits waiting for a confirmed diagnosis. Becki is a fighter and was determined to stay positive and after a bit of a blip got herself back on her feet and started aiming for the stars. She took on the Tough Mudder Challenge on 13th September and says she wants to make the very most of her life before her RA catches up with her.

As you will see from her photo she certainly did get very muddy! Even at the end of the course Becki had a huge grin on her face, not sure whether that was because she enjoyed it so much or because it was finally over! She raised a fantastic £248; thank you so much Becki, for taking on such a huge challenge for NRAS.

These events are for all age groups, children and adults alike. Archie (six), took on the challenge of a lifetime along with his friends Amelia (six), Bea (eight) and Thomas (eight) in the Junior Tough Mudder challenge in memory of his mum, Georgina, who had RA. The junior course is a 5k arduous cross country event with lots of mud, muddy pits, slop, slime and filth!

Archie's dad said, "Archie and his sister, Ava, were 3½ and 1½ at the time they lost their mum. Archie didn't really understand the concept of NRAS until I explained it to him. When he understood he realised he would be doing it for his mummy and making others better. Seeing first hand the effect RA can have



From left to right: Thomas, Archie, Bea and Amelia



Archie

Becki Burrows on the rings and at the finish line

on the quality of life of someone you love is something I'll never forget and that is why it was incredible to see Archie and his friends take on a challenge to raise awareness of the condition and the important work NRAS does to help support people."

The children raised a whopping £3,412 for NRAS, absolutely fantastic!

Thank you all for taking part in such a tough event for NRAS.

There are events to suit all abilities and age groups, whether you are looking for a fun event to join or looking for a more extreme challenge. For more information contact fundraising@nras.org.uk or call 01628 501547 or visit our website at www.nras.org.uk/takepart.



Rat Race Dirty Weekend – Debbie Sorby raised an incredible £700 for NRAS

Our runners take to the streets once again

Great North Run

On a surprisingly sunny September morning Val, our Events Fundraiser and Oli, our Fundraising Manager, made their way to South Shields in Newcastle to meet some of our Great North Run runners who were taking to the streets to complete the half marathon course.

The Great North Run is the most iconic of all half marathons and those who line the streets to cheer runners on are second to none. Team NRAS had 17 runners make their way over the finish line, they were greeted by Val and Oli who had goodies at the ready to help replenish lost calories (kindly donated by Mars in the Community).

A good day was had by all and it was a great opportunity for the fundraising team to thank our runners personally for their hard work and support. So far Team NRAS has raised over £5500, a great achievement by all.



Fancy a place in our 2015 team? Email val@nras.org.uk now to secure your place.

Royal Parks Half Marathon

Our runners were lucky enough to have good weather when they once again took to the roads for the Royal Parks Half Marathon in October. 18 people ran the half marathon course in perfect running conditions.

We were supported by some of our corporate partners on the day, who not only raised funds, they also helped to raise awareness as it was World Arthritis Day (12th October). Pfizer, UCB and AbbVie were all represented, along with some of our healthcare professionals.

Val was on hand, along with fundraising colleague Keren, to give Team NRAS a huge pat on the back and to take the odd photo or two, and the trusty Mars bars were once again on offer!

Thank you to everyone who took part, helping to raise almost £5,000, a fantastic team effort.



Fancy a place in our 2015 team? Email val@nras.org.uk now to take part.

If reading this has given you the incentive to take on a run we now have guaranteed places in a number of runs throughout the country.

Or if you have been lucky enough to get entry into the London Marathon why not join our team taking part in the Silverstone Half on the 15th March? It's a great training run for a marathon distance.

If your goal is to take on a marathon try the Brighton Marathon on 12th April; join our team for a day at the seaside and the challenge of 26 miles. For more information on all our runs visit our website at www.nras.org.uk/runs

Anytime is NRAS Tea Party time!

2015 is an ideal time to think about holding an NRAS Tea Party

Pippa, one of our younger fundraisers decided she would hold an NRAS Tea Party during her half term holiday and with the help of her mum, Maria, baked lots of delicious cakes (the chocolate and orange cake was a particular favourite!) Everyone had a thoroughly good time and helped to raise £70 for NRAS.



Pippa's tea party

Annie was diagnosed with RA in May last year. She not only decided to take on a 10k run but on the same afternoon

hosted an NRAS Tea Party to thank her supporters! Annie said, *"It has been a massive adjustment to my life and a lot to get my head around. I could not have done it without the support of my friends and family who have been amazing."* Annie even managed to get her family involved, some ran with her and others helped to bake delicious treats for their much earned cup of tea after the run! Annie raised £2,116 from her two events.



Annie at her tea party



Annie and her team

Peter does it again for NRAS!

Peter Gill, one of our long time supporters held another very successful golf day for us. Peter has been organising his golf days since 2009, putting in an immense amount of work to ensure those taking part have a great day, whilst at the same time raising funds for a cause very dear to his heart.

Peter has made the difficult decision to make this his last golf day, which is hardly surprising as this year was his 6th event! He is going out on a high having raised £1602.50, an incredible amount. Overall Peter, with the support of friends has raised a fantastic £17,416.20 for NRAS. We would like to thank Peter for all his hard work, he is an inspiration to us all.

Thank you Pippa and Annie (and your helpers) for all your hard work for NRAS.



Supporters of NRAS having a tea party

If this inspires you to hold a tea party we have a great tea party pack full of ideas on what to do to hold a successful event. There are recipes from celebrity chefs, tea party invites, posters and so much more.

If you are feeling really adventurous you might like to theme your party - why not have a World Book Day party and come dressed as your favourite character or author from a book? How about a Eurovision Song Contest party and have cakes from around the world?

If you would like to hold a tea party email fundraising@nras.org.uk or visit our website at www.nras.org.uk/tea-party and download your tea party pack. We would love to hear from you and please make sure you take lots of photos!



Stoke Rochford Golf Club

Are you be brave enough to take up the challenge?

In 2014 we had some incredibly brave people taking on huge challenges for us, ranging from cycling through South Africa to climbing to the top of Mount Kilimanjaro. Here are a few of their stories.

Maxine takes on Burma

Maxine Evans had been living with RA for five years, when in 2012 she began to see improvement in her condition. In typical Maxine style she had thought she would be able carry on as normal, working and playing hard. Sadly her disease had other ideas and she had to give up her beloved role as a headmistress.

Maxine got incredible support from healthcare professionals and finally came out of a very difficult period in her

life and decided she needed to take on a challenge and having talked about her impending retirement to a good friend, who stared at her in disbelief when she said she would be having some 'me time' and perhaps go to a yoga retreat - along came the Burma Trek as this was something that seemed to fit - it felt right.

Maxine says it was the most amazing experience and she felt privileged to have trekked part of a stunning country and she managed the whole trek!

Michelle Summits Kilimanjaro

Way back in January, Michelle and her friend Hannah decided they wanted to take on a big challenge in 2014 and help raise awareness and funds for NRAS and the Motor Neurone Disease Association (MNDA). Michelle's mother was diagnosed with RA when she was 37. Michelle says, *"Watching her struggle every day, unable to hold coins in her hands as she can't grasp the change or trying to get dressed in the morning is heartbreaking to see."*

Whilst Michelle knows there is currently no cure for RA she wanted to make a difference in some way. Although her mother's disease has progressed at a rapid pace Michelle wants to help others living with the disease.

The girls didn't realise just what a task lay ahead of them. It takes its toll on your body and is one of the hardest things they have ever done, however achieving it is one of the most rewarding gifts they could be given. Knowing why they were doing it gave them extra determination and strength to complete the challenge.

They finally hit the summit at 6.40am on 9th October, it was -20 degrees Celsius with accompanying winds of 50mph which made each and every step harder and yet they still did it, the relief was overwhelming!

Michelle says, *"I hope what we achieved helps with awareness and motivates others to get involved, it was such a great feeling at the end of the day knowing what we have done to help, even in a small way."* Between them the girls raised an incredible £4538.55 for NRAS and MNDA.



Michelle and Hannah at the summit

Clare climbs Mount Toubkal

In early 2010 Clare was diagnosed with rapid onset RA and life became pretty bleak for a once very active 34 year old. Thanks to the miracle of modern medicine and the amazing response of the NHS, in April, Clare was able to climb Mount Toubkal, North Africa's highest mountain.

A friend of Clare's had suggested the trip in January whilst they were on holiday and after a couple of glasses of wine it seemed like a very good idea! Clare set off on her three day climb, the scenery in the High Atlas region was beautiful and the snowy caps of the peaks spurred her on, however 100ft from the summit the wind was at 80mph and it, along with the altitude, made it impossible for her to complete her climb.



Clare Kendall - Mount Kubal

Whilst disappointed Clare does recognise it wasn't her RA that got the better of her, it was the conditions that even the fittest of climbers would be beaten by; her RA didn't give her any trouble during her climb and she is incredibly proud of herself, she gave it her all and certainly didn't let her RA get in the way! Clare says, *"Whatever you consider a challenge, big or small, take that one step out of your comfort zone, the satisfaction of taking control of your condition is worth every moment."*

Thank you all for taking on such life changing challenges for NRAS. If these stories inspire you why not contact our fundraising team at fundraising@nras.org.uk or visit our website at www.nras.org.uk/takepart to find out more about our challenges.

Improving the health of future generations



Rheumatoid arthritis is an all too common disorder, affecting approximately 690,000 people in the UK each year. We know its toll on quality of life and that there are many efforts by researchers and doctors to find out what causes the problem and to find cures.

That battlefield has recently been expanded by the creation of a unique, large and powerful health resource called UK Biobank, and who knows, you may even be a participant.

The resource 'banked' health and wellbeing information provided by 500,000 volunteers during its recruitment phase from 2006-2010. Participants were weighed and measured, and crucially provided samples of blood, urine and saliva for long term storage and analysis, including genetic research.

They also agreed to UK Biobank following their health through medical records, so that the project can paint a picture of their long term health and wellbeing, the illnesses they develop and their treatments.

UK Biobank is funded primarily by the Medical Research Council and the Wellcome Trust charity. It will allow scientists from around the world to find out why some people develop illnesses



like rheumatoid arthritis and why others do not. This ought to help prevention, treatment and ultimately find cures for a wide range of common, painful and life threatening illnesses in mid to later life.

It is the big numbers and the detailed information that make UK Biobank so valuable to scientists now and in the future. Biobanking, and UK Biobank in particular, has taken a lesson from industry in terms of organising such a study, while remembering that it is its volunteers that make the visionary project possible.

UK Biobank is currently working on two new projects – both highly technical, world leading and designed to make the resource even more powerful for research:

- All 500,000 participants are having their genetic information read, so that scientists can start to see how genes and lifestyle combine to affect health
- A feasibility study is underway to see if it is possible to scan the brains, hearts and bones of 100,000 participants. Nothing like this has been attempted before. The information, once combined with genetic and lifestyle data, should provide an important new resource for tackling bone and joint diseases

One researcher already using UK Biobank to study rheumatoid arthritis (RA) is Dr Duncan Porter, at the Gartnavel General Hospital at the University of Glasgow.

We know that some people are more prone to develop the disease because of their genes, but other lifestyle factors, such as smoking, are also important.

Interestingly, some people develop special antibodies in their blood stream which indicate they may develop RA, though at this stage they don't have any symptoms.

Months or years later, some (but not all) will develop aches and pains, and some time later full blown RA can emerge.

The team will analyse UK Biobank genetic and other data to find out more about risk factors for developing RA and the illnesses that are sometimes associated with it (such as osteoporosis and heart disease). They will do this by comparing those people who already have RA, with those who have the antibodies but no apparent disease and with the rest of the UK Biobank population.

This study will identify the world's largest group of subjects with antibodies to RA before they are diagnosed with the illness, which ought to be a great boost to research.

UK Biobank is at the leading edge of a new kind of research revolution. It involves the generous spirit of volunteers combined with the latest IT which allows it to collect, store and compare large quantities of information, with exciting new research techniques.

The resource has been assembled over the past eight years to provide health researchers with a wide range of tools to undertake research on the most common – and sometimes intractable – diseases of the 21st century.

More information about the studies underway and results can be found at the UK Biobank website:

www.ukbiobank.ac.uk

More information about Dr Porter's research can be found at: <http://www.arthritisresearchuk.org/about-us/what-does-arthritis-research-uk-do/meet-the-expert/dr-duncan-porter.aspx>



My Story... *By Ailsa Riddle*

It all started with pain in my right wrist which I put down to lifting and carrying Magnus, my eight month old baby, around but as time went on my hands started to swell up and I had pain in both my feet. I initially put the pain in my feet down to wearing a pair of boots that I hadn't worn for a while.

However, it soon became apparent that the pain and swelling in my hands and feet was something more serious. I was in constant pain, getting out of bed was a struggle, pulling on clothes, opening shampoo bottles, jars of food, milk tops; everything was so difficult and painful. I was in tears most mornings and was overwhelmed with fatigue. I was working part time as a marketing executive so getting to work and carrying out my usual duties was a struggle. Initial blood tests at my GP practice ruled out any disease activity but after two more appointments, I was referred to see a rheumatoid specialist at the local hospital. The rheumatoid consultant confirmed that I did have RA. I was devastated and didn't know how I would cope looking after my very active 16 month old son. My granny had rheumatoid arthritis and her hands were so badly affected they were deformed. My immediate thought was 'I don't want to end up like granny'. I was only 31 years old and a busy working mum with a young son to look after.

My consultant was brilliant and started me on a blind trial where I was given either tocilizumab or methotrexate or a combination of them both. Unfortunately, after six months on the trial my symptoms were not improving so my consultant decided to take me off the trial and started me on triple therapy of methotrexate, sulfasalazine and hydroxychloroquine. During this time my joints were very swollen and painful. I had a couple of steroid injections which relieved the pain slightly but not significantly. Getting myself dressed was agony enough but I also had to dress, feed, change, bathe, play with and run around after Magnus. I felt very low and cheated of being able to do all the things other mums were doing. It was at this time that I spoke to someone via the NRAS telephone peer to peer support service. The person I spoke to was a mum to two children and had RA prior to pregnancy. This phone conversation really

helped me feel like I wasn't alone and gave me hope that things would get better.

I was a keen cyclist before RA and had cycled a number of long distance routes across the country. I did one long distance cycle ride with my friend during this time and managed only with a huge amount of support from her including helping me get dressed in the mornings. After that ride I knew I had to put my cycling on hold temporarily as I didn't want to risk any long term damage to my joints. I remember my consultant saying to me that his aim was to get me back on my bike and this gave me some hope.

After six months on the triple therapy it was obvious it wasn't working and so I was referred to see the biologic specialist at the Freeman Hospital in Newcastle. In October 2011 I started on Enbrel (in combination with methotrexate) and within two weeks I noticed the difference. The inflammation began to decrease and I was able to do everyday tasks without being in unbearable pain. Within a couple of months I felt like I had gained some of my previous life back. I could run around the park with Magnus, push him on swings, and ride my bike again without being in agony; things I took for granted before RA.

My husband and I had always wanted another child but knew that I needed my RA to be in remission before we even considered it. After six months of being in remission on Enbrel and methotrexate combined and in discussion with my consultant I decided to stop taking methotrexate and see how my body coped. My RA remained in remission during this time and so we decided the time was right to plan for another baby.

Iona was born on 27th October 2013. During pregnancy my RA continued in remission and I didn't take any medication at all. I felt great! I was monitored closely by my consultant and also a rheumatologist who specialises in RA during pregnancy at the Royal Victoria Infirmary hospital, Newcastle. I enjoyed a normal pregnancy and birth. I was also able to breastfeed for six months, something which was very important to me and during this time my RA remained in remission. When I stopped breastfeeding I felt my joints beginning to swell and become painful so I started back on Enbrel. I was also returning to work at this time.

My RA is still in remission and I am able to enjoy activities like cycling and walking. Last August we had a family holiday in Wales and I managed to climb Snowdon – a real sense of achievement. I do still get some pain and swelling in my joints, especially my wrists and hands, and find changing nappies one of the hardest things! But compared to where I was a few years ago I am a different person with a much better quality of life.



Ailsa, Matt, Magnus and Iona before climbing Mt Snowdon, August 2014

My family and friends have all been very supportive and understanding of my RA (my brother has ankylosing spondylitis) and I couldn't have coped without their constant encouragement and positivity. My husband, Matt, has been extremely supportive and helps enormously by doing the majority of household duties - tasks I struggle with. Magnus is now five and understands that sometimes I can't do certain activities due to my RA. As a family we enjoy an active lifestyle and with my RA in remission, I am able to continue leading that lifestyle with some adaptations.

My consultant (Professor Isaacs) and other members of the medical team at the Freeman Hospital (notably Karl Nichol, Biologics Nurse Specialist) have been fantastic. From day one their aim was to help me to lead the lifestyle I had led before RA and I feel together we have achieved this aim.



Targeted treatment for RA that minimises side effects

Researchers at Queen Mary University of London, funded by Arthritis Research UK, have carried out a study involving the development of antibodies that target damaged cartilage specifically. When these antibodies are combined with drugs, they can be delivered directly to the arthritic joint, thus avoiding some of the side effects that occur with existing technology.

Many of the treatments currently used such as non-steroidal anti-inflammatory drugs (NSAIDs), disease modifying anti-rheumatic drugs (DMARDs) and biologic therapies work by suppressing the immune system, sometimes leaving the patient at increased risk of infection. Research suggests that this new approach offers a number of advantages.

Researcher Dr Ahuva Nissim said: "We believe that our targeted approach may become one of the new ways to treat arthritis patients."

"Targeting of biologic drugs to the inflamed joint will result in high local concentrations and low systemic concentrations, increasing efficacy while minimising side effects. Additionally, a lower dose may be effective, thereby reducing cost of the treatment."

The biologic drug used in the study was the anti-inflammatory cytokine IL-10. Research in this field has the potential to be of great benefit to people who have rheumatoid arthritis.

Molecule in parasites could suppress autoimmune conditions

Scientists at Monash University, Australia have identified a molecule in parasitic worms that may find use in the treatment of rheumatoid arthritis. These molecules are peptides, which are naturally occurring biological molecules.

Lead researcher Professor Ray Norton, from the Monash Institute of Pharmaceutical Sciences (MIPS) says that experts are still not sure why the body's immune system turns on itself but cases are rising in the west.

One theory as to why the number of cases is rising is that the western world is too focused on cleanliness and so people's immune systems are not being exposed to as many infections as in previous generations.

To counter this, there is a form of therapy called helminthic therapy which is used by some people to try and treat their condition by deliberately infecting themselves with parasitic worms. It is thought that the worms have some sort of dampening effect on the host's immune system. This helps them to survive in their host's body.

Rather than using worms, researchers isolated the chemical from the worm that is responsible for the dampening effects on the immune system. They identified a peptide called Ack1 which is similar to ShK, a peptide found in a sea anemone. ShK has been shown to suppress autoimmune diseases and is currently being trialled for the treatment of multiple sclerosis.

The idea of taking a pill made from a worm may not be appealing to everyone, but hopefully the benefits of such a treatment will make it acceptable enough for people to put those thoughts aside.

Feeling fed-up?

Yes, because the majority of people are not super heroes, most people will feel fed-up faced with a diagnosis of rheumatoid arthritis. The situation physically, emotionally and it is hoped, socially, will start to improve when effective treatment begins to make a difference.

BUT, there will be some people for whom life may have become, for whatever reason, too difficult and they suffer from varying degrees of depression, or indeed have already been sufferers of clinical depression when the new diagnosis of rheumatoid arthritis adds to their burden.

A published article in the medical journal *Clinical and Experimental Rheumatology* [September 2014] carried an article from Mexico's National Institute of Medical Science and Nutrition. 73 patients were investigated to find any association

between major depressive episodes and their compliance with treatment for rheumatoid arthritis. All the patients were assessed for both their rheumatic and psychiatric health states. Current major depressive episodes were diagnosed in 30% of the whole group; of these 53% had clinically important depressive symptoms with 10% having severe depression. The results showed that a high depression score was linked not only to a greater disease activity but also to an increased struggle to comply with the treatment for their arthritis.

If you are feeling depressed, speak to your GP or call our helpline team on 0800 298 7650.

Anti-TNF treatment and the risk of breast cancer

A recently published report by Pauline Raaschou, MD, and colleagues from the Karolinska Institute in Stockholm suggests that women with rheumatoid arthritis (RA) and a history of breast cancer had no increased risk of cancer recurrence if treated with anti-tumor necrosis factor (TNF) therapy.

The Swedish team analysed data from the Swedish biologics and cancer registries to investigate the possible influence of anti-TNF treatment on recurrence rates after cancer remission. They followed 120 women receiving the biologic treatment who had a history of breast cancer and 120 matched controls with RA who had never had a biologic drug and also had a history of breast cancer. With an average follow-up of five years, they found no difference in the risk of breast cancer recurrence between those who had received TNFi-treatment and those in the control group.

Although anti-TNF therapy for rheumatoid arthritis and other autoimmune diseases is widely accepted, concerns have persisted

about cancer development and recurrence because of the potential effects of these drugs on the tumour biology. Accordingly, current treatment recommendations advise using anti-TNF treatment for patients who have had cancer within the previous five to 10 years.

Dr Raaschou and colleagues concluded that the results offer support to clinical guidelines which state that TNF inhibition may be started in patients with a history of breast cancer more than five years ago, but cautioned that what this means for patients with more recent or active breast cancer or other tumours with less favourable prognoses is still unclear.

Study shows the beneficial effect of hand exercises in people with RA

According to findings recently published in *The Lancet*, tailored hand exercises could be a valuable addition to drug therapy for patients with rheumatoid arthritis of the hands, according to new UK research.

Researchers conducted a large, multicenter study to measure the effectiveness and cost of a hand exercise regimen for people with RA. The 490 patients who participated had been on regular medication for RA for at least three months before the start of the trial. They were divided into two groups for the study: one continued with medication, and the other continued with medication and added a routine of hand stretching and strengthening exercises (which were supervised by physio or occupational therapists). Both groups maintained their regular care during the study.

The groups were followed up after 12 months and were assessed using a hand specific questionnaire which enabled researchers to measure the participants' overall hand function. The patients who did hand exercises in addition to taking medication had significantly improved overall hand function (more than a doubled improvement) compared with the medication-only group. There were no serious adverse events associated with the exercise program. These findings suggest that hand exercises in addition to appropriate medication appear to be an effective, safe, and affordable therapy for patients whose hands are affected by RA and could have a positive impact on quality of life for people living with RA.

Join the



We launched the NRAS Lottery in September 2013 and a huge thank you to all those who have signed up already. We now have over 350 players, and are seeing a regular stream of winners each week.



But we need more

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

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

A week in the life of..

a Rheumatology Specialist Nurse

I completed my Registered General Nurse training in 1992 in Exeter with Tor College of Healthcare. My journey to becoming a Rheumatology Specialist Nurse found me gathering experience in the general outpatient department where I worked for many years when my children were young. The rheumatology clinics sparked my interest and the Disease Modifying Anti Rheumatic Drugs (DMARD) Nurse Led monitoring clinic enabled me to build on my knowledge base. This prepared me for the Support Nurse role that I started in 2005. My mentor Lorraine Cooke inspired and believed I could be a specialist nurse in this field and I was appointed in 2008 as lead rheumatology specialist nurse.

I work in a team of three consultants, a registrar on rotation and three specialist nurses including myself. We are situated in our main District General Hospital (DGH) - Musgrove Park Hospital, Taunton, Somerset. Our team has changed and expanded in the last six years and is essential in providing the public with a robust county wide rheumatology service.

Last year I was privileged to receive the Healthcare Champion Award from NRAS which was an excellent accolade.

This was a week in my career I will never forget. This year has been one in which our team has also been selected to have nursing students on eight week placements. This has been a new challenge but one which I have embraced. I have found this opportunity to teach, be a mentor, and share my knowledge rewarding.



Teresa Jewell

1. Monday

The first and second Monday in every month, following an early breakfast, I travel to the community hospitals where I run all day nurse-led clinics. My community clinics run parallel with our consultants - Dr Leslie Goh and Dr Luke Gompels.

My journey to each of these destinations is my time to listen to my latest audio book download, as I drive to both rural and seaside destinations.

Back at our base Kui-leng runs the nurse-led urgent access clinic.

Monday is our busiest day on the advice line and Clare Herbison manages the calls and administration.

Mondays later in the month incorporate service development time. On these Mondays our team are all in one place together.

2. Tuesday

Today is my day off.

This is an ideal opportunity for meeting up with friends and family.

I devote some hours to helping out with our local NRAS Group, Mid Somerset Rheumatoid Group (MSRG), either attending the planning meeting where a soup and cake lunch is put on by our committee or attending evening meetings. These run six times throughout the year.

Three years after our local group's launch the committee tells us that continued nurse support is paramount to its ongoing success.

3. Wednesday

Today I'm at our base with Clare while Kui-leng enjoys her day off. I try to be at my desk bright and early, this is much easier now my children have grown up. Throughout the week we support the Medical Day Unit (MDU) where our patients attend for treatments. Inpatient ward visits lead up to our weekly team meeting. At this meeting we have an opportunity to discuss the current ward work. We also address any complex patient cases or department issues.

After lunch, Clare travels to Bridgwater Hospital for her first clinical session of the week and my afternoon clinic begins at Musgrove Park alongside Dr Catherine Laversuch.

4. Thursday

This is often our busiest day of the week. We need to incorporate a large amount in to the morning. Today, Clare takes her day off as we all work four long days a week.

Our morning activities incorporate the ward round and attending the MDU. In MDU patients requiring urgent input can also be reviewed. We try to complete the morning which passes in a whirlwind with a coffee, in Marks & Spencer. The only difficulty is resisting the delicious cakes!

Thursday is our weekly visit from a drug representative and this informative session comes with a light lunch and a chance to hear updates about the latest treatments available to our patients and further discuss them as a team. After lunch Kui-leng endeavours to see inpatients for treatment counselling, together with office based work whilst I embark on a further clinic session. Nursing and medical students observe these sessions and hopefully it will inspire them to consider rheumatology in their future career.

5. Friday

As we reach the completion of our working week Kui-leng and I travel out to Bridgwater to provide further clinical sessions. Friday is a day where lots of the week's tasks and challenges require completion. This is in preparation for the weekend, as our service is provided Monday to Friday. Clare is at our base handling the advice line, inpatient and day patient work.

After clinic, travelling back is another golden opportunity for me to enjoy another chapter in my audio book. The traffic starts to build up, particularly, in the summer months and this short journey can become a timely one. Friday afternoon sees Clare's final clinical session of the week. We arrive back at the office just as Clare leaves to review her patients in clinic.

I remind myself and my colleagues at the end of our busy weeks that a specialist nurse's desk is never empty. However in the lives of our patients coping with RA our weekly achievements are vast.

6. Out of Hours

My family time is very important and having time at home is essential for a good work life balance. Reading and sewing are hobbies I enjoy when I have quiet moments.

Last year my eldest son flew the nest. He is happily settled and engaged.

My youngest son finished his GCSEs this year and started on his college construction course, so in the future I hopefully won't need to do any painting and decorating!



Kui-leng Marrow, Teresa Jewell & Clare Herbison

Group News Winter 2014

What a busy autumn the newly named 'External Affairs' (previously the Volunteer Network) team have had, with five group launches taking place in just eight short weeks! Clare, Gill and Kim have been on the road from Salford in the North all the way to Truro in the South West.



Gwent launch

Gwent in South Wales was the first group of the autumn season to be launched on 15th September with Kim and Gill hosting the event. Dr Piper, Consultant Rheumatologist at Ysbyty Ystrad Fawr Hospital, was instrumental in driving the formation of this new group. NRAS worked with Dr Piper two years ago when she again was the driving force behind the launch of the Bath NRAS group, that has been running successfully ever since. The evening in Caerphilly saw a good cross section of healthcare professionals in attendance forming the Q&A panel. Since then, Gill has been to meet with the enthusiastic group of people who will be coordinating group meetings and they are currently planning their 2015 programme.



Chesterfield launch

NRAS Chesterfield was next to launch with Gill and Clare acting as hosts on 7th October as a direct result of the determination of one particular NRAS Member and Volunteer, Julie Bates. Julie was very well supported by the entire rheumatology team at Chesterfield Royal Hospital. The multidisciplinary rheumatology team were all represented on the evening to answer questions from the packed room. Regular meeting dates have already been planned for 2015 – well done Julie! This just demonstrates that what is needed to make any group successful is individuals with vision and drive.



Octogan Room at Queen Mary University

October 13th saw the launch of the East London NRAS group at Queen Mary University of London hosted by Clare, Kim and Gill. Dr Frances Humby and Arti Mahto (Rheumatology Research Student) worked hard getting the venue organised and patients involved in the new group. The evening was held in the spectacular Octogan Room of the University where the expert panel consisted of Professor Pitzalis (Chair of Experimental Medicine and Rheumatology), Dr Humby (Senior Lecturer and Honorary Consultant Rheumatologist), Dr Kelly (Consultant Rheumatologist) and Matron, Debbie Chagadama. Planning is underway for regular group meetings to take place in 2015 in East London. If you missed the meeting but are keen to help establish this group we still need your help. Email volunteers@nras.org.uk if you think you can help in anyway. Perhaps you can suggest a good regular venue for the meetings?



Salford HCP Panel

Just one week later, the External Affairs team was on the road again, this time to Salford for another launch meeting at Salford Royal Hospital. Seven members of the rheumatology team, lead by Dr Hector Chinoy, answered questions from the floor. It was a very successful evening with seven people coming forward to help coordinate future group meetings - watch this space for more information!



Truro launch with their pasties

The final 2014 NRAS group launch took Kim and Gill on a road trip to Truro in Cornwall on 12th November. The collaboration of Research Associate at Royal Cornwall Hospital, Jo Erwin (MSc MPH PhD) and local NRAS Members, Jim Cooper and Aline Turner, contributed to the successful planning of the launch taking place at Richard Lander School. There were over 60 people in attendance on the evening who listened to a talk on the advances in treatment of RA by Professor Anthony Woolf (BSc, MBBS, FRCP) and the panel of five healthcare professionals took questions from the room. There are now seven keen people joining Aline and Jim ready to plan future meetings and hope to be able to hold their first regular group meeting in early 2015.

A big thank you to all the Volunteers and the rheumatology healthcare professionals who made all these group launches possible. Kim, Gill and Clare wish these new groups every success and all at NRAS are here to support them for many years to come!

2015 is shaping up to be just as busy with the first group launch taking place on 15th January in the Wirral with the support of the rheumatology team at Arrowe Park Hospital. There are many more launches already in the pipeline so be sure you have given your up-to-date email address to NRAS as this is the best way of being kept up-to-date with group meetings and new launches.

For more information on any of these new groups please contact groups@nras.org.uk or call NRAS and speak to Kim or Gill.

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

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The Only Way is YOU

*So many ways to help, so few people to offer that help.
Can YOU make up the difference by making a difference!*



By Clare Jacklin, Director of External Affairs

As NRAS staff, many of us travel up and down the length and breadth of the country representing the society and we meet the most amazing people with interesting and varied life experiences of living with rheumatoid arthritis. As you read this magazine you may think, "I wish I could do something to help the society and others like me," but you might think that the only way to help NRAS is by raising funds by doing weird and wonderful challenges. Well you're wrong! Think again...while you are correct, we desperately need more people to fundraise for your society, that isn't the only way of offering support. Let me answer some of those questions that may be going around in your head right now.

Reader Question: I'm not interested in running marathons or swimming lakes even if my body did allow me to do so and as I work full-time as a teacher, I can't do much for NRAS, or can I?

Clare's answer: As a teacher I am guessing you are articulate and used to reading quite a considerable amount. Did you know that NRAS is sent lots of research proposals to comment on and to be honest it is difficult to find the time to read them all fully to give quality feed back to the research proposer. All research, be it clinical or social, must be seen to have a clear patient benefit and who better than a "real-life" patient to tell them what they need to know. Is that something you'd be willing to do? Read an academic research proposal over a coffee on a Sunday morning in the comfort of your own home, or sitting in the garden on summer's evening, wherever and whenever suits you? Then let us know what you thought of the proposal. Tempted... you could be an **NRAS Research Reviewer!**

Reader Question: I used to run my own business before RA made it difficult to continue but often feel like I could do more but I live in a rural community and everything seems to go on in the big towns and cities which I can't travel to these days. So wish I could help but nothing I can do... or is there?

Clare's Answer: NRAS is part of the Information Standard accreditation scheme which means that each and every piece of information that we publish needs to be not only Peer Reviewed but Reader Reviewed too. This ensures it is user friendly information and meets the exacting standards to be awarded the IS kite mark. Tempted...you could be an **NRAS Reader Reviewer.**

Reader Question: I really struggled with my medications when I was first diagnosed and I felt really isolated. Noone I knew had RA and it would have been really nice to speak to someone who knew what I was going through. Now my RA is pretty much in remission most of the time (fingers crossed) but I am not good at organising meetings or anything so I can't do much... or can I?

Clare's answer: As someone who has been through a lot and come out the other end so to speak, your experience could really help someone who, like you felt, is feeling very alone with their diagnosis of RA. We find that talking to someone over the phone can offer a real lifeline to many people who just want to talk to someone else who really gets it. Tempted...you could be an **NRAS Telephone Support Volunteer!** Training can be done from the comfort of your own home via a video link or DVD and workbook.

Reader question: I work part time and can't commit to doing anything on a regular basis as I have lots of other commitments looking after my children and involvement in my local amateur dramatics group so wish I could help but guess you can't have some people on ad hoc projects... or can you?

Clare's answer: One thing we are keen to capture that would involve just one day of your time would be some Members' stories on camera. Your experience of being on stage would be fantastic as we'd like to act out some real-life scenarios as part of some training materials for rheumatology health professionals. Tempted... you could be an **NRAS Film Star!** Alternatively there are often speaking engagements that might include speaking to pharmaceutical company employees or medical students or health care professionals. Tempted...you could be an **NRAS Public Speaker!**

Reader Question: I once went along to a meeting organised by my rheumatology department. They wanted to know how to improve their appointments system. They really listened to my viewpoints and I felt truly appreciated. I often wish there were more ways I could improve the experience of others living with RA but as we have a good service where I live now there aren't any local opportunities so that's it then... or is it?

Clare's Answer: If you are willing and able to travel a bit then there could well be opportunities to have a say in rheumatology services/care and research. NRAS is often asked for people living with RA to join research steering committees. As part of a steering committee patients help researchers develop the research questions, ensure information is clear for recruiting people into clinical trials and most importantly that the aim of the research will ultimately be to the benefit of patients. This is how you could be **the patient voice.** Tempted... you could join the **NRAS Patient Research Panel!**

If you are interested in any of these opportunities send a 250 word biography to volunteers@nras.org.uk or post to NRAS, 4 The Switchback, Gardner Road, Maidenhead, SL6 7RJ.

Please make it clear what area of NRAS' work you'd like to be considered for and why. What is your motivation and what personal skills you have that would make you ideal for that type of involvement.

YOU can make a difference by just being YOURSELF.

You've hit a milestone! 6,000 of you have now joined the NRAS HealthUnlocked community

HealthUnlocked (HU) is a social network for health. By finding others with similar health backgrounds people can take on day to day health concerns together. NRAS set up a HealthUnlocked community for people with rheumatoid arthritis in 2010 and the support it has given our Members has been invaluable.

Whenever our Members write a post, ask a question or reply to someone, they are touching the lives of other people with rheumatoid arthritis by spreading the benefit of shared, personal health experiences. And beyond that they have built a resource that will benefit people for years to come.

Join now to become part of a thriving community - <https://healthunlocked.com/nras>

We spoke to some of our HealthUnlocked users to find out what the NRAS HU community means to them...

'The NRAS HealthUnlocked site offers me an oasis of understanding and shared experience in the dark, lonely world of being newly diagnosed with RA. When my Dad died my Mum found the hardest thing was not having someone to share her daily experience with, no one to talk about the 'little' things with. Being diagnosed with RA, for me, has been a similar isolating experience as few understand fully how the disease affects the entirety of a sufferer's life and on this site I can talk about the 'little' and the 'big' with no one trying to 'fix' me or judging me as 'weak' for feeling physically weak at times.' **Ali**

'I see HealthUnlocked as an invaluable link to fellow sufferers which is so easily accessible; it's as if they are in the room with you. Any time you are worried about some aspect of your illness, the medication you are taking, or just feeling low or helpless, there's always someone quick to reply with help, advice, or a sympathetic shoulder to cry on. Giving help and support to others in return is so rewarding. It's always good to know there are so many lovely people out there who are unfortunately in the same position.' **Angela**

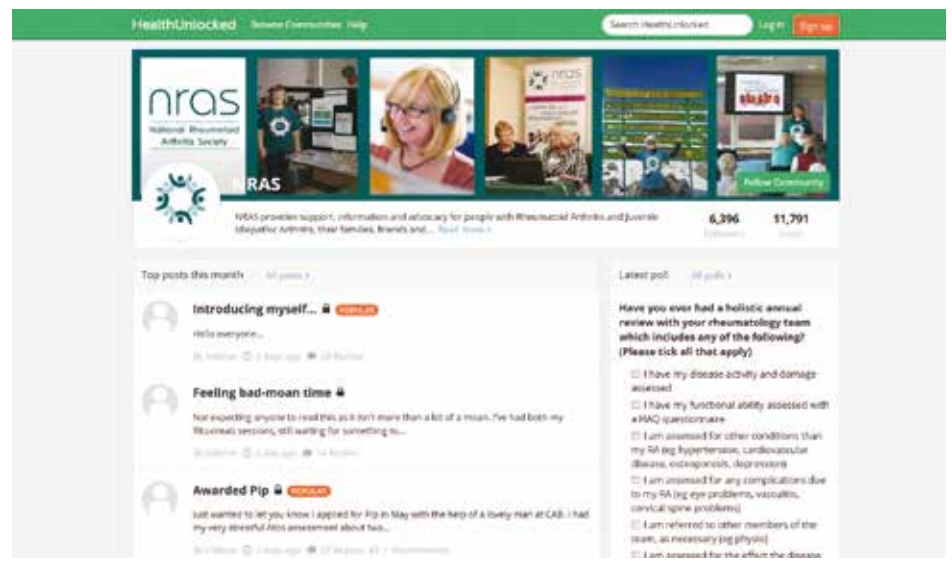
'The HU forum is really good for helping with isolation. It is very difficult for people who don't have RA to understand how it feels. Indeed, I can barely understand it myself. Having somewhere I can go for a bit of advice and support from people in the same situation is amazing. And it's a bonus that I don't have to physically move very much to get to that place because it is online. I also don't have to struggle to articulate how bad it can get. The people on HU already know and many of them have got through bad times and come out the other side. Just knowing that is priceless.' **LucyLocket42**



'What does the NRAS HealthUnlocked site offer me? I am not alone with my RA. Only other people with the disease really understand what life is like with it. I did my first post in February; I had a chest infection and was having a bad flare too. I was crying and feeling really sorry for myself. I didn't know what to do with myself; I grabbed my iPad and went to the site. Within a few moments I had a response, a lifeline. I was not alone. I had a fellow sufferer offering support. Many others followed.' **Patsy-57**

'When I was first diagnosed I really found it difficult to get out of the house due to pain and mobility problems. But I found HU and no longer felt on my own or isolated. It helped me realise there are many other RA sufferers out there who could support me and I owe them my new life.' **Allannah**

'I find the HealthUnlocked site a great source of information and the support given by other members is wonderful, there are so many nice people here who are in the same boat. It's easy to feel isolated, especially when first diagnosed, it's scary, so it's good to know that there are others experiencing the same problems and there's no such thing as a silly question. There is always someone going through the same as you and it's sometimes just good to have a rant and get it off your chest. No one understands what you are really feeling unless they too have RA.' Julie Warwick



HealthUnlocked Forum

JIA-at-NRAS

The JIA-at-NRAS team had a busy October travelling to meet health professionals in the North West, Yorkshire and Warwickshire. It was good to at last be able to put names to faces and to talk face-to-face about our ideas, how we can work together to develop the service and what information they would want to see on our website for families and professionals.

Since we've been back we have been busy working on incorporating these and the feedback from our recent survey on ideas for the new JIA website.

We had a great time at the British Society of Paediatric and Rheumatology (BSPAR) Meeting Annual Conference in Leeds, meeting even more health professionals as well as the other JIA charities, and learned more about treatments and the different ways children, young people and families living with JIA are helped. We had a great joint discussion with the other charities and talked about ideas for projects which we could all collaborate on to 'globally' raise awareness of JIA, provide information and support families further.

During the October half term holiday, Maria-Benedicta's (JIA Services Manager) nine year old daughter, Pippa, hosted her very own Tea Party in aid of JIA-at-NRAS. Pippa invited her Year 5 classmates and their parents round and

the event raised a fantastic £70. As well as lots of cakes and cookies, there was lots of fun but more importantly, no one was sick after all that cake!

In the JIA news, Jaz, one of our youth members, wrote a very moving but inspiring account of her experiences of having JIA from a very young age. Jaz's story can be found on the JIA-at-NRAS website and is definitely worth a read. We have also received articles from parents of children with JIA who, as well as wanting to offer support and hope to families living with JIA through sharing their experiences, also want to help us raise awareness of the disease and dispel the myth that arthritis only affects older people. If you have experience of a family member having JIA and feel able to share this, whether as an adult with JIA, a parent of a child or young person with JIA, a brother or sister or a grandparent, we would love to hear your story. Please email us at jia@nras.org.uk.

Last but not least, please take a look at our brand new 'hot off the press' JIA pamphlet which is available to download from the JIA-at-NRAS website.



Pippa and her friend Amy hosting a tea party

My Travels with Rheumatoid Arthritis...

by Chris Wills

I was first diagnosed with RA 24 years ago. During my diagnosis conversation I recall my doctor looking at me very concerned and somewhat awkwardly. Not quite a big C moment but he was clearly very uncomfortable with the news.

I thanked him and asked what's next, where's the cure? 'No silver bullets,' he proclaimed, 'but we will give you all the support you need.' With this encouragement I left, not knowing what journey I was about to embark on. I was recently married, ran my own business and had a stiff ankle. What was there to worry about?

My condition took a swift turn for the worse and I started a regime of painkillers and steroids. All a bit clumsy and I swiftly realised that RA and I needed to come to an agreement, and on my terms. The new drugs, which were rapidly becoming available, were only going to be part of the solution.

The early TNFs made a great deal of difference but I still felt hostage to a condition that had no right to take over my life. What I needed was a bit of physiological warfare with the beast (RA).

I'd never been the type to go for a jog; I was more likely to take a cab, but I decided to take up horse riding with my wife. Exercising other people's horses worked as an antidote to my condition and proved to me I could be active, albeit the horse being the most active one. One thing led to another and by this point we had two bonny daughters who also, after a fashion, rode horses.

We had been travelling as a family to some interesting places but as my condition deteriorated the idea of walking while on holiday became untenable. My lust for family adventure increased and I was not going to be beaten by stiff and swollen joints. The idea we might travel to far-flung places on horseback took root and we started a number of adventures in Eastern Europe,

riding local horses across mountain ranges. First were the Carpathians, then the Balkans, Caucasus and finally the Himalayas. Horse transport meant I could travel with my family to some fascinating places and learn about remote communities whilst defying the potential limitations of RA.

These journeys were not without their highlights. Whilst riding in Georgia during the war with Russia in 2008, we found ourselves in a war zone. In 2009 I caught Legionnaires' disease in China, which proved interesting. A few sticky moments but all driven along by my determination not to be beaten by RA and to live life to the full.

This summer my wife and I travelled once again to Georgia near the Chechen border. We rode up into the mountains to

stay with Azerbaijani shepherds, to learn how they make sheep's cheese, a quest previously scuppered by an interpreter in South Ukraine who confused cows with sheep!

At 57 I am getting far too old for this type of caper and I struggle to walk without my trusty stick but I'm not beaten yet. It is remarkable how easy it is to travel with a couple of syringes and a cache of drugs. You just need a little grit and determination and the world is your oyster. For me, RA has been the catalyst for adventure with my family, introducing all numbers of unlikely encounters with tribal chiefs to humble shepherds on the mountainside. The power of positive thinking has ensured RA knows its place and I have got the most out of life in spite of a bit of pain along the way.



Chris on his travels



If you wish to learn more about our family adventures try these links to a number of blogs I've written about some of our destinations. Not all of our travels have been documented but you might be inspired to do something similar, in spite of RA.

<http://travelsintusheti.blogspot.co.uk>
<http://travelsinmacahel.blogspot.co.uk>
<http://travelsinyunnan.blogspot.co.uk>
<http://hutsulshchyna.blogspot.co.uk>



Dear Helpline...

I have assessed for an anti-TNF therapy but have been told that I need to be tested for tuberculosis before starting on the medication. Why and what does this test involve?

TNF-alpha inhibitors (adalimumab, certolizumab, etanercept, golimumab and infliximab) are effective medicines but, as with all medicines, there is the potential for unwanted side effects. One of the most important side effects associated with TNF-alpha inhibitors is that they increase the risk of developing infections, including tuberculosis. Tuberculosis is uncommon in patients who are treated with a TNF-alpha inhibitor, but can be very serious, and potentially life threatening. In order to reduce this risk, patients are screened for TB ahead of starting this therapy. (1)

The Medicines and Healthcare products Regulatory Agency (MHRA) is the

government agency responsible for regulating medicines used in the UK. They have contacted NRAS recently to ask for our help in making patients more aware of the possible side effects of tumour necrosis factor (TNF-alpha) inhibitors and the increased risk of infections, including tuberculosis.

Patients are advised to look out for signs of an infection such as a persistent cough, weight loss, feeling tired, fever or night sweats, and to tell a doctor straightaway if they get these symptoms. Patients should also receive a special credit-card sized alert card when they start their treatment. The alert card has information on the risk of infections

and is designed for patients to carry with them and show when consulting a healthcare professional.

Guidelines state that before starting on a TNF α inhibitor you need to be screened for latent TB. This involves having a newer type of blood test called an Interferon gamma release assay (IGRA). If the results of this test show you to have a latent tuberculosis infection then you will receive treatment for that before being given the anti-TNF treatment. Treatment for latent TB involves either taking a combination of rifampicin and isoniazid for three months, or isoniazid on its own for six months. (2)

For more information on tuberculosis, the symptoms and treatment visit the NHS Choices website.

I have been having real trouble with my teeth; is there any link between dental problems and arthritis?

Gum disease is the commonly used description for periodontal disease. This is an inflammatory condition of the structures which support the teeth. Recent evidence has shown that there is a higher incidence of gum disease in people with RA. For this group, the physical difficulties of cleaning teeth are likely to increase the risks, as do the treatments with immunosuppressive drugs and smoking. Scaling, root planing and good oral hygiene instructions have been shown to be beneficial, so, it is really important for people with RA to visit their dentists' regularly.

There has been a good deal of research worldwide into periodontal disease (gum disease) and the links with rheumatoid arthritis. **The findings can be summarised as follows:**

- tooth loss is a feature of gum disease and may predict the severity of RA;
- the fewer the teeth the greater the risk for joint inflammation;

- there is increasing evidence that gum disease does not always come after RA, it may precede it;
- people with periodontitis who test positive for CCP are more likely to have moderate to severe periodontitis, be a smoker and therefore at greater risk of RA;
- there is a plausible connection between periodontitis and RA, but the relationship is more complex than previously thought;
- there has been found to be an association between periodontal disease and arthritis in under 16 year olds.

The American Dental Association list the following risk factors for periodontal disease?

- smoking or chewing tobacco
- having a systemic disease (RA is a systemic disease)
- taking certain types of medication (including steroids)

- having a bridge with an improper fit
- crooked teeth
- fillings that have become loose or defective
- using oral contraceptives
- pregnancy

Warning signs include:

- gums that bleed easily
- red, tender or swollen gums
- gums that have receded or pulled away from the teeth
- persistent problem with bad breath or taste that seems off
- loose teeth
- change in your bite
- change in the fit of partial dentures

So, if you have RA, the message is to take care of your teeth. Arrange regular dental check-ups, eat healthily, brush and floss and if necessary ask advice about how to make dental care easier.

I am looking for some advice about foods that I should avoid as I am currently taking a biologic drug. What can you tell me?

Taking drugs which have an effect on your immune system may make you more at risk of picking up infections. So being careful about what you eat and how you store, prepare and cook food is important to minimise this possible risk of infection. Some foods may be more likely to make you ill and should therefore be avoided and some foods are particularly susceptible to making you ill if not handled, stored or cooked properly, these include:

- raw meat and poultry
- raw eggs
- raw shellfish
- unpasteurised milk
- 'ready to eat' foods, such as cooked sliced meats, pâté, soft cheeses and pre-packed sandwiches

When preparing food, whether or not you are taking a biologic drug, it is important to ensure that food is

- cooked thoroughly (particularly poultry, pork, burgers, sausages and kebabs)
- stored correctly
- not left for too long at warm temperatures when cooked – not more than an hour

- not handled by someone who is ill or who has dirty hands touching the food
- eaten within the 'use by' date
- not contaminated by other foods (be careful to keep uncooked foods and cooked foods separate)

What are the sources of contamination?

Food contamination is usually caused by bacteria, but it can also sometimes be caused by viruses or parasites.

Some common bacterial sources of contamination are campylobacter, salmonella and listeria.

Campylobacter bacteria are usually found on raw or undercooked meat (particularly poultry), unpasteurised milk and untreated water. Undercooked chicken liver and liver pâté are also common sources.

Salmonella bacteria are often found in raw meat and poultry and untreated water. They can also be passed into dairy products such as eggs and unpasteurised milk.

Listeria bacteria may be found in a range of chilled, ready-to-eat foods including:

- pre-packed sandwiches
- pâté

- butter
- soft cheeses, such as Brie, Camembert or others with a similar rind
- soft blue cheese
- cooked sliced meats
- smoked salmon

It's important that all of these foods are eaten by their 'use-by' dates.

Common viruses include E. Coli which can cause food poisoning which occurs after eating undercooked beef (particularly mince, burgers and meatballs) or drinking unpasteurised milk.

The virus that most commonly causes gastrointestinal illness is the norovirus. It's easily spread from person to person, from contaminated food or water. Raw shellfish, particularly oysters, can be a source of this type of viral contamination. However, the Foods Safety Agency advises that older people, pregnant women, very young children and people who are unwell should avoid eating raw or lightly cooked shellfish to reduce their risk of getting food poisoning.



A year in the

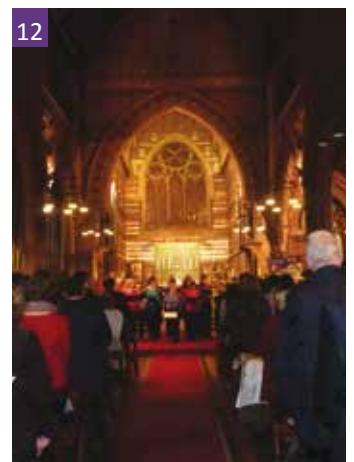
Here is a selection of this year's e



1. January – Official Opening Ceremony of new offices 2. February – Launch of JIA Report & service 3. March – The first Roadshow of 2014 at Elstree 4. April –
7. July – NRAS launched the new Welsh ambassadors 8. August – Garry Cormack takes on Ben2Ben fundraising challenge 9. September – Annual Conference f

Life of NRAS

Events at NRAS. Thank you to all!



1. New website 2. 5. May – BSR conference 2014 3. 6. June – RA Awareness Week. Ailsa and Jeremy Vine on BBC Radio 2
4. 7. July – RA Awareness Week. Ailsa and Jeremy Vine on BBC Radio 2
5. 8. August – Rheum 2 Talk training for NRAS members 9. 10. October – Rheum 2 Talk training for Healthcare Professionals 10. 11. November – Truro Group Launch 11. 12. December – Christmas Concert

RA Awareness Week

2014 saw another successful Rheumatoid Arthritis Awareness Week campaign and the date for next year is 15-21 June.

We will once again organise a RAmble fundraising walk, have information packs to help you get involved, as well as your favourite awareness raising activities – tea parties, awareness stands and many media, campaigning and press opportunities! We will have an update in our Spring Magazine and members' e-news with more details of the week and how you can take part, so keep your eyes peeled!

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



NEWS &

Ask yourself these questions?

- Have I got a story to tell about living with RA?
- Could my experience of coping with everyday life perhaps help someone else?
- Have I got some time on my hands that I wish I could do something useful with?
- So my legs might not work so well these days but my brain is still working so I wonder if there is anything I can do to help?

If you relate to any of the above then turn to page 29 to find out what opportunities there are to turn what you know about living with RA into helping others living with RA.

Put on some extra p... the Christmas period

Head to the exercise section of your health. Here you can view mobile in their own homes as information and other resources with RA. www.nras.org.uk/e

Or

Why don't you take up a challenge and get fit and the same time runners for the Great North Royal Parks Half Marathon. www.nras.org.uk/takep

EVENTS

Pain survey

NRAS is pleased to let you know of an opportunity to take part in research into pain. Please note this is not an NRAS survey but one being conducted by the University of Derby.

The survey is aiming to measure changes in painkiller use over time and investigate the role of factors such as pain acceptance, pain medication beliefs and emotions.

If you would like to take part, here is a link to the survey which will provide you with more information or you can find the link at www.nras.org.uk/research

The survey closing date is end of January 2015.

Thank you for all your festive support!

Thank you everyone for all your support over the festive period. Once again we have been overwhelmed with the flurry of Christmas card orders we received and the generosity of our supporters.

It was also fantastic to see so many recognisable and new faces at our Christmas Carol Concert, held near our offices in Maidenhead; it is always a wonderful evening to get you ready perfectly for Christmas. All Saints Junior School once again delighted us with their voices. Thank you to all those who performed on the evening.

Thank you to everyone who has supported us over Christmas and throughout this last year, we are most grateful and are looking forward to bringing you new and exciting opportunities in 2015.

Pain and prescriber use questionnaire

Please take a few minutes to complete the following questionnaire about the research in question concerning the use of painkillers in the community. The questionnaire is available in English and Spanish. The questionnaire is available in English and Spanish. The questionnaire is available in English and Spanish. The questionnaire is available in English and Spanish.

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our website to improve
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allenge for NRAS this year
me? We are looking for
h Run in September and the
n in October. Visit
art to find out more.

Apply now for a 2015 Flying scholarship

Anyone wishing to apply for a 2015 flying scholarship with Flying Scholarships for Disabled People should submit their full application form to them by not later than Wednesday 31 December 2014.

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

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

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

All enquiries to Julie Bull (contact details as above)



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Please Gift Aid your Donations

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

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

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Tweets

TWEETS 4,014 FOLLOWING 1,592 FOLLOWERS 3,039 FAVORITES 181

Daniela NRAS @Daniela_NRAS · Nov 14
I will be supporting @NRAS_UK this #GivingTuesday



10 replies 4 likes [View more photos and videos](#)

Allan Mooney @MooneyAllan · Nov 11
I have signed up to do the @CyclingScotland 110 miles in September and the RideLondon 100 miles in August both for @NRAS_UK

The King's Fund @TheKingsFund · Nov 4
Phil Baker of @NRAS_UK: "CCGs should include a minimum requirement for patient self-management in new provider contracts" #peoplehealth

Please Remember NRAS in your Will

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

A Gift in Your Will Supports Our Future



nras
National Rheumatoid
Arthritis Society

National Rheumatoid Arthritis Society
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SL6 7RJ

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