nras
National Rheumatoid
Arthritis Society

SPRING 2015

Magazine

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First biosimilars for Rheumatoid Arthritis launch in UK

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ONE OF BRITAIN'S BEST VOLUNTEERS!

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Dear Members…

Signs of spring are always welcome after a long winter, and being greeted by crocuses and snowdrops, as well as signs of my tulips coming up when I leave for work on a cold but sunny morning lifts the heart.

The year got off to a very busy start as always and I am delighted to tell you that on 14th January, our granddaughter, Alba (Gaelic for Scotland), was born. Being a grandma is fab and I can recommend it to anyone. Not that I am in any way biased of course (!), but she is gorgeous! Lorraine, who many of you will know from our helpline team, has also just become a grandma to Zack, so there have been lots of baby photos going around the NRAS office.

In spite of the exciting developments above, life is still personally challenging as, after many years in reasonably good control on biologics, my RA has now been uncontrolled for a year, in spite of trying 2 new biologic therapies in the last 6 months, but this only serves to underline the unmet need which remains in the treatment of this awful disease, despite the amazing progress made in rheumatology research and treatment in the past 15 years.

In the run up to the general election in May, it is interesting to see that the NHS is taking over as the hot issue from immigration in many quarters and we know that whatever shade of government takes over, there are going to be difficult times ahead for the NHS across the whole of the UK. Sir Simon Stevens, CEO of the NHS, launched his Five Year Forward View at the end of October and we were pleased to see real recognition of the importance and value of patient supported self-management in the NHS, something that we at NRAS provide, promote and implement.

Support for self-management in the NHS

"Even people with long term conditions, who tend to be heavy users of the health service, are likely to spend less than 1% of their time in contact with health professionals. The rest of the time they, their carers and their families manage on their own. ...we will improve the information to which people have access, not only clinical advice, but also information about their condition and history. ...we will do more to support people to manage their own health. With the help of voluntary sector partners, we will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge." ***From the Five Year Forward View***

We shall be seeing some new faces in the NRAS team this spring. We are pleased to welcome our new Head of Development, Kiera Ridge, who joined us on 1st April. We hope to also shortly appoint someone in the role of JIA Youth & Family Services Manager to continue to develop this new section of NRAS.

I have taken on the challenge of doing the Great North Run in my wheelchair this year ably pushed by two of our wonderful and supportive Medical Advisors David Scott and Chris Deighton. I think I must be mad but it is a great event (as long as it's not raining!) and so if you want to support us, you can do so by visiting **https/www.justgiving.com/GNRDreamteam**. All funds raised go directly to NRAS and therefore to supporting ***you*** and everyone living with RA and JIA.

We have a huge work programme this year, with more groups launching, lots going on with our campaign networks in Scotland and Wales, and will be keeping you all up to date with everything through the e-bulletins and the website, but don't hesitate to call us or email us about anything you want to draw to our attention or you feel we can help you with. A lot of areas across the UK are looking at re-designing their local musculoskeletal and rheumatology services and are inviting local patients to get involved at stakeholder meetings. We can help and support you to do this if this is happening where you live.

This year we are going to be taking a fresh approach to how we measure the impact of NRAS and we will need your help with some of this work which will mean we will be asking you more about your interactions with NRAS in different ways. I do hope that you will support us in this endeavour as it is important that we are able to demonstrate

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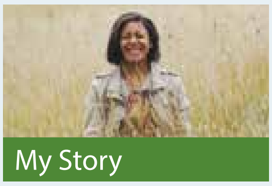

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to our funders and to the NHS where we are now starting to deliver patient supported self-management services, evidence of the difference NRAS makes. Wishing you all the very best till next time.

Ailsa

NRAS Founder and CEO


Ailsa's Granddaughter, Alba


Lorraine's Grandson, Zack

Welcome Kiera Ridge – Head of Development

We are delighted to welcome Kiera to the NRAS team. Kiera brings a wealth of experience of working in the charity sector as she joins us from the Terrence Higgins Trust. Kiera says, "I'm thrilled to be joining NRAS in the role of Head of Development. NRAS, being a patient led organisation was what really attracted me to the society. So many organisations think they know what their beneficiaries want however I'm excited to be working somewhere where they are actually asking people with RA - and acting upon it. I have many years experience working in fundraising for organisations that support people with long term health conditions and I hope this will make me a good fit and enable me to hit the ground running!"


Kiera Ridge – Head of Development

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Meet the Team...

Laura on Phil

Phil joined the NRAS team in 2014 and is NRAS Director of Commissioned Services. He has previously held many high-level roles within the charity sector including as a director and acting CEO of Arthritis Care. Phil is a great member of the team, always happy to offer a new perspective on any policy or campaigning puzzle I might be dealing with that day and has an infectious sense of humour. He is also obviously a man of many talents – when he's not grappling with the complexities of commissioning in the NHS, he likes gardening on his 3(!) allotments, playing music and spending time with his four grandchildren.

Mark on Oli

Oli joined NRAS in February 2011 as our Trust and Grants Fundraiser before being promoted to Fundraising Manager at the beginning of last year.

Since joining the fundraising team last year, I have had the pleasure of working with Oli and he has been a great source of advice and knowledge on the world of fundraising and NRAS. As Fundraising Manager, Oli is actively involved in every part of fundraising at NRAS, from writing applications and speaking to health care professionals, to helping organise events, merchandise and generally ensuring we are an efficient, well oiled fundraising machine.

In his spare time Oli enjoys being active, regularly playing squash, mountain biking and more recently training for the Windsor triathlon later this year where he will be raising funds for NRAS. **www.justgiving.com/OliverHoare**

I can honestly say Oli is one of the best managers I have ever had and it is great to work with him at NRAS (even if he is a Spurs fan!)

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 visiting the NRAS website, www.nras.org.uk.

External Affairs

Our volunteer network is made up of volunteers throughout the UK, many 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** or email **volunteers@nras.org.uk** for more information.

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

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

A Health Care Professional on your high street or in your supermarket....really?

by Clare Jacklin, NRAS Director of External Affairs

Yes it's true but these highly qualified health professionals are not being utilised as much as they should be. There was a great deal of media coverage over the recent winter months about the increased, often inappropriate, demands on NHS hospitals, A&E, Urgent Care Centres and out of hours services by people trying to access medical advice and intervention but who, perhaps, do not actually need to see a doctor. Your community pharmacists, who are often available late at night, at weekends and much closer to your home, can offer so much more than you may realise.

The Royal Pharmaceutical Society and the Centre for Pharmacy Postgraduate Education has launched Medicine Optimisation Briefing prompt sheets on many long term conditions e.g. MS, Diabetes, Asthma, Depression, COPD etc. I was delighted, along with NRAS Member and Volunteer, Teresa Shakespeare Smith, to have input into the briefing sheet being made available to community pharmacists on the topic of Rheumatoid Arthritis. These Optimisation Briefings give your community pharmacist a wealth of additional information about RA and equips them to help you in many aspects of living with your rheumatoid arthritis. Community pharmacists have an in-depth understanding about how medicines work and interact, for example if there are any contraindications to taking a variety of medications for two or more conditions. Many people living with RA also live with one or more other conditions but perhaps see different clinicians for each condition so having someone to review all your medicines on at least an annual basis can be really useful in managing your condition(s). Book your MUR now with your local pharmacist.

A Medicines Use Review (MUR) is a free NHS service offered by pharmacies in the UK. The review involves an appointment with your local pharmacist, in a private consultation room. It is an opportunity for you to discuss your medicines with a pharmacist, to understand how your medicines should be used and why they have been prescribed, as well as solving any problems you may have with them.

ROYAL PHARMACEUTICAL SOCIETY

CPPE CENTRE FOR PHARMACY POSTGRADUATE EDUCATION

Medicines Optimisation Briefing

This medicines optimisation briefing focuses on patients with rheumatoid arthritis (RA) and is designed for pharmacy professionals in any sector to use in their practice.

Patient experience

Evidence – is the medicine appropriate?

Safe and effective

Medicines optimisation as part of routine practice

www.rpharms.com

www.cppe.ac.uk

RHEUMATOID ARTHRITIS

Medicine Optimisation Sheet

Note for health professionals: for full access to further information on Medicine Optimisation please visit www.nras.org.uk/for-professionals where you can read the full article published in The Pharmaceutical Journal January 2015.

NRAS Rheumatoid Arthritis – Self Management Programme

A six week programme delivered by a rheumatology health care professional and an expert patient. So let's hear from the tutors what their experiences of delivering the programmes have been.

Fiona Lovegrove, Lead Nurse Rheumatology in Fife.

It was with some trepidation that I ran my first NRAS RA Self Management Programme course along with a co-tutor, Margaret, who suffers from RA. Group sessions are not for everyone. It is well known that a good programme may have 10 participants attending initially but these 10 will slowly decrease to 2 or 3 by the final session. We started with 9 and finished with 9, the old and the young, the working and the retired – a real mixed bag!

NRAS provides a wealth of resources for the participants as well as the facilitators. Information on particular problems with RA, as well as topics such as Social Care and Benefits, were all available. Contact details of groups and activities in the local area were made known.

Course topics range from "Understanding your medication" and "Making the most of your consultation" to "Managing stress and anxiety" and "Planning for a major event." Each week, the participants set goals for themselves. These were reflected upon the following week with congratulations or help and advice given by their peers in the group.

Over the course of the 6 weeks, strong bonds were made between participants. They shared their woes and problems, and their emotions. They looked out for one another, helped one another, and this was wonderful to observe.

Was it all worth it?

At the reunion, one month after completion of the course, one participant was heard to say *"I've had RA for 25 years. I initially thought "There's nothing anyone can teach me about it. I don't need to attend a course. I should be teaching them." How wrong I was!"* Another participant initially thought he would come along for the first week but probably not go to the second – he never missed one week!

So, I think the answer to my question is Yes, it was well worth it, and I hope many more similar courses are made available to those with RA. The above course was very much appreciated by all participants.

RA Self-Management Programme Fife

Jacquie Dodd & Sue Smith - Lay tutors for the RASMP in Bath tell us what it was like for them as lay tutors.

Jacquie and I first heard about the programme as we are the NRAS Bath Group Coordinators. They say "Never volunteer" but as usual we did anyway! The training for the RASMP for volunteers and health care professionals (HCPs) was run over four days with a weekend break to recover, it was tiring, but also motivating.

Armed with our manuals the four of us met up later to decide who would be delivering each topic. It was also decided that the HCPs would prepare all the necessary flip charts for the six week course. Prior to each session, we would meet up an hour before to go over the delivery.

Our first course arrived and eventually we all settled down to business. Group ground rules and hopes were written down on a poster, these were displayed at every session. Concentrating for three hours was tiring but the group remained focussed and interactive throughout.

The content of the course provided supportive information, there were plenty of relevant useful handouts and of course the knowledge of the participants and the tutors. Our final activity was setting goals and action planning. It was a revealing process, participants were unaware of how much they asked of themselves and how much was actually achievable. Over the coming weeks the group bonded well and were supportive to each other and us. By week six, action planning and problem solving was becoming automatic, they solved their own problems and helped others with theirs.

Our second group followed a similar pattern. Each group had its own identity but had similarities as well.

What does being a Lay Tutor on the RASMP mean to us? When you hear a group member say they "feel inspired, or how the course has changed their life, that they know they're not alone, how they wish the group could continue", it is extremely rewarding. The time and effort is well worth it, knowing you can help to change a person's life for the better is priceless and uplifting. 'The feel good factor' at full flow. We're now looking forward to meeting our next group and hopefully many more.

By Sue Smith and Jacquie Dodd Lay Tutors

Brentford Pilot Session

Glasgow RA Self Management Group

Future RASMP courses

Bath

Royal National Hospital for Rheumatic Diseases, Bath

For people living in Bath, Wiltshire, Somerset, North Somerset, North East Somerset, South Gloucester, Gloucester, Bristol, Swindon

Every Tuesday commencing Tuesday 6th October - Tuesday 10th November at 13:30 – 16:00.

For more information and to book your place please contact the Rheumatology Therapy Department on 01225 473416.

Fife

Fife Whyteman's Brae Hospital, Kirkcaldy

Every Tuesday commencing 19th May until Tuesday 23rd June from 13:00 – 16:00.

For more information and to book your place please contact the Rheumatic Diseases Unit on 01592 648193.

Glasgow

Victoria Infirmary, Langside Road on the south side of Glasgow.

Every Friday commencing 4th September until Friday 9th October from 14:00 – 17:00

Contact Liz McIvor on 0141 355 1062 to book your place.

Alternatively please contact Nicky Freemantle nicola@nras.org.uk (01628 823524) to register interest in participating in any of these RA Self Management Courses.

My Story...

By Andy Williams

I was diagnosed with rheumatoid arthritis (RA) in 2007 at the age of 44, it came as a huge shock to me. My first reaction, like lots of people, was why me? Previously I had led an active sports life playing competitive rugby from school days onwards and in my 40s I was still enjoying five-a-side football on a weekly basis.

I had to give up contact sport and felt like part of my identity had been erased. It was also difficult not being able to even kick a football around with my young son as I had done with his two older brothers. For a period I suffered from depression which led me to take time off work and reassess my life. I found this time of reflection invaluable. In my younger days I had some poetry published and I began to write about how having RA made me feel. It was a way of expressing my anger and proved very cathartic.

Gradually I began to accept that my illness wasn't going to go away and began to focus on ways to improve my wellbeing. I modified my diet and gave up alcohol, not easy as I was something of a party animal! I also began to investigate which sports could provide me with the exercise that had always made me tick as a person. I looked at non weight bearing sports because I have sore wrists and ankles. Swimming was a good option but frustratingly it is not something I am keen on or good at! This may be a legacy of learning to swim in an outdoor pool in November in my Welsh schooldays with the teacher poolside in a sheepskin coat!

Finally, I decided that cycling might be a good idea as I had spent my youth climbing some steep valleys with my friends and it conjured up fond memories. I bought a cheap second-hand bike and began to explore the canal paths around London. I felt like a bird released and benefited physically and mentally in a surprisingly short period of time. I started to ride more regularly and for longer distances, faster too! I lost weight and began to feel good about myself.

My partner is South African and I visit there every year. I enjoy cycling with her dad and together we hatched a plan to raise money for NRAS. In August, seventeen of us cycled 200km over three days. We climbed over 3300 metres on dirt tracks with a full back-up team. I love a challenge and the feeling of elation when I achieved my objective was truly magical. I hope my cycle trip inspires others to push the boundaries; go on, you can do it!

Thank you, Andy, for raising £658.75 to support the valuable work of NRAS.


nras

First biosimilars for Rheumatoid Arthritis launch in UK

"At a time when the burden of chronic diseases is increasing across the world, ensuring that patients can access safe, quality, affordable and modern medicines such as biological medicines is vital to improving health ….. It is therefore essential that patients have access to clear and impartial information about what biological and biosimilar medicines are and what their growing availability will mean for them." International Alliance of Patient Organisations Briefing paper (November, 2013)

NRAS cautiously welcomes the introduction of biosimilar medicines to the UK, as they could help to increase the choice of treatments available in the NHS and provide further opportunities to help patients get their disease under control. However, it is important that clinical effectiveness and patient safety should be the overriding principles for prescribing biosimilars. They should not simply be prescribed as a quick cost saving alternative to the originator biologics, just because they may be priced more cheaply.

The only currently approved biosimilar medicines for use in rheumatoid arthritis in the UK are based on infliximab (Remicade). These biosimilars have been filed under two separate names with the European Medicines Agency (Inflectra and Remsima) and, they were introduced by two different companies, Hospira (Inflectra) and Napp (Remsima) in February, 2015.

So, what is a biosimilar?

A biosimilar medicine is a biological medicine manufactured to be similar to an existing licensed 'reference' biological medicine. A biosimilar has no meaningful differences from the original biological medicine (originator) in terms of quality, safety or efficacy. Due to the complex manufacturing process, as these medicines are made from living organisms using biotechnology techniques, biosimilars are not classed as 'generic' medicines, because they are not absolutely identical to the original biologic medicine.

Generic Medicines

You may be more familiar with the term 'generic' drugs which are 'me too' drugs which are identical to the original branded drug and a good example of this in the field of pain medication is Ibuprofen which is the generic drug. As stated above, biosimilars cannot be classed as 'generic' drugs, because they are not absolutely identical to the original.

Why are biosimilars being introduced in RA now?

Biosimilar medicines already exist in other areas of medicine. The reason this is happening in RA is that some of the first biologic medicines - Anti-TNFs - are starting to come off patent. This means that other manufacturers are now permitted to produce similar versions of these medicines called biosimilars.

What is the NICE position on the introduction of these biosimilars? Will they go through the same Technology Appraisal process as the original drugs?

NICE will consider biosimilar products notified to it by the National Institute for Health Research Horizon Scanning Centre for referral to the Technology Appraisal topic selection process. However, these products will usually be considered in the context of a Multiple Technology Appraisal (MTA) (or the review of an MTA) in parallel with their reference (originator) products in the indication under consideration. Basically what this means is that any new biosimilar medicine, once approved under the European regulatory framework, will not be required to go through the 'normal' Single Technology Appraisal process which the originator products had to go through, in order to be made available for prescription in the UK.

Are these new biosimilars as safe and effective as the originator drug?

When compared to infliximab, these biosimilars have demonstrated similar therapeutic efficacy and incidence of drug-related events, are well tolerated, and have a comparable record of safety. However, owing to the complexity of these drugs and their relative newness, we still believe that ongoing safety monitoring is vital.

How will safety be monitored?

NRAS recommends that all manufacturers of biosimilars subscribe to the British Society for Rheumatology Biologics Registers so that pharmacovigilence protocols are the same as those of the original biologics and long term safety data is properly collected. This view has been echoed by the Association of British Pharmaceutical Industries and by the British Society for Rheumatology.

Biosimilars stakeholder event

How do the prices of the new biosimilars compare to the originator product?

It is anticipated that biosimilars will generally be between 20-40% cheaper than their originator products.

It is for this reason that both NRAS and the British Society for Rheumatology have made clear in their respective position papers that: Biosimilars should not be prescribed simply as a quick cost saving alternative to biologics and that people who are stable on originator products are not switched to a cheaper biosimilar without the full consent of the prescribing clinician and with patient agreement.

Where can I get more information on biosimilars?

This is a complex subject and you can get more information by visiting our website www.nras.org.uk/biosimilars-medicines and following the links to read the report on a stakeholder event on the topic of biosimilars we hosted last year in conjunction with other charities, health professionals and regulatory bodies; see also the NRAS position paper in full and other relevant position papers such as the British Society for Rheumatology. For further information and help on any aspect of living with RA, please call our Helpline team on: 0800 298 7650.

The Introduction of Biosimilars – Uncharted Waters?

Report from a Stakeholder Event

Government Affairs

by Laura Wetherly, Senior Government Affairs Officer

There have been some steps forward for our welfare campaigns, the Care Act 2014 regulations come into force and the countdown to the General Election 2015 gets underway.

Over the past few months, NRAS has continued its work around welfare and disability benefits. We have continued to attend the Department of Work and Pensions (DWP) Personal Independence Payment (PIP) Engagement Forum and we are now also part of their Improvement Working Group, which aims to devise ways to improve the process for claimants. During the last quarter we have attended meetings of this group and made suggestions for how the process could be improved. We are very pleased that the Department is now looking to develop an online claims process for PIP, as this is one of the things NRAS has called for.

The First Independent Review of PIP, led by Dr Gray, has been published and responded to by the Government. NRAS submitted a lengthy consultation response to this last year. The review made a number of welcome recommendations including clearer communication with claimants, a digitally enabled claims process and improving how evidence is collected. The Government's response to the review currently only addresses the short term recommendations. However, they have committed to review communication with claimants, establish an online service and deliver additional training for assessors and case managers on consistent application of the reliability criteria and assessment of fluctuating conditions.

Whilst we believe this represents a step in the right direction, more improvement is needed. We know there are still ongoing issues of delays and access to the correct level of support. NRAS will continue to campaign to ensure people with RA receive the support they need.

There is much more mixed news in relation to Employment Support Allowance (ESA) and Work Capability Assessment (WCA). NRAS has been continuing to lobby for changes to the ESA and WCA to make them more suitable for those with fluctuating and progressive conditions such as RA. We took great steps last year, building successful relationships with the Work and Pensions Select Committee who echoed a number of our recommendations within their report on ESA and WCA. However, more recently, we have been disappointed by the Government's response to Committee as they largely failed to adopt the recommendations around progressive conditions.

Dr Paul Gray, Independent Reviewer of PiP

Despite this, NRAS has continued to campaign on these issues. Our campaign received a mention in a parliamentary debate on the Work Related Activity Group (WRAG) and we have written a CEO letter to the Minister for Disabled People, Mark Harper, to invite a meeting and highlight our concerns. I have also attended meetings with DWP officials in the last few months to stress this issue.

The fifth Independent Review and the Government's response have also now been published. Dr Litchfield recommended that long re-referral periods in the WRAG be re-examined, something NRAS would support. The Government committed to take forward this recommendation as well as extending re-referral periods in the Support Group for those with degenerative brain disorders to five years when referrals start up again. NRAS is campaigning to ensure this will be extended to physical conditions which can also be degenerative, such as RA.

Social Care

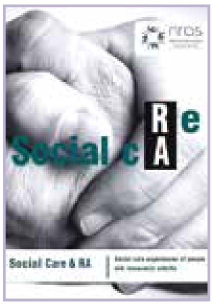
The Care Act 2014 and its regulations come into force this month, bringing with them big reforms of how the social care system works. On the back of the report into social care we produced last year (now available to read on our website), NRAS has continued to campaign around the new social care laws and provision for those with long-term and debilitating conditions such as RA. Having completed a submission to the original draft guidance and regulations last year, informed by the findings of our survey, NRAS has now also responded to a consultation on proposals for a cap on care costs and the creation of a social care appeals process, and has attended meetings with Department of Health officials.

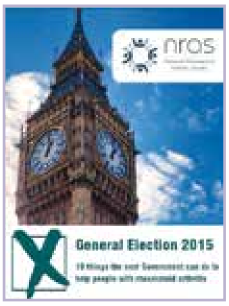
With the launch of JIA@NRAS and the new website jia.org.uk this year, the Government Affairs team have been providing policy support, working to ensure consistent and high quality care and support for the 12,000 children with Juvenile Idiopathic Arthritis (JIA) throughout the UK, their families and carers. We are responding to a consultation from NHS England on how they decide which specialised services are the priority and have provided comment on the NHS England Service Specification for paediatric rheumatology, highlighting the need for greater provision and geographical coverage of specialist services.

For the last few months the Government Affairs corner of the office was quite preoccupied by the looming date of May 7th. By the time this goes to print, we will be getting very close indeed to the 2015 General Election. NRAS is keen to use this opportunity to highlight, to politicians and the public, the important issues for people with RA. This is a great opportunity for you to get involved both before and after the election. We have developed a pack of resources for you to use, which highlight the key issues for RA services and patients. Our manifesto, which you can find on our website, makes 10 key calls to the next government, including introducing a national public awareness campaign, making access to 'self management' a right within the NHS constitution, and improving the Employment Support Allowance for those with progressive conditions.

This document can be used as a prompt for discussion with your new MP once elected. There are a number of ways to spread the word about NRAS and campaign for improvements for people with RA:

- After the election, write to your new MP to highlight the major issues. An e-campaigning tool is available on our website to help you do this.
- Attend your newly or re-elected MP's constituency surgery and highlight the local issues.





- If you are a member of an NRAS group, and holding a tea party, you might consider inviting your local MP.

Our Guide to Campaigning gives you some information and advice about how best to go about raising issues with politicians and some of the things to be aware of.

If you would be interested in taking any action to raise awareness of RA and the NRAS manifesto amongst politicians, please contact the Government Affairs team who will be able to advise and assist.

For further information about any of NRAS's campaigning work, or if you would like to know more about opportunities to get involved, please contact: Laura Wetherly, Senior Government Affairs Officer at campaigns@nras.org.uk or on 0845 458 3969.

A tribute to Helen Claxton, NRAS Member & Volunteer

By Clare Jacklin

I joined NRAS way back in 2007 and one of the very first NRAS Members I actually met was the lovely Helen at a meeting at Queen Mary's hospital in Sidcup. Helen made me feel so very welcome at that group meeting when I was feeling particularly out of my depth, being new to RA and NRAS. Helen, along with her good friend Maggie Smedley, kept the Sidcup NRAS group going for a long time despite having many other commitments and demands on their time. That was typical of Helen though, always putting others before herself. Helen was an amazing NRAS Volunteer not only running the group for a while and more recently supporting the Maidstone group but she also participated in many focus groups; offering a listening, supportive ear as a telephone peer to peer volunteer; contributed to local service redesign meetings and research work, she was also a terrific fundraiser for NRAS with her "Helen's Hats", and in more recent times, hosting an NRAS Tea Party.

Helen Claxton, 18th June 1946 - 2nd March 2015

Helen will be very sadly missed not just by her immediate family, Bob, Katie, Lucy and Christopher but by the NRAS family of whom she was very much a part. Helen was an inspiration to many living with rheumatoid, giving support and encouragement to those she met and spoke to over the years. Her legacy will live on through others she has helped along the rocky road of living with RA. All the NRAS community would like to pay tribute to Helen's selflessness and compassion for others and I, on a personal note, would like to say not only how very proud I was to have had Helen as one of our Volunteers but also how privileged I was to be able to have counted her as a dear friend.

May she rest in peace.

Helen's Hats

Scotland campaigns update

NRAS has had a busy few months in Scotland. We have held two events in the Scottish Parliament and the Scottish Campaigns Network, under the chairmanship of Sheila MacLeod, has continued to raise the profile of RA throughout Scotland.

In December, NRAS's Scottish Campaigns Network held an exhibition in the Scottish Parliament, in partnership with the Rheumatic Diseases Unit in NHS Fife, kindly sponsored by Patricia Ferguson MSP. The exhibition drew attention to the importance of early diagnosis and treatment in minimising the economic burden of RA and the link between smoking and RA. NRAS Scottish Ambassadors staffed the exhibition along with clinicians from NHS Fife, including Dr Helen Harris, Consultant Rheumatologist and Fiona Tweedie, Occupational Therapist. Over 30 MSPs stopped by our stand throughout the week, including former First Minister, Alex Salmond, and a number offered future support.

Sheila Terry, John Paton and Patricia Ferguson

At the beginning of the year, NRAS was invited to take part in a review of specialist nurse funding. The Scottish Government is trying to decide which specialties to allocate £1.5 million of funding to. NRAS will be contributing to make the case for additional funding for vital provision of Rheumatology Nurse Specialists.

Update from Chair of the Scottish Campaigns Network, Sheila MacLeod

'Meet the Patients' event

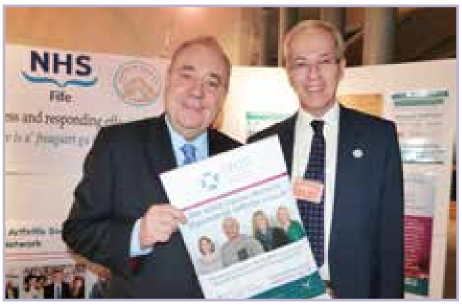
In January 2015, NRAS built on previous success by hosting a highly successful 'Meet the Patients' event in the Scottish Parliament. This created an opportunity for people with RA from across Scotland to meet with politicians - and one another - to raise awareness and understanding of the condition. Duncan McNeil, MSP, Convener of the Health and Sport Committee kindly sponsored the occasion in support of NRAS and highlighted the key priorities of early recognition, diagnosis and treatment and provision of ongoing, good quality multi-disciplinary care.

Duncan McNeil, MSP, Ailsa and Laura

Ailsa Bosworth, Chief Executive, and several Scottish Ambassadors took part as well as a number of clinicians; all were encouraged by the keen interest taken by Parliamentarians, with promising offers of support for the future. Clear ,too, was the vibrant nature of the RA community in Scotland; NRAS has a terrific resource in its membership and, in turn, we are supported by excellent and highly committed healthcare professionals.

Quality Improvement

NRAS in Scotland continues to contribute actively to the progress being made by the Scottish Society for Rheumatology (SSR) in its promotion of key priorities through Quality Improvement Projects supported by Government; three such projects have been agreed for funding and a further initiative is under way to establish a system of metrics for measurement of quality in delivery of RA treatment, which our CEO, Ailsa Bosworth is also involved in.

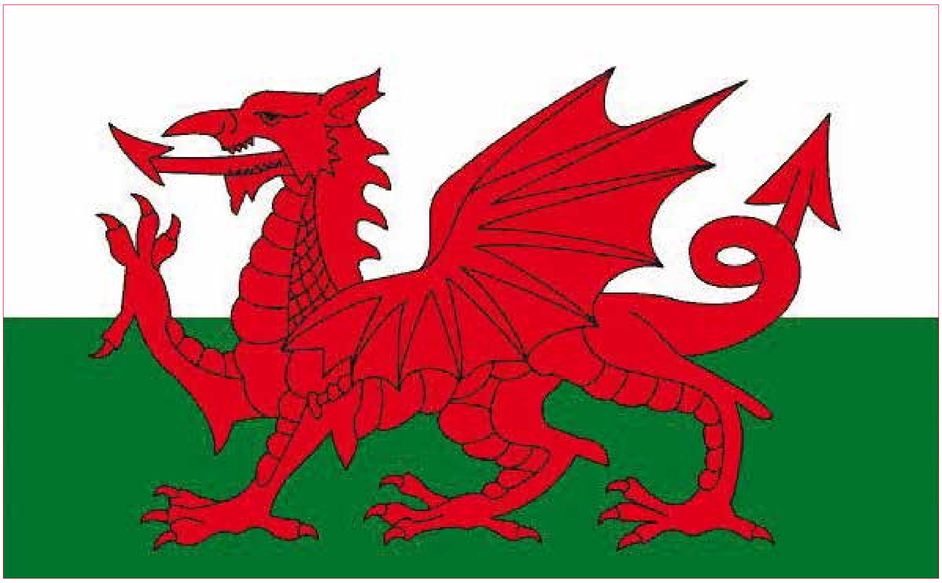


Former First Minister, Alex Salmond and NRAS Scottish Ambassador, John Paton

Sheila MacLeod, Chair of the NRAS Scottish Ambassadors Network

Wales campaigns update

Last year, NRAS increased its presence in Wales through establishing the Welsh Campaigns Network. Now under the chairmanship of Huw Roberts, NRAS Member & Volunteer, the Network has continued to develop and provide a voice for Welsh RA Patients.



NRAS has met with the Wales Health Specialised Services Committee (WHSSC) to highlight the lack of a fully resourced specialist children's rheumatology treatment centre within South Wales and to call for a paediatric rheumatologist lead specialist multi-disciplinary team to be provided at Cardiff Children's Hospital. We will be continuing to engage with them to take this forward.

Update from the Chair of the Welsh Campaigns Network, Huw Roberts

Annwyl Pawb/ Dear all,

Whilst I must congratulate our Welsh Rugby Team on their superb performance during this year's Six Nations, I must also applaud Professor Simon Jones of the Cardiff School of Medicine, University Hospital of Wales in securing much needed research funds. Professor Jones quotes,

"Arthritis Research UK have just agreed to fund us for another 5 years...[this] means we can continue to explore the mechanisms that drive rheumatoid arthritis in patients. Hopefully this will mean we can help tailor therapies more appropriately for patients. We now have funding until 2020, which is truly fantastic"

Although the Wales Six Nations Rugby campaign has come to an end, the NRAS campaign continues to gather momentum in all parts of the country.

Following on from the first Annual Ambassador meeting in March, we will now be conducting hospital visits and gathering patient feedback concerning all the health boards in Wales. Nationally, we will pursue the completion of the review into the 2007 Service Commissioning directives for Arthritis and Musculoskeletal Conditions. A review of the Directives was started last year and we are expecting the process to resume sometime in the coming months. This will be strengthened by Jean Bailey -Dering ,our Pembrokshire Ambassador, who has been asked to be a patient representative with her local health board for the development of an MSK Directive.

After we emerge from the uncertainty of the General Election, we will be carrying on our pursuit of a Cross Party Group on Inflammatory Arthritis involving politicians and stakeholders.

The importance of organisations such as NRAS was yet again evident following events at Withybush Hospital (Hywel Dda Health Trust) last year and the Welsh NRAS Ambassadors are looking forward to helping lead awareness and fund raising events in Wales this coming summer. Your support would be greatly appreciated. We are also exploring engaging a Gwent Ambassador and securing the services of an additional North Wales Ambassador to represent the North East of Wales. If you are interested then please contact the NRAS campaigns team on campaigns@nras.org.uk

Finally, Chris Murphy, partner of our N.Wales Ambassador Nia Blackwell, will be running the London Marathon and has chosen NRAS as his charity. Please give your support to Chris by visiting www.justgiving.com/chris-murphy69

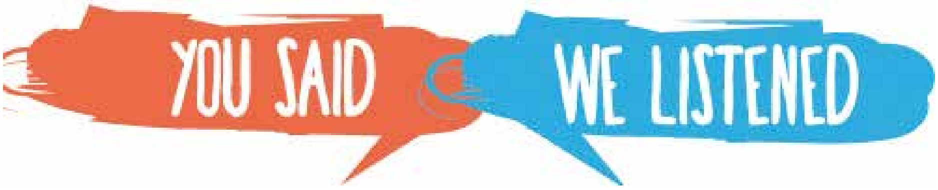
Pob lwc Chris / Good luck Chris.

Chris Murphy

Huw Roberts, Chair of the NRAS Welsh Ambassadors Network

We asked the questions we have listened to your answers.

We had 310 people respond to a recent questionnaire sent to those who are no longer or were never NRAS Members. All comments both positive and negative have been welcomed. Like any organisation we need to regularly review what we do and how we do it so your feedback has been really helpful.



The online survey was sent out to people on our database who have interacted with NRAS in some way but are not currently registered as Members, in order to explore why that might be. We apologise to any existing Members who may have received this survey in error. Sometimes the gremlins get into the system and re-enter the same person twice with a slightly different spelling or name abbreviation! If you would like to check your membership status and your database record please email membership@nras.org.uk or call 0845 458 3969 and we'll be happy to help.

The survey was sent out in January 2015 and we summarise some of the key results here. 36% of the 143 people who had let their Membership lapse had done so as they no longer could afford the £20 annual membership fee. A reduced membership of £10 is available to those on income support and some other benefits. We do understand that priorities have to be made in the current economic climate and so we have taken your concerns on board and will be reviewing the cost of membership during 2015.

17% of people who used to be Members told us they had "just forgotten" to renew and many have now rejoined which is great news. A further 23.5% of those who had never joined said they had intended to but "had just not got around to it".

The lack of local activity was the next biggest reason for not joining NRAS, so to address this issue we would like to ask that all NRAS Members consider how they might be able to engage with any suitable local health events, even if it's just on a once a year basis, to raise the profile of RA and NRAS. For example, does your local medical centre have a health awareness event or perhaps your local HealthWatch may have a public health event - could you man a stand to represent your society? It is also possible to have simple information stands in hospitals on occasions, so perhaps you could ask your Nurse Specialist next time you're in clinic if this is something they would consider. The good news is that NRAS has plans to launch new groups this year and will reach an amazing 50 groups across the UK, by summer 2015, so even though there may not be a group in your area just yet, doesn't mean there won't be in the future! Perhaps you would like to find out more about how groups are established and how you, working with other Members in your area, might be able to help get an NRAS group in your town. To find out more about groups contact Gill or Kim at volunteers@nras.org.uk.

We ask all NRAS Members to spread the word to others with RA about the benefits of joining NRAS – keeping up to date with latest developments in treatments and living with RA: being inspired by others: having the opportunity to influence and shape the future of rheumatology through interaction with our campaigns, events and surveys and being supported to self-manage better in different ways. However, an equally important reason to join NRAS is that by benefitting as a member yourself, you also support the society to continue to grow which means we can support thousands more across the UK living with RA. We've just reached 5,000 Members which is fantastic but with 690,000 people living with RA in the UK we need to grow that figure substantially to be able take on the challenges of the next decade.

Even though only 5 people said they had left NRAS because of negative interactions on the NRAS Members' forum there is a lesson for us all to be mindful of how interactions on all online forums and social media can sometimes have perhaps unintended consequences and can negatively impact on other individuals and this can in turn affect the reputation of the organisation and others within the online community.

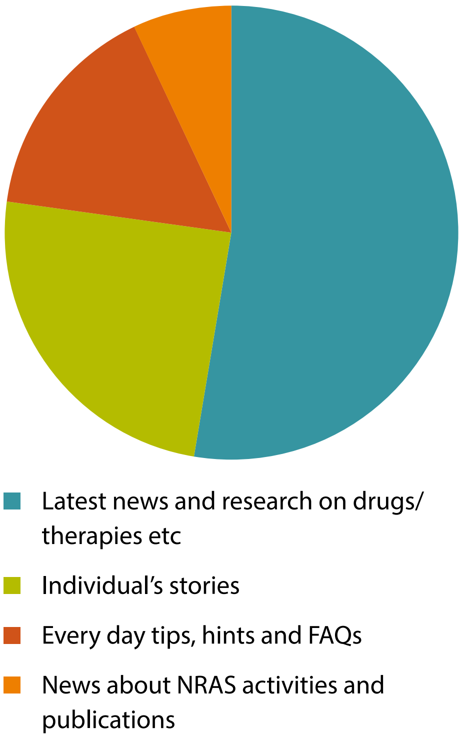
We asked if being a "Member" had any implied commitment or if being called a "Friend" or "Supporter" would make any difference. Interestingly the majority did not have any preference around the name "Member" and while 38% did feel membership implied a commitment to action an equal number neither agreed nor disagreed with that statement. So the conclusion is that we will retain the "Membership" scheme and will endeavour to offer greater engagement in activities to those who wish to be more active and find a way of indentifying those who wish only to subscribe to the magazine and support the society from afar, this way ensuring all NRAS Members are contacted in the most appropriate way. This won't be easy but we are working on it so please bear with us.

Health Professional's Survey

NRAS exists for all within the Rheumatology World...patients, families, consultants, nurses, allied health professionals, commissioners and the public. With over 1000 NRAS Health Professional Members we wanted to know if the society is meeting your needs too. Thank you to all who took the time out of their busy schedules to complete the online survey. One thing that was immediately apparent from trying to reach all our wonderful NHS colleagues is that email addresses have changed or have not been shared with us so our first plea to all rheumatology health professionals is please email your up to date email address today to emma@nras.org.uk. You will be missing out on important information and opportunities for you and your patients if we are unable to contact you by email.

32% of health professional respondents said they received the magazine into their departments rather than as an individual – if you would like to receive the magazine directly to you please just let us know as 96% of health care professionals told us they find the NRAS magazine 'very' or 'somewhat useful' to them as a health professional, with 82% saying the magazine was 'very useful for their patients'.

What health professionals find most useful in the NRAS magazine was clearly the update on research, drug advancements and treatment studies.



What would health professionals like to see more of in the magazine?

30% said more information about self management techniques e.g. joint protection, exercise, fatigue management. You can help us to provide more of this type information by showcasing your work - do you have a good example of any work/research within your unit that you think would make a good feature article for a future edition of the magazine? If yes please email enquiries@nras.org.uk.

NRAS Publications

It was gratifying to learn that almost 72% of health professional respondents said they use NRAS publications in their clinics and most order the booklets via the NRAS website ordering facility.

There is a clear demand for a publication on fatigue again (the current one being only available as a download) and you will be pleased to know it is on our schedule of NRAS work for the near future. Many units were unaware of the "Newly Diagnosed" A5 packs that NRAS make available, these include the NRAS Newly Diagnosed booklet, NRAS Helpline contact details, "10 Healthcare Essentials for RA" and any local information as appropriate. If your unit would like a sample pack or would like to order in bulk just call 0845 458 3969 or email enquiries@nras.org.uk.

It was interesting to realise how important it is that NRAS continue to supply these valuable information resources free of charge to hospitals as 53% respondents told us they have no patient education fund and a further 39% did not know if the rheumatology department had such a budget. So how can NRAS continue to supply such vital information to those who need it? Only with ongoing support from YOU. every penny spent on publications, patient and health professionals' resources etc. has to be raised by NRAS.

Ask yourself if your rheumatology team can take part in an NRAS fundraiser? We have something for everyone from skydiving to baking cakes. Recycling your old jewellery to swimming the channel! Every penny counts. 55% of HCP respondents had never made a donation to NRAS – can you change that today?

48% of respondents were involved with an NRAS group which is fantastic and NRAS has already started a waiting list of other units wishing to establish an NRAS patient group in their area.

Finally some comments from HCPS:

> *"Your work is excellent and supports our patients. I encourage my patients to join"*
>
> *"NRAS is an amazing resource for both patients and practitioners...keep up the good work and the fantastic progress."*
>
> *"Thank you, you are doing a great job and have been of massive benefit to large numbers of our patients as they come to terms with this lifelong condition... thanks!"*
>
> *"I feel that NRAS is a first rate organisation and an ideal partner in developing and delivering services for patients with inflammatory arthritis"*

NRAS couldn't do it without YOU!

NRAS is very fortunate to have a great group of fundraisers who, come hail or shine, take on all sorts of challenges for NRAS - they put NRAS first! Here are the stories of just a few of them.

Super Sam Lucking has been fundraising for us for several years now. His fundraising has included a tandem skydive, half marathon, bungee jump, London Marathon and most recently the Total Warrior Challenge – an impressive list!

The reason behind Sam's inspiration is his stepfather Lee who was diagnosed with RA in 2001. Lee lived with RA for two years until sadly he passed away when Sam was only sixteen. Lee had a massive impact on Sam's life; he helped him to achieve his ambitions and still does. Thank you Sam for all you do for NRAS, it means a great deal to so many.

Super Sam

Running Richard Evans has been fundraising for NRAS for the past 3 years with his passion being running. In 2012 while Richard was training for his first Snowdonia Marathon, he found out that his Mum had been given a diagnosis of RA. He knew a little about the disease, as his grandmother had also lived with RA, but he wanted to know more. After much searching on the internet to see what support was available it was in his words "a no brainer" for him to raise funds for NRAS.

With three Snowdonia marathons under his belt, another bucket list ambition was to take part in the London Marathon: this year he will be able to tick this off his list as he will be running for NRAS on the 26th April. He has also organised a charity football match to raise funds to go towards his sponsorship of the marathon. Richard has raised to date almost £3,000 for NRAS. Keep up the good work Richard and good luck in the marathon!

Running Richard

Amazing Alan Clarke is a very loyal NRAS supporter who year in year out takes part in The Great Eastern Run; slightly less well known than the Great North Run but still a challenging half marathon distance in Peterborough. Alan has been taking part in this event now for five years and over time it has grown into a real family affair! In 2014 Alan was joined by his two daughters, Cara and Natasha, and his son-in-law Daniel. They even had a little cheerleader in the form of his granddaughter, Leah! The money raised is in memory of Alan's mother who lived with RA. Thank you to all the Courageous Clarke Family for raising over £700 for NRAS.

Amazing Alan

Heroic Helly Berger has been an NRAS Member since 2004 and has thrown herself wholeheartedly into fundraising for the charity. She braved the skies and took part in a tandem skydive in 2011, and as if that wasn't enough she decided she would like to be pushed around the streets of Newcastle in her wheelchair at the Great North Run in 2012, 2013 and 2014! Helly says that the Great North Run is no ordinary half marathon. Last year she was joined by Dr Chris Deighton, dressed as the pub landlord, and Helly was his buxom barmaid! The previous year they each chose their favourite super hero to dress up as – definitely going above and beyond for NRAS!

Helly has raised over £1,600 for the society and we are expecting great things in 2015!

Heroic Helly

Marvellous Martin Hoare has been fundraising for NRAS for over three years, first taking on the Brighton Marathon in 2012 and more recently the 2014 Ride London 100 Mile Cycle Ride.

Oli, NRAS Fundraising Manager, is Martin's son, which explains why he doesn't get off lightly, but it was after hearing about the impacts of living with RA on everyday life that Martin decided to do something to help the thousands of people with RA by supporting NRAS. Not only has he raised over £7,500, but it has been life changing for Martin and has turned him into a bit of a sports nut! Martin is saddling up for the Ride London again this year and we wish him all the very best.

Marvellous Martin (Left)

Helpful Helen Wilkinson & Lovely Laura Mitchell have both been running for NRAS for many years. Helen ran the Great North Run and the Great Scottish Run in 2011, the London Marathon in 2012 and this year will be taking part in the Brighton Marathon for NRAS! Helen's mum is an Occupational Therapist, specialising in caring for patients with RA and knows how devastating a diagnosis of RA can be.

Laura ran the Asics 10k in 2011, the Royal Parks Half Marathon in 2012 and the London Marathon in 2014 and will again be donning the NRAS t-shirt as she pounds the streets of London this year. Anyone who knows Laura is aware running doesn't come easily for her, her inspiration is her mum who has battled RA for nearly 25 years.

I think you will agree Helen and Laura have certainly gone that extra mile, between them they have raised over £3,000 for the charity. Thank you Helen and Laura, for all your dedication and support for the cause!

Helpful Helen and Lovely Laura

These are just a few of the many magnificent, wonderful supporters who come back time and time again to raise funds for NRAS and awareness of the disease. There are so many more of you out there doing marvellous, heroic, epic feats of endurance as well as those doing less scary fundraising activities. NRAS wants to thank each and everyone of you for all your hard work - NRAS couldn't do it without you!

Feel like taking on a run for NRAS? Visit our website at http://www.nras.org.uk/runs or email fundraising@nras.org.uk.

Chapel-en-le-Frith Golf Club 'putts' NRAS on the map!

We are most grateful for the generosity of the 2014 Captains (Mrs J Brightmore and Mr T Hesketh) of Chapel-en-le-Frith Golf Club who supported NRAS as one of the their three chosen charities throughout their captaincies, raising a fantastic £1,135 for NRAS.

Funds were raised by raffles, social events such as race nights and a Clarins beauty evening hosted in the fantastic course grounds, which are nestled in the valley between Whaley Bridge and Chapel-en-le-Frith, and built on gently rolling parkland surrounded by the magnificent scenery of the Peak District.

Thanks also to Mrs Hazel Sargeant, NRAS Member and Group Coordinator, for accepting the cheque on behalf of NRAS from the two Captains.

Chapel-en-le-Frith Golf Club

Congratulations to Kate Viner, our second £1,000 lottery winner!

"I was absolutely delighted to win the lottery and it couldn't have come at a better time for me. The cold winter has played havoc with my RA, and with my £1,000 win I was able to afford a family holiday in Spain. The warmer weather has really helped my symptoms and I am feeling so much healthier now. Thank you NRAS!"

Playing the NRAS lottery couldn't be simpler! It costs just £1 per week with 50p going directly to NRAS. The weekly draw takes place every Saturday with prizes from £5 to £25,000. For more information on how to join the NRAS lottery contact Keren Otto on Keren@nras.org.uk or call 01628 823524, alternatively please visit www.nras.org.uk/nras-lottery.

Kate Viner on the right

Commemorate the life of your loved one with an NRAS Cherry Blossom Tribute Fund

NRAS are pleased to announce the launch of the new online Cherry Blossom Tribute Fund which can be viewed at http://tributes.nras.org.uk. An NRAS Tribute Fund is a special and lasting way to commemorate and celebrate the life of a loved one, whilst helping to support those living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) in the UK.

Cherry Blossom Tribute Fund Website

Working in partnership with a not for profit organisation called MuchLoved, NRAS can help you create a beautiful, personalised, online memorial which you can use to share photos, videos, messages, or light a candle and capture a memory. The candles can burn from a day to a 100 years and friends, family and anyone from around the world can leave messages of remembrance and condolence, making this one of the most comforting and positive ways to help cope with the pain of losing someone special. These messages will last forever and keep your loved one's memory alive.

Kaye sadly lost her mother, Jean, due to complications arising from RA. She and her family set up an NRAS Tribute Fund in her name, and found this to be of great comfort to them. Kaye said, "My Mum suffered with RA for many years, but she never complained. It was complications from the disease that prematurely took her from us in 2008. When she passed away I looked for something to give to in her memory. I contacted NRAS who have been so helpful and supportive and I really do feel they understand how we feel. My Mum's Tribute Fund with NRAS has not only been a comfort to us but has also given us a channel to think of her and help others. We will continue to support this wonderful charity and think of Mum."

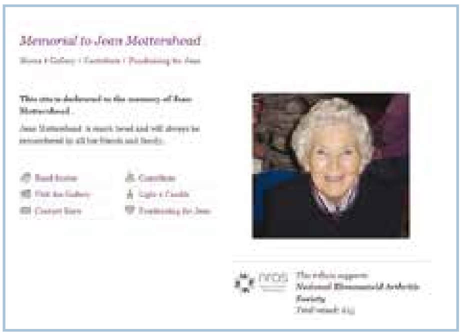
Jean & Family

Kaye's two children, Ben and Ruth, have also raised money for their Grandma's fund.

"Grandma's Tribute Fund has meant we can do things for her, and although she isn't here to enjoy them with us, it has allowed us an outlet of remembrance and we can help others at the same time."

Jean and Ben

Like Kaye, many people have chosen to honour the life of their loved one by making a donation to NRAS in their memory and with a tribute fund all current and future donations made by you, family and friends can be attributed to the fund in their name. Once started, your Tribute Fund will last forever, helping to keep your loved one's memory alive while continuing to support those who need NRAS' support the most.



Tribute Fund

To find out more about setting up a Tribute please visit http://tributes.nras.org.uk. Alternatively please contact Keren in the fundraising team on 01628 823 524 or email Keren@nras.org.uk.

Brighton Marathon

A huge thank you to all the NRAS runners who took part in this year's Brighton Marathon on the 12th April, raising needed funds for NRAS.

Val and Bronwen, from our fundraising team, were on hand to cheer them over the finish line as they completed the 26 mile route along the sea front. A great day was had by all... will you fly the flag for NRAS next year?

NRAS is in SAFE hands with Professional Security Magazine

In January, NRAS were delighted to be invited to the Gala Dinner of the Midlands Security Twenty 15 Conference and Exhibition. NRAS, chosen as the charity beneficiary for the evening, was nominated by Stella Lewis, Business Researcher for Winsted Control Room Solutions, who has been an exhibitor for a number of years. Stella's husband has RA and she wanted to use the opportunity to raise awareness of RA and the work NRAS does, having accessed many of our resources:

"My husband Martin has had RA for 5 years and although it is painful and he occasionally feels quite ill, he goes to the gym regularly and plays golf at weekends. Sport is in his blood, but since being diagnosed I would say that this continuation of exercise has helped immensely. His medication is a combination primarily of methotrexate and Humira injections and the support and information from NRAS on his medications and the importance of exercise has been invaluable."

Oli received a warm welcome on the evening as well as a cheque for £1,800 towards our work. Special thanks indeed to Stella for nominating NRAS and to Roy and Liz, from the magazine, for all their support.

Oli sincerly thanking Roy on behalf of NRAS as the big cheque changes hands!

Textile recycling banks; can you help us find some suitable locations?

Recycling has proved a vital way to help raise much needed funds for NRAS and we are hoping to expand our clothes fundraising by setting up textile recycling banks up and down the country. However we need your help. Do you know of any businesses that would be happy to accommodate one of the NRAS textile recycling bins in their grounds e.g. car park?

Please contact Keren@nras.org.uk or call 01628 823524 for more information. Thank you for your help!

Clothes recycling

Donate to NRAS via text!

Can you spare just £3 to help support our vital services? Everything you see in this magazine is funded by voluntary donations, the more we raise, the more we can do, and will make a real difference to those living with RA and JIA.

Text NRAS to 70660 to donate £3

nras National Rheumatoid Arthritis Society

Thank you for your support!

'Dream Team' take to the streets of Newcastle for NRAS

On the 13th September Ailsa will once again join the NRAS team of runners taking part in this year's Great North Run. She will be joined by Dr Chris Deighton and Professor David Scott, both NRAS Medical Advisors.

Chris and David are no strangers to the run; Chris has taken part for the last 4 years and when asked why he runs year after year he said:

"Most importantly because I want to raise money for a brilliant cause, by pushing someone in a wheelchair you certainly raise the profile of NRAS. It also means we don't have to run, the team walk a little, jog a little and then walk again!

It's great fun taking part in this race. The Geordies turn out in their droves, regardless of the weather, and line the streets offering us cash (they also offer sweets, biscuits and bottles of Newcastle Brown!). This is the only half marathon you can compete in and put weight on! Last year the team (with Helly, NRAS Member) in her wheelchair were interviewed by Radio Tyneside. When asked whether we were aiming for a finish time I said that we would like to be finished by Wednesday, the race was on Sunday!

We dress up to demonstrate to the crowds that we aren't athletes and don't take ourselves seriously, whether it be pub landlord or super hero! Maybe we'll be just normal this year and dressed for the weather instead!"

The highlight for Chris is the final hill at the end of the race where you see the sand and sea at South Shields. The steep hill downwards towards the final straight is a challenge – the team of pushers have to make sure they are holding onto Ailsa's wheelchair properly as they don't want her and her wheelchair ending up at the bottom a lot sooner than the rest of the team!

David is also no stranger to the run, having taken part with Ailsa in 2009, wearing fairy wings and waving his wand!

Ailsa and David Scott (on left) - GNR

As our Chief Medical Advisor and long standing supporter of NRAS for 15 years, David thinks NRAS is a fantastic charity, with those living with the condition at the heart of it.

David has huge respect and admiration for Ailsa and all she has accomplished with the charity. Her successful lobbying, the recognition she has quite rightly achieved for RA and most importantly her passion, it never wavers.

This will be David's 15th Great North Run, he says, *"each year I get a little slower and a little older!"* David didn't hesitate when asked if he would consider being part of the 'dream team', even though he knew dressing up would be involved!

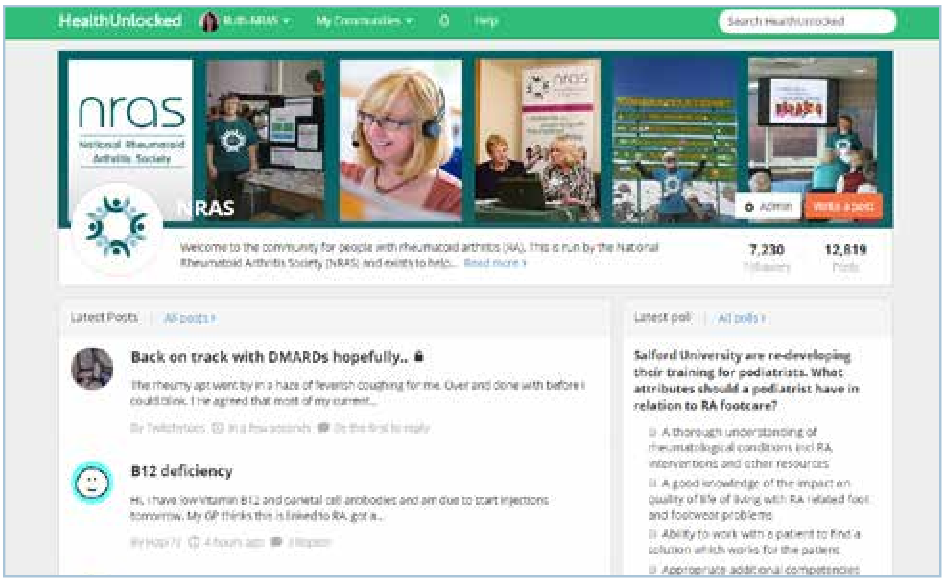
Ailsa has categorically made it clear this will be her last year taking part. It will be particularly challenging and gruelling for Ailsa especially if the weather doesn't behave, as her RA has not been well controlled for quite some time but she is determined to brave the elements one more time. Please do consider sponsoring the "Dream Team".

If you would like to sponsor the dream team please visit their Justgiving page at https://www.justgiving.com/GNRDreamteam. If you would like to join the team on the day and run for NRAS we would love to have you. Email fundraising@nras.org.uk or give Val, our Events Fundraiser, a call on 01628 501547.

Chris, Dean and Donna at 2014 GNR

Help is just a touch of a keyboard away!

The impact of the NRAS HealthUnlocked Online Community



Welcome to the community for people with rheumatoid arthritis (RA). This is run by the National Rheumatoid Arthritis Society (NRAS) and exists to help... Read more ›

7,230 Followers

12,819 Posts

Latest Posts | All posts ›

Back on track with DMARDs hopefully..

The rheumy apt went by in a haze of feverish coughing for me. Over and done with before I could blink. I He agreed that most of my current...

B12 deficiency

Hi, I have low Vitamin B12 and parietal cell antibodies and am due to start injections tomorrow. My GP thinks this is linked to RA, got a...

Latest poll | All polls ›

Salford University are re-developing their training for podiatrists. What attributes should a podiatrist have in relation to RA footcare?

- ☐ A thorough understanding of rheumatological conditions incl RA, interventions and other resources
- ☐ A good knowledge of the impact on quality of life of living with RA related foot and footwear problems
- ☐ Ability to work with a patient to find a solution which works for the patient
- ☐ Appropriate additional competencies

Online forum research

Dr Tessa Sanderson of Durham University and Associate Professor Jo Angouri of Warwick University have been invited to study the impact of the NRAS HealthUnlocked community. They found that the forum provides the online community with a valuable resource for sharing information, personal experiences on living with rheumatoid arthritis (RA) as well as finding peer support. Tessa says, *"Our work has shown how important online forums are for supporting people living with long term conditions. The more we understand the needs of the participants the more we can improve them."* Access to the data was granted on condition that usernames were anonymised and users had the option to opt out of having their posts analysed.

Tessa and Jo focused on threads posted by newly diagnosed patients. Their findings provide evidence that the forum is a unique space for developing skills in coping with RA and for increasing confidence; the need for information and support is crucial in those early days of being diagnosed and those with experience with the condition use the online community to share their knowledge, to provide empathy, reassurance, practical advice, as well as signposting to other appropriate support. This makes the online community a point of reference for the users and the active engagement of the participants indicates that the space has covered a significant gap in the management of the individual's RA. *"The users are supported in the process of coming to terms with a diagnosis of RA and in establishing rapport with a buzzing and knowledgeable community of peers,"* says Jo. The existing users welcome the 'newbie' into their 'club' and introduce them to social events and activities that go beyond sharing information about the condition. Long term users of the forum clearly value the wealth of information and support within the community but also protect the new Members from being overwhelmed by the amount of information that is available: a "take it at your own pace" is advised. The importance of taking prescribed medications, whilst acknowledging the anxieties that people will naturally have about the potential side effects, is a common topic of discussion.

While the community is actively engaged and users' posts are always responded to, some topics are more emotive for existing users than others; for example, new mums posting about being newly diagnosed whilst caring for a young baby typically received a large number of responses which indicates the community's empathy and willingness to help. Replies commonly provide both emotional support and reassurance that life will get easier, *"to hang in there".* The following quote nicely illustrates this:

> *"I just wanted you to know that there are those of us out there that have been in similar situations to you [new mum] and have come out the other side. Sending you a massive hug x"* Louise (Authors' emphasis)

New users typically make it clear that they have limited knowledge about RA and this allows experienced community members to share their considerable expertise about the condition. Newly diagnosed posts commonly include a description of the person's journey to diagnosis, initial treatment, emotions experienced, unfamiliarity with jargon, and a specific request for help such as this one:

> *"Sorry, last question, coping with my baby? Now she is getting heavy I worry that when my steroids wear off how on earth can I lift her, when she starts crawling, what if I can't keep up?" Teresa*

The NRAS HealthUnlocked online community is moderated and evidence-linked, to ensure that information about medication, doses and the relationship with the health care system are correct. This is important for the forum's 'trust-ability', to ensure that information is in line with current policy and practice, and to avoid misinformation being propagated. The research shows that an online community is one of many social spaces that a person may be part of and may be more important at certain times than others. One user commented that, *"people who are doing well tend not to post because they don't need to."*

Clearly, NRAS would like these researchers to do more research on the impact of online support mechanisms, particularly as Jo says *"This research just looked at the tip of the iceberg, there is so much valuable work that could be carried out by conducting a bigger project on this online RA forum, to support online communities across other health conditions and inform the Department of Health's Patient Information System initiative."*

Review of a new range of footwear for women with rheumatoid arthritis

There is a growing number of women with RA experiencing increasing difficulty in finding stylish, comfortable footwear due to foot problems. Joint damage and articular changes to the joint structure are the two main causes of shoe induced foot pain, requiring wider fitting shoes to accommodate the broadening forefoot.

Women with shoe fitting problems due to forefoot pathology often seek medical intervention. If a surgical correction option is not available, extra wide footwear is prescribed. However, there are difficulties with the aesthetics and wearer acceptance of this prescribed footwear.

In a study by Williams, Rome and Nester (2006), 80 patients were recruited for footwear provision and assessment of compliance. Ten patients refused the footwear outright with a further 34 patients withdrawing from the trial. This trial indicates the challenge faced by footwear designers and manufacturers in that, footwear that is designed to fit the foot is often rejected as being too big, too bulky and too ugly. Quite rightly, women reject this footwear even when it is provided and rely on retail shoes which may not accommodate the feet well and are often detrimental to foot health.

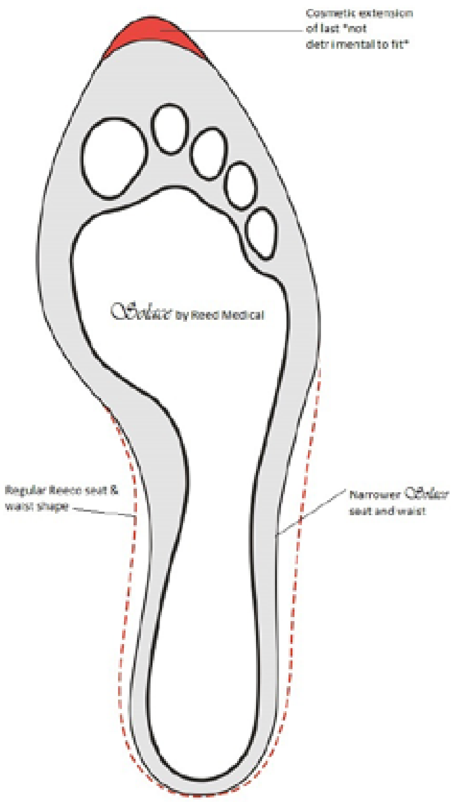
Reed Medical have worked with women with rheumatoid arthritis in order to develop their new footwear range. The issue with women's footwear is the conflict between the shape of the foot and the shape of the shoe. Incompatible shoe/foot shapes create pressure on joints and increased levels of discomfort. The shape of the shoe is dependent on the shape of the last (a metal, wood or plastic form used to create the shape of a shoe). The Solace last has been modified to increase levels of comfort.

With intelligent aesthetic last design the Solace range of shoes maintain the width needed across the joints (with an extension in the toe area which is purely cosmetic). That is, the toes are positioned in the wider part with a small gap at the front. Also, the heel area and the 'waist' of the shoe is narrower in order to hold the foot securely. Due to the fact that 90% of RA foot problems are in the forefoot, this allows for a narrow seat and waist enabling the design of a more appealing shoe. New lightweight and ultrasoft leathers have been used in 7 stylish pearlised finishes, 5 muted satin finish leathers and silver splashed suede teamed with gold and silvers to create feminine styling. They have an extended opening for comfort and ease of donning, strong heel stiffeners for a secure hold and superplush anti-bacterial foam backed lining. The Solace accommodates the inclusion of an insole to provide cushioning and pressure reduction under the metatarsal heads. The cushioning is required to compensate for the degradation of the met joint tissues and alleviate the feeling of 'walking on marbles'. These are all features that can contribute to comfort and potentially improved foot health. The important aspect of these shoes is the 'marriage' between comfort, foot health and fashion.

These shoes are certainly worth a try – if you are seeing an orthotist for hospital footwear ask about being measured for these shoes.

For more information about the shoes and how to find a supplier contact

Reed Medical Ltd
Thwaites Close
Shadsworth Business Park
Blackburn, Lancashire
United Kingdom BB1 2QQ
Tel: 01254 503333
Email: admin@reedmedical.co.uk



Solace intelligent design

Rheumatoid Arthritis Awareness Week 2015

Once again NRAS will be trying to raise the profile of rheumatoid arthritis in the UK by hosting our annual Awareness Week from 15th – 21st June – save those dates!

This year's theme is around that of self-management and taking control of your disease. At the time of writing, the campaign is still in development so keep an eye out in the Members' e-news and www.nras.org.uk/RAweek for updates on what NRAS will be doing and how you can get involved.

As usual we'll need your help to make a bigger noise, so please get involved in any way you can!

Here's a few things you can do to help:

Get Social

The easiest way you can raise awareness is to spread the word online and join the conversation on Facebook and Twitter. Social media is a simple and effective way of spreading the message far and wide so please do get involved leading up to, and during, the week.

Thanks to NRAS followers sharing posts during last year's campaign, we managed to reach 208,557 people on Facebook alone, so we need your help to spread the message even further in 2015!

Plan an Event

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

RA
Awareness Week

Rheumatoid Arthritis
Awareness Week

15th – 21st June – save those dates!

You can also request to hold an information stand in your GP surgery, pharmacy or rheumatology unit to raise awareness of RA and share NRAS materials to patients and healthcare professionals. If you are interested in hosting a stand, please call 01628 823524.

NRAS Tea Party Pack

Wear your NRAS Wristband

Start a conversation about RA through wearing an NRAS wristband or other merchandise. It's a simple way of raising awareness and you may meet others in your community with RA who want to help.

You can purchase an NRAS wristband and other merchandise on the NRAS online shop at www.nras.org.uk/shop

Biomarker may predict heart attack risk in patients using arthritis drugs

A group of drugs that lost favour because of fears over their possible side effects in some patients may find use again in treating arthritis. A possible way of predicting which patients should avoid using these drugs is being developed.

Non-steroidal anti-inflammatory drugs (NSAIDs) are often used in the treatment of inflammatory conditions such as arthritis as well as being used for general pain relief. These include many very familiar drugs such as ibuprofen, diclofenac and aspirin.

However, some NSAIDs can cause stomach ulcers in some instances. To try to alleviate this side effect the COX-2 inhibitors were developed in the 1990s, including Vioxx and Celebrex. However, after these drugs were linked to an increased risk of heart attacks, their use decreased and some of them were withdrawn altogether.

A new study led by Imperial College London has investigated how these drugs increase the risk of heart attack in some people.

Professor Jane Mitchell, from the National Heart and Lung Institute at Imperial and Dr James Leiper led the study using mice and human volunteers. Professor Mitchell said, “Although the majority of arthritis sufferers could safely use the COX-2 inhibitors, the fear of heart attacks has left some patients confused and worried about their medication and GPs nervous about prescribing them. This problem is made worse by the fact that we know that most NSAIDs, not just COX-2 selective drugs carry a similar risk of heart attacks in some patients.

“If we could identify which people have an increased risk, these patients could be offered more appropriate treatments and we can start to look at ways of reducing or averting the risk entirely.”

NSAIDs work by preventing the production of pro-inflammatory prostaglandins – the chemical messengers in tissues and joints some of which can trigger pain and inflammation. Prostaglandins are produced by 2 different enzymes known as COX-1 and COX-2 which are found at sites of inflammation.

The study, funded by the Wellcome Trust, The British Heart Foundation and the Medical Research Council (MRC), found that knocking out COX-2 caused changes in three genes in the kidneys of mice, which predicted the rise in levels of a molecule linked to cardiovascular disease. This molecule, ADMA, was found by researchers in subsequent tests to increase in mice and human volunteers when taking NSAIDs. ADMA interferes with the normal function of an amino acid called L-arginine, which plays a key role in protecting the heart’s health.

Dr Leiper, from the MRC Clinical Sciences Centre at Imperial, said, “ADMA is an independent risk factor for cardiovascular disease. In people increases of ADMA similar to those we found are linked with significant increases in cardiovascular disease and death. Our discovery that COX-2 inhibitors raise ADMA levels provides a plausible mechanism for the increased cardiovascular risk associated with these drugs and provides insight into how the risks might be mitigated”

Professor Mitchell thinks that higher ADMA levels might work as an indicator of who may be at increased risk of a heart attack and said “If we are right then ADMA could be used as a biomarker in a simple blood test to identify who may be at risk. Regular screening by GPs would allow them to ensure that these levels remain within safe limits whilst taking the drugs.”

New 3D-printed implant to replace the knee’s protective lining

The meniscus is the knee’s protective lining. At present, torn meniscus injuries are very difficult to treat. Small tears can be sewn up but when the damage is substantial, the meniscus often has to be removed surgically. Whilst this may reduce the pain and swelling, it leaves the knee without shock absorption between the femur and tibia.

A new type of personalised implant could be used to replace the meniscus. Columbia University Medical Centre have found a way of using a 3D printed implant or scaffold infused with human growth factors to prompt the body to regenerate this lining on its own.

A magnetic resonance imaging (MRI) scan of the intact meniscus in the undamaged knee is transformed into a 3D image. This can be printed out in 30 minutes in exact detail.

The scaffold is made of polycaprolactone, a biodegradable polymer that is also used to make surgical sutures. It is infused with two recombinant human proteins that can attract existing stem cells from the body and induce them to form meniscal tissue.

This process has been successfully applied in sheep, the knees of which closely resemble those of humans. Animals that have undergone this process were walking normally again after 3 months.

Dr Jeremy Mao, Edwin S Robinson Professor of Dentistry (in orthopeadic surgery) at Columbia University Medical Centre said, “This is a departure from classic tissue engineering, in which stem cells are harvested from the body, manipulated in the lab and then returned to the patient. This approach has met with limited success. In contrast, we are jump starting the process within the body, using factors that promote internally derived stem cells for tissue regeneration.”

Do recent infections affect the risk of rheumatoid arthritis (RA)?

A recent Swedish study of people with RA and healthy controls was conducted to determine if recent infections can affect the risk of RA. The researchers investigated the effect of several types of infection including gastroenteritis, urinary tract infection, genital infection, prostatitis, sinusitis, tonsillitis and pneumonia, in the 2 years before the study started. They found that the people who had infections in the gastrointestinal and urogenital tract before symptoms of RA were identified, were associated with a lowered risk of RA.

In contrast, in those who had sinusitis, tonsillitis or pneumonia, no difference in risk was found.

The researchers concluded that gastrointestinal and urogenital infections, but not respiratory infections, are associated with a significantly lowered risk of RA. Their results indicate that infections in general do not affect the risk for RA, but that certain infections, hypothetically associated with changes in the gut microbiome (important microorganisms in the body that help to keep us healthy), could lessen the risk.

Depression in patients with RA linked to low therapy concordance.

Researchers have found that people who have rheumatoid arthritis who are concordant with their treatment (meaning that they have agreed and follow a shared-care agreement between themselves and their clinician about therapy) experience less major depressive events than those who are not concordant.

73 patients with RA were studied at a centre for rheumatic diseases in Mexico City. Treatment groups included patients receiving steroids and DMARDs in varying combinations. 77% were considered to be in agreement with their therapy. This concordance was measured by a locally designed questionnaire that asked questions about therapy compliance (the degree to which a patient correctly follows medical advice).

Each study participant completed the Beck Depression Inventory (BDI) (one of the most widely used assessment tools for measuring severity of depression).

Using these results it was found that 24 patients (30.8%) had major depressive events. Forty one patients (53%) had clinically important depressive symptoms. Patients who were non-concordant with therapy had severe or moderate depression more frequently than their counterparts.

The conclusion of this study was that patients who were concordant with treatment were less frequently diagnosed with major depressive events, had lower BDI scores and a better quality of life.

Join the nras LOTTERY

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!

New JIA website!

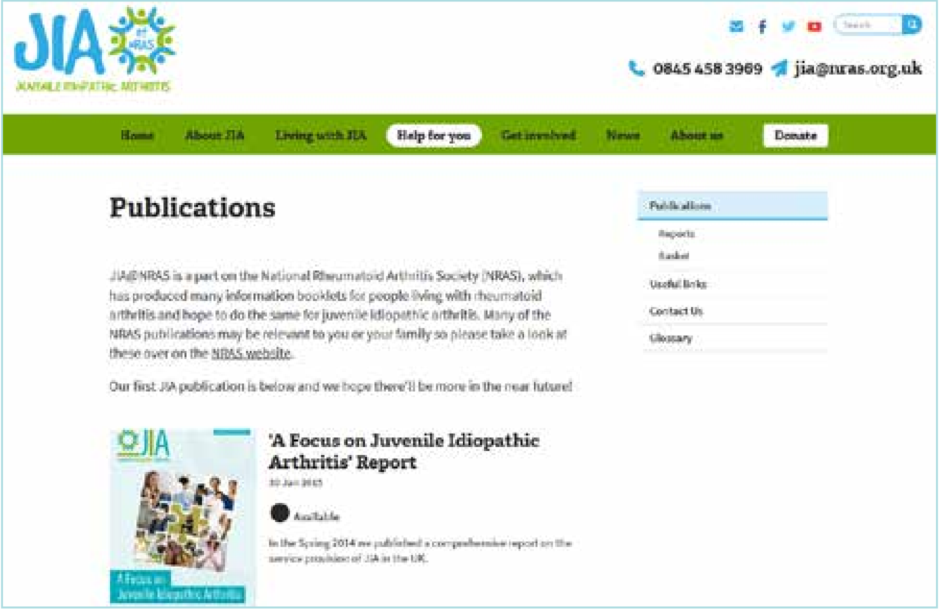
In February, we were excited to announce the launch of our new JIA@NRAS website for parents and families of children and young people with Juvenile Idiopathic Arthritis (JIA), as well as for health professionals involved in the care of young people with JIA.

The information on the new website is Information Standard accredited and covers a wide range of topics from getting a diagnosis and understanding how to negotiate the NHS in order to get the right care for a child/young person, to living with JIA and the personal stories of young people and their families. Thank you to everyone who has contributed and we look forward to hearing from more of you in the future.

Ailsa Bosworth said, *"Our aim is to provide parents, families, young people and health professionals with the best and most up to date resource in the UK on all aspects of JIA from a family/patient perspective. Getting to a diagnosis is often a difficult and sometimes traumatic process for parents and we hope that this website will help parents who are concerned about their child, to get the right help more rapidly. We will link to other organisations and charities who provide relevant sources of help and support so that everything a parent could want to know is in one place."*

The launch of this website is in response to requests for such a resource from parents, families, young people, health professionals and NHS Managers who were interviewed for our 'A Focus on JIA' Report which was published at the end of 2013.

Dr Clarissa Pilkington, President of the British Society for Paediatric and Adolescent Rheumatology (BSPAR), said of the work, *"We are very pleased NRAS is launching its new website for families in the UK who are living with Juvenile Idiopathic Arthritis (JIA). This new service is very much wanted and needed by families and health professionals alike. The reputation of NRAS is well established in the adult rheumatoid arthritis community and is synonymous with empowering, educating and improving people's lives as well as campaigning on behalf of those affected by rheumatoid arthritis. We believe they have the knowledge and expertise to successfully support families, children and young people affected by JIA and look forward to working with them on the service."*



Publications

JIA@NRAS is a part on the National Rheumatoid Arthritis Society (NRAS), which has produced many information booklets for people living with rheumatoid arthritis and hope to do the same for juvenile idiopathic arthritis. Many of the NRAS publications may be relevant to you or your family so please take a look at these over on the NRAS website.

Our first JIA publication is below and we hope there'll be more in the near future!

'A Focus on Juvenile Idiopathic Arthritis' Report

● Available

In the Spring 2014 we published a comprehensive report on the service provision of JIA in the UK.

New JIA website

Clare Jacklin, NRAS Director of External Affairs said, *"We will continue to build this resource, providing important articles, case studies and information about 'living with JIA', during the course of 2015 and invite families and young people who wish to get involved, to support this work."*

You can visit the new website at **www.jia.org.uk**

We'd love to hear what you think about the new website and any suggestions you'd like to make for further content. Please email us at jia@nras.org.uk if you'd like to get involved.

Other news

We said farewell to our JIA Service Manager, Maria-Benedicta Edwards at the end of February and at the time of writing, we are recruiting for a new Youth & Families Services Manager to help us develop the service further.

Our JIA family day is once again in the pipeline so save the date, Saturday July 18th! This will be an opportunity for children, teenagers and family members to attend a free event which is set to be a fun afternoon for all the family, where children can take part in all sorts of exciting activities, and parents have the opportunity to 'Ask the Professionals'.

Email your interest for the event to jia@nras.org.uk. You can also sign up for JIA e-news updates at www.jia.org.uk/newsletter

Dear Helpline...

I have been out of work for the last 2 years while I have been trying to get my RA under control and as I am now feeling much better, I would like to go back to work. I could really do with some advice and support as I have lost confidence and don't know whom to turn to for help.

Contemplating going back to work after a period of ill health can be quite daunting but there is help available. A good starting point is the Disability Employment Advisor (DEA) at your local Jobcentre who can help you find a job or gain new skills. The DEA can also tell you about the programmes, grants and other opportunities that are available to help you get back into work. These include:

- **Work Choice** – to help you find a job, build your confidence, develop your skills and get support when you start work
- **Residential Training** – to give you work experience and training
- **Access to Work** – money towards a support worker or for the cost of equipment or travelling to work

To find out more about the services of the DEA, contact your local Jobcentre.

The **National Careers Service** also has a very helpful section on their website which addresses the issues that people face when they are contemplating returning to work after a long period of ill health – nationalcareersservice.direct.gov.uk. They also offer a telephone advice service which can be accessed by calling 0800 100 900. Lines are open from 8am to 10pm, seven days per week. This same number can be called to make an appointment to talk to someone face to face.

The **Shaw Trust** is the UK's largest third sector provider of employment services for disabled and disadvantaged people. They work in partnership with public sector organisations including the DWP and provide diverse services for businesses. They deliver both mainstream (Work Programme) and specialist (Work Choice) employment support schemes across Britain and help over 50,000 people per year. You can read more about their work at www.shaw-trust.org.uk.

I am currently on higher rate Disability Living Allowance (DLA) for mobility and have a motability vehicle. I have been called in for an assessment for the replacement for DLA, Personal Independence Payment (PIP), and wonder how this might affect my motability car.

Firstly the Motability Scheme will work with PIP in the same way as it did with DLA. In order to use this scheme you must be in receipt of certain benefits:-

- The higher rate of the mobility component of DLA
- The enhanced rate of the mobility component of PIP
- The War Pensioners' mobility supplement **or**
- The Armed Forces independence payment

For people like yourself who are current users of the scheme, your ongoing eligibility for motability will depend on the outcome of your PIP assessment. Unfortunately there is no automatic transfer from DLA to PIP. PIP has different eligibility criteria from DLA and so you may not qualify for the enhanced rate under these new criteria.

If you are awarded the enhanced rate of the mobility component of PIP then you should not have any disruption to your Motability lease. If, however, you are not awarded the enhanced component then you will not be eligible for the scheme and will be forced to leave it.

The PIP decision can be challenged, but, during this period of reconsideration and possibly appeal, the DWP will not continue to make DLA payments and so the Motability Scheme will therefore not be able to leave a vehicle with you. If the challenge is successful and the enhanced rate of the mobility component of PIP is awarded to you then you will be able to re-join the Scheme.

The Motability Scheme realises that this will be very difficult for people and so have put into place a one-off package of support for those who can no longer use the Scheme they were using under DLA because they have not been awarded the enhanced rate of PIP. This includes:-

- DWP payments of DLA for 4 weeks after the PIP decision is made and the ability to retain the lease vehicle for 3 weeks after the last DLA payment.
- If the car is returned in good condition and within the agreed time, subject to terms and conditions, an amount of £2000 may be payable to those who entered the Scheme before January 2013 when PIP was introduced and £1000 for those who joined after January 2013 up to December 2013.

The full details of this transitional package can be found on the Motability website www.motability.co.uk or by calling their customer services advisors on **0300 456 4566**. Please note that this package will be reviewed during 2015 and is therefore subject to change.

Jazmin's JIA Journey...

By Jazmin Scarlett

I cannot recall a time when I did not have juvenile idiopathic arthritis (JIA). That was because I was diagnosed at 2 years old.

Mum told me the first time she noticed something was not right was when at 18 months, having learned to walk, I stopped walking and would shuffle on my bum. Mum would try to get me on my feet again but then I would sit straight back down.

My granddad told mum to take me to the hospital. The local hospital dismissed my mum saying there was nothing wrong with me, but my mum, carrying me in her arms, stood her ground. She refused to leave, as she knew that her first born was not well.

After being misdiagnosed, I was in Great Ormond Street Hospital for months on end being a newly diagnosed systemic JIA sufferer. I do not remember much of the 'bad stuff' at that age. I remember I had a doll called Sally and I lost it in the hospital, and I asked all the nurses if they had seen her.

It was when my sister was young and I was a little older that I noticed I was 'different' from her. "Why am I hurting? Why do I have to go to hospital? Why do I have to take this medicine? Why me?" I was an intelligent and inquisitive youngster who enjoyed school and was sociable too on my good days, but I was a little more reserved on bad days. Sometimes when waking up I would be in too much pain due to a flare so mum, my dad or even my sister had to either help me get dressed or my Nan had to come round and look after me while mum and dad were at work. Before moving towns, I remember every Friday morning, just after the first lesson, I would leave school to go to hydrotherapy and I remember how much fun that was.

I became more aware of how important medication, appointments, taking care of myself and seeing the OT, podiatrist, consultant and physiotherapist was around the time I started secondary school. I knew I had an illness that made me hurt all the time and I knew that kids I was with in primary and secondary school would not have it. At the age of 12 I was quite self-aware of that and greatly independent, and at this time or a year later, I started to do my own methotrexate injections.

It was when I was about 13 or 14 I went to a Children's Chronic Arthritis Association (CCAA) weekend and met other kids like me and it was completely life changing, not just for me but for the whole family. I am still friends with some of those I met! Throughout secondary school I learned more and more about my condition and my limits. But also realised what I wanted to be in life. Being a teenager is about finding your place in the world but I think with JIA or any chronic condition, you have to learn to co-exist with it.

By the time I reached the end of 6th form at 18, I appeared to not have any more flares and due to a long period of gradually reducing the amount of methotrexate and then putting it back up when I flared, I was completely off it.

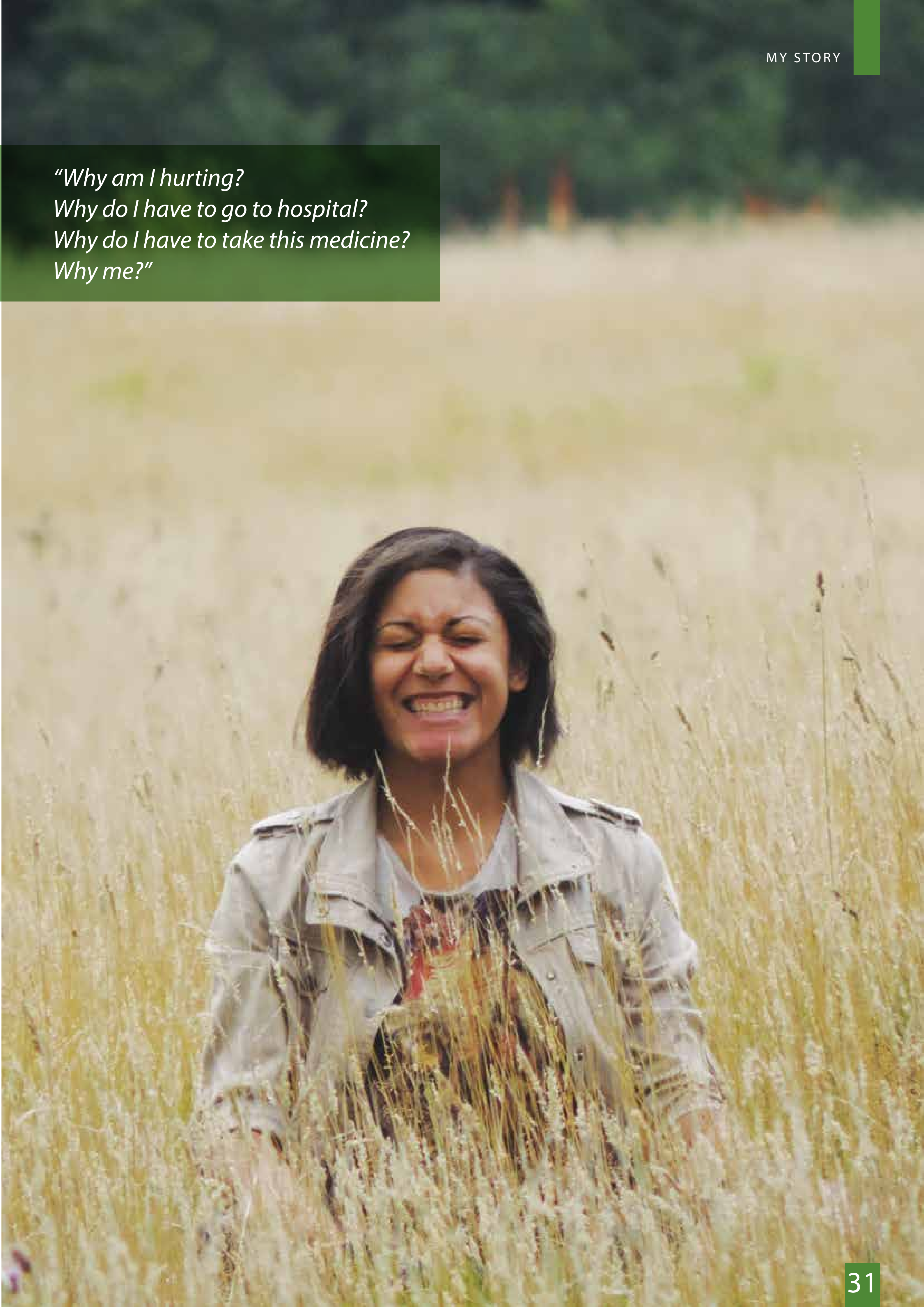
At university, I was still off methotrexate and not having joint injections (apart from one exception when the pain in my wrist was bad) and finding my confidence as an individual. I was in complete control of my illness and was doing a degree I wanted to do. The main JIA problem that arose, and now is persistent, was the chronic fatigue. I had always had it but it felt like it 'caught up' with me, maybe because I was staying out later. But that was a learning curve for me, I now know the rough time I need to call it quits and just go to sleep! Now that I am older, I see that my health takes precedence, socialising can suffer a little while I recharge.

And people who know me well enough understand and respect that.

Four years after the undergraduate degree, I went straight into a full-time masters. It was demanding both mentally and physically (due to the subject and length of time of the course) but I knew what I could and could not do because I had learned that for the past 20 years.

Now after 21 years of having systemic onset juvenile idiopathic arthritis I am a PhD student and the illness does not stop me from what I am doing and want to do. My journey so far can only be described as an emotional rollercoaster for myself, my family and friends and filled with self-awareness, self-education and understanding. And would not change it for the world. Although I wish I found Sally.

More stories at www.jia.org.uk



“Why am I hurting?
Why do I have to go to hospital?
Why do I have to take this medicine?
Why me?”

Group news so far… 2015

After a really busy autumn with five group launches, most of the new groups are now holding regular meetings successfully. Well done to these new groups, we wish them the best for 2015 and beyond.

Kim and Gill headed north to launch the Wirral NRAS group on 15th January. Local patient, Sheila Orr, has been running a group from Arrowe Park Hospital for some time but struggled to get many people to attend which is why she contacted NRAS to ask for support from the society. It was agreed that the group would re-launch in January as an NRAS Group. Sheila has put in lots of hard work organising meetings, building relationships with the rheumatology team and meeting patients in clinic to inform them of the group. We'd like to thank Dr Chiu (Consultant Rheumatologist) and Anthony Lake (Clinical Trials Coordinator) at Arrowe Park Hospital for supporting Sheila in this venture and helping NRAS plan what, despite the weather, was a very successful event.

Kim and Sheila at the Wirral Launch

Despite the cold, windy evening an impressive 70 people attended to hear more about the group and NRAS. Gill and Kim were very pleased to meet 11 healthcare professionals who came and supported the event presenting on their specific areas within rheumatology and forming a Q&A panel to answer lots of interesting questions from the audience. Since then Gill and Kim met with the keen coordinating group of 9 that came forward on the evening to volunteer alongside Sheila to plan the way forward for the group. Keep a check on the NRAS website for details of their first group meeting!

Our intrepid duo then headed back north to Preston on 12th February to co-host the NRAS launch of the Preston and District group. This group has previously been run for almost 10 years by local representative Harry Goulding, with the support of the fantastic rheumatology team from the Minerva Health Centre in Preston. The rheumatology team and the existing group were keen to now be linked with NRAS so that meetings could be publicised more widely and reach a broader audience.

Preston Team give full support to new group

The entire rheumatology team supported the evening with some of them presenting on their areas of expertise and formed a Q&A panel. We'd like to thank Dr. Lizzy MacPhie (Consultant Rheumatologist) for all the hard work she put in helping to organise this highly successful event and all the members of the team who gave up their evening to support the event. Planning is now in progress for more evening meetings to be held in 2015 which will reach those who are unable to attend the afternoon get-togethers.

By the time you are reading this the third launch of 2015 will have been held in Harrow, North West London at Northwick Park Hospital on 25th March. A group of NRAS Members with support from the rheumatology team have been the driving force in launching this new group, they've all been busy putting up posters and manning information stands in and around the area to raise awareness of NRAS and the event to form this new patient group. We will update you in the next magazine with full details of the evening and ongoing meetings.

Harrow Launch meeting

Already planned for summer is the launch of the West Suffolk NRAS group in Bury St Edmunds on 10th June. Gill attended a meeting with the whole rheumatology team at West Suffolk Hospital back in January who are all really supportive of the new group and we look forward to working with them. If you would like more information on this event please contact Kim or Gill on 01628 823 524 or email groups@nras.org.uk. If you live in the Bury St Edmunds area and would like to be involved in the planning and running of this new group we'd love to hear from you.

Bury St Edmunds new group to launch in June

Raising Awareness in the North East

At Gosforth Park in Newcastle a Health and Wellness Fair took place on Saturday 7th February, 2015. Eleanor Houliston's Zumba Instructor, Lindsey had a table there to promote her zumba classes. Lindsey kindly offered to display on her table NRAS

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

Leaflets along with photographs of the zumbathon the North East NRAS group held last year to raise money for NRAS.

Lindsey was approached that day by someone waiting for test results confirming either RA or Lupus. The lady was quite amazed that someone with RA did Zumba.

Lindsey by her table promoting Zumba and NRAS

Lindsey told us that a lady attending her Zumba gold class, which is a slower form of zumba, originally did the classes sitting down but after a few weeks she is up doing it on her feet. Thank you so much Lindsey for not only helping individuals with RA to keep moving but for raising awareness of the condition.

The North East NRAS Group looks for every opportunity to raise funds and awareness of RA and the group. Before Christmas the group had a tombola stall, craft stall and display table at the Santa Special weekend at the Railway Museum in Shildon, County Durham. Eleanor, Chair of the group, explains "We enjoy these days out and about as you meet some lovely people. These types of events are very well supported by the general public which gives us the opportunity to reach out to an even greater number of people making them aware of NRAS and what it does and can do for people living with RA"

Full steam ahead for North East NRAS group

Donna - Runner up in nationwide "Britain's Best Volunteer" competition!

Markel UK, the specialist charity insurer, and Small Charities Coalition, the support organisation for small charities, recognise the vast number of small charitable organisations in the UK who, without the help they receive from their volunteers, would quite possibly not be able to continue.

The two organisations' "Britain's Best Volunteer Award" is to reward those who volunteer their time to help small, local charities, community groups and not-for-profit organisations. NRAS nominated Donna Saunders, Volunteer extraordinaire back in February and 853 people voted for her!

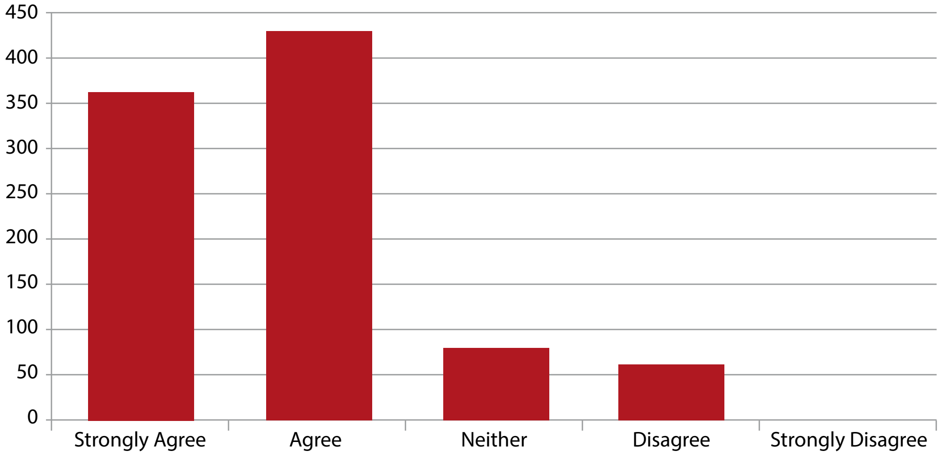
Donna has been a Volunteer with NRAS for almost 8 years. She helped launch and subsequently runs the educational and social group for people living with rheumatoid arthritis in Worcester and the surrounding area: bi-monthly meetings have taken place for the last 7 years and have provided people with invaluable support and friendship. Donna is also an NRAS Peer to Peer Telephone Support Volunteer offering 1-1 support over the phone to those with RA all over the UK that would otherwise feel isolated by their condition. Donna also organises many fundraising events for NRAS, such as a walk during RA Awareness Week for as many as 100 people! And instead of receiving birthday gifts at her recent milestone birthday, she asked everyone to donate to NRAS which raised over £300. In 2013 Donna represented NRAS as the RA patient voice at a European conference in Iceland amongst many other patient organisations. We feel Donna goes over and above her role as a Volunteer as she does all of this as well as battling her own RA, which she has had for 20 years and bringing up her young family. She is a truly selfless individual and our organisation relies on people like Donna volunteering their time to the cause! Donna made it to the final 4 with 853 votes which is no mean feat!

Worcester's Wonderful Donna in top 4 of Britain's Best Volunteers!

"Rheum2Talk"- Health Care Professional training on addressing emotional issues with patients

Following a short survey of nurses and allied health care professionals it was clearly apparent that many felt "out of their depth" or "lacking in training" to adequately address many issues their patients face around the impact RA has on their emotions, relationships and sexuality. We know from the 2013 survey of patients that 96% felt worried or upset about their RA but less than half had talked to a health professional about how they felt.

Patients were asked how much they agreed or disagreed with the following statement, **"To me the emotional side of having RA is as significant as the physical side of RA,"** it was very clear, as shown here, how patients felt.



Nurses and allied health professionals often have more time to spend with patients than their consultant colleagues and it is very clear they really want to be able to offer more support and advice on such things as sexuality, self esteem etc. But have had little or no training in this area.

NRAS worked with Sarah Collins, author of the NRAS publication "Emotions, Relationships and Sexuality in RA", who has had RA for 34 years, 20 of which have been spent in clinical practice as a Psychotherapeutic Counsellor and workshop facilitator to plan a one day training pilot. Also supporting the training was Dr Rod Hughes, Consultant Rheumatologist from St Peters Hospital in Chertsey. Rod has worked extensively in research around patients' perception and thoughts about their experience of all aspects of RA.

Our innovative and interactive workshop is designed to enhance Rheumatology Specialist Nurses' and Allied Health Professionals' understanding of the emotional needs of their patients. The training takes a fresh look at the various rheumatic conditions and the possible side effects of drug therapies, and provides an opportunity to integrate theory with practice. Participants were made aware of the many emotional and psychosexual aspects of living with chronic conditions, with a focus on RA and received informative handouts to support their work in this sensitive area.

Session and workshop topics include:

- Responding to the emotional needs of patients
- An overview of rheumatic disease, treatments and the physiological effects on patients
- What we know about the emotional experiences of patients, and nurses
- Exercise to enhance listening skills
- Experiential exercises
- Feedback and group discussion

NRAS was extremely grateful to UCB Pharmaceuticals in Slough for hosting the one day pilot of the training which was attended by 18 health professionals including physiotherapists, occupational therapists and rheumatology nurses. The feedback from this pilot has allowed NRAS to make some minor adjustments to the workshop e.g. spending more time on discussing case studies.

Consultation role playing for Nurses and AHPs

When attendees were asked how likely it was that this workshop would have an impact on their clinical practice, 67% of respondents said it was extremely or very likely to change how they address this subject with patients.

Comments about the pilot from attendees:

> ***"Overall this workshop has provided me with a thoughtful insight into the relation between RA and sexuality which is not usually given due importance"***
>
> ***"Overall an excellent day, covered with empathy, discretion and humour, well done Sarah and Rod"***
>
> ***"We as health professionals struggle with 'empathy versus self care.'***

So what is the next step? NRAS is seeking funding to roll out regional one day workshops, making them accessible to any rheumatology health professional to attend. Watch this space and with luck we should be able to announce training programmes later this year.

Blackpool Group entering 5th year of support, friendship and education

By Lyn Wilson

The Fylde Coast in North West Lancashire, is an area that stretches from the former fishing port of Fleetwood in the north to the seaside town of Lytham St Annes in the south. Located between these two towns is the resort of Blackpool, known for its piers, fortune tellers, beaches and donkey rides and, of course, its landmark Tower. It was here in the summer of 2010 that Blackpool and District Rheumatoid Arthritis Group (BADRAG) was formed.

Our bi-monthly meetings feature guest speakers committed to supporting those affected by this long term condition and encouraging better disease self-management. We welcome patients, their families, friends and carers. Many people find meeting others living with RA from their own localities to be of great benefit. NRAS groups are able to offer a great source of current and ongoing information and education.

Blackpool and District NRAS Group (BADRAG) meet in the cafeteria at Clifton Hospital, Pershore Road, Lytham St Annes FY8 1PB from 7:00pm – 8:30pm on the third Thursday of alternate months, January through to November. The hospital has plenty of parking spaces with limited disabled bays for use by those with a Blue Badge We invite a 'specialist' speaker to most of our meetings covering topics with a particular focus on Rheumatoid Arthritis: past meetings have included rheumatology, physiotherapy, podiatry, occupational therapy, dietetics and more! To raise a small amount of funds to cover our immediate outgoings we have a raffle and sell refreshments.

BADRAG is co-ordinated by NRAS Members Lyn, Sue and Dave with the help of group volunteers, Maureen and Lynn.

Dave, Lynn, Maureen, Lyn & Sue make a great Volunteer team

Nurse Practitioner Janice is on hand to give general information and advice and we are so grateful for the ongoing support also of Vicky and Wendy, our Occupational Therapy team!

Vicky, OT, Janice, Rheumatology Nurse Practitioner and Wendy, OT.

Healthcare professionals attend our meetings on a regular basis and it is always good to get the opportunity to meet them outside the usual clinical setting. We have attendees from all areas of the Fylde Coast, including Lytham St Annes, Thornton Cleveleys, Fleetwood and, indeed, from as far afield as Lancaster and Southport. More information can be found on our own group website at www.badrag.org.uk as well as the NRAS website or why not follow us on Twitter - https://twitter.com/Blackpool_NRAS.

We have a busy schedule planned for 2015 in this special year as we celebrate our 5th birthday in November!. If you live locally or perhaps are holidaying in the area why not come and join us? We are a friendly bunch, with a regular attendance of between 30 and 40 people, and always welcome newcomers to our group. Our Members find the local support valuable and many have made long lasting friendships from within the group. Give us a try, we look forward to meeting you!

Research opportunity across the UK

The APIPPRA study (**A**rthritis **P**revention **i**n the **P**re-Clinical **P**hase of **RA** with Abatacept) is a UK wide 2 year study which aims to test whether medication already licensed for use in RA can prevent or delay the onset of the disease. Currently there are 19 rheumatology units across the UK signed up to participate in this study. More units are invited to join the study and if you are a rheumatologist or a research nurse and would like more information about your department participating please email the APIPPRA research team at apippra@kcl.ac.uk or call 0207 8480852.

The study is now recruiting participants and it is anticipated that close family members of people living with RA may be most interested in taking part as they may be at higher risk of developing RA.

If you know of someone who is suffering from some, currently unexplained, joint pain in feet, wrists, hands etc. and would like to find out more about this exciting and ground breaking research study ask them to please contact apippra@kcl.ac.uk or call 020 78480852.

Being the voice of people with RA all across the UK and beyond!

By Clare Jacklin, Director of External Affairs

I am often asked, when out and about, what the "External Affairs" department of NRAS actually does. Firstly let me explain what this section of the charity covers, External Affairs looks after all the external projects that NRAS staff and Members are requested to participate in as well as all "outward" facing work including NRAS publications; helpline; peer to peer support, both telephone Volunteers and NRAS groups; patient advisory groups; industry interaction; health professional training programmes and pretty much anything that doesn't fall under the remit of other departments!

Let me share with you just a few things that this busy section of the charity has been involved in recently.

Working with the various industry partners is vitally important to ensuring that future development of therapies, treatments etc. always have input from the patient's perspective. I have been involved in patient advisory groups work with Sanofi, Pfizer and NAPP pharmaceutical companies some of which is global work involving networking with patient organisations from across the world. Back in November there was a two day workshop in Boston organised by Pfizer involving patient group representatives from Korea, Canada, USA, France, Turkey, Brazil, Argentina and Australia. By the time this goes to print I will have been to Paris for another patient advisory group meeting this time with Sanofi.

As you will have read in this issue of the NRAS magazine, biosimilar medicines are entering the UK market and we are therefore working with other pharmaceutical companies and stakeholders to ensure the interest of patients is clearly heard and represented e.g. from patient information booklets to the regulation and monitoring of the use of these biosimilars. To this end I've been speaking at various meetings on this topic including the European Medicine Agency which was fairly daunting and in Lisbon at the launch of Remsima.

European Medicine Agency meeting was rather daunting!

NRAS Volunteer and Member Jane Stiles was invited to share her experiences of living with RA to industry staff in Cambridge.

Jane being interviewed at NAPP pharmaceuticals staff event

Jane says of her experience of visiting the company, *"What a warm welcome I received when I went to NAPP Pharmaceuticals to talk about my experiences of living with RA. I'd had a chat with somebody on the phone earlier that week and when I arrived we had a quick run through the type of questions they would ask so I was well prepared and very relaxed when it came to my turn. The audience was friendly and very attentive, it just made it easy for me, after all I was only talking about my own experiences."*

"We really valued the opportunity to hear from Jane, a local NRAS Member, at our company meeting to launch our new medicine. Our employees have been inspired and moved by Jane's personal journey & we would like to thank her for sharing her experience of RA with us. It is really important for us to work with organisations such as NRAS to understand the personal impact that a disease can have so that we can continue to learn and deliver medicines to the NHS that meet genuine needs and make a positive difference to patients." Alberto Martinez, Managing Director, Napp Pharmaceuticals Limited

Philip Aherne, Member and Volunteer, represented younger people with RA at a Youth EULAR Event in Estonia which he found really interesting and inspiring.

Youth EULAR meeting

As I am finalising this article I am about to head out of the office to meet up with Anne Kelt, NRAS Member and Volunteer to attend the steering committee meeting at Guy's Hospital for the Apippra Study. (Arthritis Prevention In the Pre-clinical Phase of Rheumatoid Arthritis with Abatacept). See page 35 for more information.

I was pleased to meet up with representatives of the Plymouth NRAS group who attended the "information exchange" which I was presenting at being hosted by the South West Academic Health Science Network. The SWAHS in partnership with the "Individuals at the centre" organisation and the local CCG wanted to gather feedback from those living with RA about what works and what doesn't to help shape improvements in the services that are being commissioned.

I would have to have a magazine just for External Affairs to be able to share with you everything that staff and NRAS Members are doing to represent people with RA, making sure that decisions that will impact on future treatment and services are made with patient input. Thank you to all who volunteer their time to be that Patient Voice.

Members Top Tips...

If you are thinking of making any alterations or adaptations to your home – here are some top tips other Members have found have helped. 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.

Tips and hints on adapting your home

Many of these tips were supplied by Tricia Rusling who modernised her Edwardian house!

- Consider connecting your mains water to the cold taps upstairs so you don't have to carry glasses or bottles upstairs for a drink by your bed
- Simple single or double lever taps can make life easier, can protect your joints, look attractive and are not much more expensive than regular taps
- Double walk in shower if you have space
- Additional hand rail on the stairs, so you have one on both sides
- Raised flower beds in your garden so you can easily weed and plant out
- Use containers in garden as easier to plant and weed

Top Tip

The cheapest and possibly the best thing I have bought has been a roll of non-slip shelf lining - has a honeycombed appearance. I keep squares of this in most rooms as they make gripping anything so much easier.

Top tips without expense

- If you have round taps try wrapping elastic bands or Elastoplast around them to improve grip
- Have one bag in your bedroom and one downstairs to bring up and down multiple items all in one go
- High stool in the kitchen for resting while near work surfaces preparing food etc

Share your ideas...

If you've found some useful gadget or adapted something yourself that has made a big difference why not share it with others. Send your helpful tips on making life with RA easier to **membership@nras.org.uk**

NRAS Community Services Commissioning Update

Despite the impending general election raising fresh uncertainties about the future of some aspects of the `Lansley' NHS reforms in England, the trend towards integration of health and social care services appears unstoppable. The publication of the `5 year forward review' from NHS England Chief Executive, Simon Stevens, at the end of last year underlined the intention to spread access to proper self-management support and to increase the role of the voluntary sector as a provider and partner in this ambition. With these two specific elements in mind, the context in which NRAS is developing its involvement in self-management support and its role as a commissioned provider can be seen as both positive and hugely challenging. We retain our strategic focus of pairing the more limited practical, direct service provision for people with RA, with the intention of influencing commissioners and clinicians to improve overall treatment and care. The power of this approach lies in bringing the direct experience on the ground to the discussions on service improvement.

While we are in the final preparatory stages of our commissioned services in central and east Sussex, it is gratifying to see a growing interest in our self-management support from health professionals in other areas of the country. Recent enquiries from the Manchester and Croydon areas, together with our established contact with Sheffield, demonstrate both the increase in awareness of the need to provide good support to patients and of NRAS' specific expertise in this arena.

ncsl
NRAS Community Services Limited

The introduction of our NRAS workshop for people newly diagnosed, `New2RA', is proving to be both innovative and timely, and we are now moving to develop a further `Living Well' workshop that will form part of the progressive support following a diagnosis and will be valuable to many people with existing disease. While clinicians talk all the time about care and patient pathways, our aim is to ensure the necessary support for good self-management is embedded in those pathways and is actively prescribed to people by their GPs and consultants.

How your money helps

Your help will make a difference and ensure that NRAS can continue to support people who live with rheumatoid arthritis and help them to lead as full a life as possible.

£5 pays for a helpline call to provide information and support to those struggling with their RA

£10 pays for a Volunteer to complete the online training course and become registered to offer this invaluable support to many who feel isolated, alone and frightened

£25 pays for 50 copies of our Newly Diagnosed publication to be sent to a hospital, helping those coming to terms with their diagnosis and feeling unsure of what their future holds.

Are you missing out on great opportunities?

NRAS often receives requests for patient
participation in a wide variety of activities,
which provides tremendous opportunities
to raise awareness of RA and improve
rheumatology services. The most efficient
way to make you all aware of these
opportunities is via email.

Nearly 1,000 NRAS Members do not
currently have an email address registere
with us so you may be missing out on
these opportunities and the NRAS e-ne
bulletins. It also saves NRAS money to s
out information via email rather than p
Such savings can be utilised in providi
more support via all NRAS support ser

Please email membership@nras.org.u
your full name and current email add
we can keep you fully up to date with
and activities.

NEWS & EVENTS

NRAS hosts CEO's representing 13 patient organisations

EULAR is currently funding an annual meeting of the Chief Executives from the larger patient organisations from across Europe who have higher numbers of paid staff in order to build on the achievements and synergies of these organisations who can benefit from discussing common issues such as political campaigning, fundraising, collaboration with EULAR, how to react to the economic crisis, etc. and to further ensure the early support and involvement of these organisations into all relevant EULAR activities. NRAS hosted the meeting in February at the NRAS offices in Maidenhead, where we were delighted to welcome 13 Chief Executives and representatives from the EULAR Brussels and Zurich offices.

Sue Oliver looking proud at the Palace with her OBE, awarded for services to rheumatology.

Do you know what this symbol means?

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Look out for it on all your health information, printed or online...this is the quality kite mark awarded by NHS England. Organisations with the quality mark have been filtered to ensure the pass rigorous standards. To gain this certifications information must be "accurate, accessible, impartial, balanced, evidence-based and well written".

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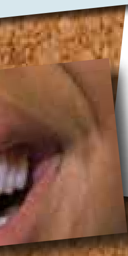

New Oral Health Information

People with RA can experience problems with oral health so we've added a new section covering this topic on our website.

Some issues are directly related to RA such as gum disease, jaw problems and dry mouth and some are indirectly related to RA; being a result of RA medication or caused by difficulty with cleaning the mouth (due to problems with other joints).

This will not be a problem for all people with RA, but it may be helpful to be aware of these potential problems, so that you know what to look out for and what you might want to discuss with your dentist.

Find out more at http://www.nras.org.uk/oralhealth

Dates for the diary

RA Awareness Week
Monday 15th – Sunday 21st June 2015

JIA Family Day
Saturday 18th July 2015

World Arthritis Day
12th October 2015

FOLLOW US
TODAY ON OUR SOCIAL NETWORK

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Twitter@NRAS_UK

To see what is happening on Helpline follow them

Twitter@helpline_NRAS

For up to date membership information follow

Twitter@members_NRAS

Tweets

TWEETS 4,341 FOLLOWING 1,637 FOLLOWERS 3,260 FAVORITES 282

Tweets Tweets & replies Photos & videos

NRAS @NRAS_UK · 23h
Are you a family member of someone living with #RA? Can you help w/ this research into prevention or delay of onset nras.org.uk/the-apippra-st …

2 1

NRAS @NRAS_UK · Mar 24
Mini legends Dion (6) and Tia (9) have decided to take on a triathlon to raise funds for us! justgiving.com/Hannah-Deacon2

1 1 View more photos and videos

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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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. A legacy can be anything from a small amount of cash to a house; a piece of jewellery to a masterpiece! Leave it to NRAS to make a difference to the lives of those living with RA.

Leave it to Us to make a Difference

nras
National Rheumatoid Arthritis Society

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Web: www.nras.org.uk
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0845 458 3969
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