



nras
National Rheumatoid
Arthritis Society

AUTUMN 2014
Magazine



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FEATURE
AbilityNet
Harnessing the power
of technology

GENERAL ARTICLE

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JIA SERVICE**

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WELSH CAMPAIGNS
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Please read and feel free to share

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01628 823 524

Dear members...

I hope you have had a lovely summer. It has been good to get a bit more sun and enjoy some longer evenings outside, so let's hope for an Indian summer before we head into autumn.

My most exciting news of the summer is that our daughter is expecting her first baby so I'm going to be a Grandma! It's due in January, usually a rather bleak month after all the Christmas partying, so next year a rather different prospect to look forward to, and she and her partner are not going to find out in advance whether it's a boy or girl, so it will be a surprise! Hurrah! I think it's much nicer not to know.

As I write, it's the end of July and a week ago we held the launch of our new JIA-at-NRAS service for families, children and young people affected by Juvenile Idiopathic Arthritis. It was a family day held in Warwickshire on a Saturday after a long week of sunshine, and of course it rained! However, in spite of the rain it was a really great event and by the end of the afternoon the sun had come out so the children and young folk could play outside and you can see a photo from the day on page 5. In the picture, Dr Clarissa Pilkington, Paediatric Rheumatology Consultant leading the team at Great Ormond Street, is cutting the cake with me. We are grateful to Clarissa and a fantastic team of health professionals who gave up their Saturday to come along and give a number of short presentations to parents whilst the children were entertained by our staff and volunteers. The following email was sent by a parent after the event which we were encouraged and pleased to get:

"It was wonderful to meet everyone on Saturday and I found the speakers both well chosen and very interesting, and on a personal front they have empowered me to ask for changes in my child's care."



Patients, families and clinicians/allied health professionals working together, as I have often said, is a powerful combination and we hope that our new service, JIA-at-NRAS, will enable us to work together to bring change and much needed support in this community. It is important to say that we shall also be collaborating with other charities working in the field of JIA and paediatric rheumatology as reinventing wheels is not something we relish. For more information about the new service, please contact our JIA Services Manager, Maria-Benedicta Edwards at maria@nras.org.uk.

We recently held the two day NRAS induction training for our new Welsh



Ambassadors (see page 11), who were joined also by some new Scottish Ambassadors who are swelling the ranks of our existing and established Campaigns Network in Scotland. It was a real pleasure to host a group of such positive and enthusiastic Ambassadors at our offices and you can read more about what they do on our website www.nras.org.uk/campaign-networks.

The cover picture showing our Welsh Ambassadors was taken during RA Awareness Week at a drop-in constituency event at the Welsh Assembly, during which 19 Assembly Members and MPs came to talk to us about current healthcare issues in Wales for people with RA and JIA.

I'm very much looking forward to going on holiday for a couple of weeks later in September. It's been a busy year as always and I'm ready for a break! Need to gird the loins for an even busier final quarter – what happened to 2014 and why does time seem to race past at a rate I can barely keep up with? Must be because I'm enjoying myself and love my job.

With my best wishes as always

Arlisa

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We congratulate our own Sue Oliver!

We were absolutely delighted to learn that Sue Oliver was awarded an OBE in the Queen's Birthday Honours 2014 list, for her services to rheumatology healthcare. Sue was, for many years, our Chief Nurse Advisor and she has done a huge amount of work with NRAS over a long period of time.

Ailsa, our CEO, who has worked closely with Sue since the NRAS launch in 2001, commented, "I couldn't be more thrilled, Sue is not only a colleague but also a good friend. We have worked very closely over many years. I remember Sue at our launch in 2001 – she actually asked what I thought was an awkward question which I found irritating at the time – little did I know that we would become firm friends and do so much great work together!



Sue and Ailsa presenting the poster on the Mapping Project at the BSR 2008

We did lots of really important projects, but two in particular spring to mind, well, three! First of all, Sue travelled all over the UK with us during 2003/4 helping us to set up the NRAS Volunteer Network. Secondly, in 2007 we researched and published a significant mapping project in collaboration with the London School of Economics, mapping the journeys (and their cost to both the NHS and the individuals) of 22 RA positive patients from symptom onset to three years into their disease. Thirdly, Sue and I were Joint Chairs of the Rheumatology Futures Project Group which was responsible for commissioning the King's Fund Report into RA Services, published in 2009.

We share Sue's passion to champion the interests of the patient at all times and couldn't be more delighted that her work and dedication to rheumatology has been recognised in this way.

NRAS Magazine

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Meet the Team...

Bronwen on Kim

Kim is our Volunteer Network Coordinator and has worked at NRAS since August 2012. Just part of her role involves helping to launch new NRAS Groups. This she does alongside her colleague Gill, and by the end of 2014 they will have launched eight new groups. Kim helps to source venues and advertises the launch event as well as attending it, which can mean a good deal of travelling and overnight stays. She also helps to support the other 42 NRAS groups we have, offering a friendly and helpful voice on the end of the phone with all their queries. Another area that Kim deals with is the Peer to Peer telephone volunteers - this means matching suitable volunteers to offer support to others.

Kim is a cat lover and has two of her own, Ferris and Tia, but her other interest and passion is motorbikes – which I don't think on meeting her you would probably guess. She says she is not brave enough to learn to ride one herself but I think her bravery is riding pillion behind her boyfriend! Kim's favourite holiday destination was a trip to Northern Italy, where she travelled around and had an 'amazing time' experiencing the country, its culture but more importantly the delicious Italian food! Kim loves various types of music but most of all loves anything that she can have a good dance to!



Nicky F on Dani

Dani was the new girl at NRAS until I came along about 10 days later! When I first met her, she made me feel very welcome and helped put my nerves at rest about being the new girl. That was over a year ago now and we both now feel we are part of the furniture.

What can I say about Dani? Although she is the NRAS Media and Communications Officer (and editor of this magazine!), she is definitely not a PR lovey and is very down to earth and laid back. She has made a great impact for NRAS in PR, communications and media, putting NRAS firmly in the public eye. Her greatest achievement so far is getting Ailsa a live interview on the Jeremy Vine show on Radio 2 with over 15 million listeners. Dani is always looking at different angles and ways to get NRAS mentioned in the media and is not shy about contacting any celebrity she possibly can to get them involved in any way. She is a very dedicated and enthusiastic part of the team, always wanting to get involved with as much as she can both within the office and out and about. Since joining NRAS she has already run in the Super Hero run in Hyde Park dressed as 'Super Woman', was part of the RA Awareness Week team and spent the day looking after children during one of our recent events. She somehow even manages to get "the other Danny", her 6ft 9 boyfriend involved in everything as well!



Get involved...

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



Membership

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



Fundraising

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



Volunteers

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

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

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

The launch of our new JIA service

Family Fun Day and Information Day in Warwickshire attracts over 100 people

NRAS was delighted to welcome families and health professionals to the official launch of our new service for families living with Juvenile Idiopathic Arthritis (JIA) at a 'Tea on the Beach' party on 19th July 2014 at the Heart of England Conference Centre, Fillongley, in Warwickshire. It was such a great day and even the threatened stormy weather was kind to us.

The feedback from parents, health professionals and all the volunteers who helped on the day has been very positive. We had a pirate ship on the lake – great when a thunderstorm occurred to add to the atmosphere - giant swan pedalos and exciting quad pods which zoomed the children through the forest and delivered them back to us covered in mud with the most enormous grins on their faces! Parents weren't left out either. We had talks by a paediatric rheumatologist about the current treatments/drugs pipeline, another by a rheumatologist on transition from paediatric to adult services, a talk from a paediatric clinical nurse specialist who explained what her role is, a physiotherapist talked about the importance of exercise and how to keep motivated, two occupational therapists spoke about the role of the OT and, finally, the house was brought down by a team of play specialists who gave a fantastic and funny role play showing ways play can help both parents and their children feel more confident and relaxed about giving medications at home. We had a Q&A session with some great questions and debates followed by afternoon tea with masses of cake and the 'official' cutting of the cake by Dr Clarissa Pilkington, the lead Paediatric Rheumatology Consultant at Great Ormond Street Hospital, who is also President of the British Society of Paediatric and Adolescent Rheumatology.

We received many messages of support including one from Norman Lamb MP, Minister of State for Care and Support who said:

"I welcome the launch of the new JIA-at-NRAS service and wish the National Rheumatoid Arthritis Society and its supporters the very best of luck in this new endeavour. Juvenile Idiopathic Arthritis is a distressing disease that affects thousands of children and young people around the UK. I hope this new service will provide them with much needed information and support. Thanks to everyone who has worked to make this possible."

Another came from the Cabinet Secretary for Health and Wellbeing in Scotland, Alex Neil MSP, who said:

"Congratulations to NRAS for launching the new JIA-at-NRAS service. As this news demonstrates, the voluntary sector can play an important role in helping to enhance care and support for people in Scotland with serious long-term conditions like Juvenile Idiopathic Arthritis, as well as their families. I am sure the new service will be a big success and I look forward to hearing more about the new service in due course. On our part, we have just published our rare disease strategy which sets out our comprehensive plan for supporting people with conditions such as this. Working together, the public and third sector can build a strong network of support and both of these initiatives are important parts of that picture."

Seeing the faces of the children and the excited chats between parents, health professionals and each other was inspiring and confirmed to us the importance and need for this support, and we are determined to champion the cause and make JIA a priority, not just a Cinderella service. We were able to gather lots of great ideas and plans on how we can shape the new service with the help of parents, children and young people and build a strong JIA community which is supportive, inspirational and understanding.

Perhaps the best way to convey how the day went are from comments made by the parents and health professionals who helped make this such a great day:

"Please accept my thanks for a brilliant afternoon on Saturday – my daughter really enjoyed herself with your team... it was very useful to hear issues first hand, and meet the very dedicated professionals involved in JIA."

"Thank you very much for a great day and event. It was a privilege to be involved and to see so many familiar faces." (health professional)

"I'd like to thank you and the NRAS team for organising such a great event on Saturday. It exceeded all our expectations; the talks were incredibly useful, it was lovely to meet other families with children who have JIA and both our children had a super time. So much so that my daughter was very sad to go home at the end of the day!"

"I just had to drop you an email to say a huge WELL DONE to you and your team at NRAS. The event was brilliant and very well organised; the speakers were so very informative and gave us a huge amount of confidence and little more knowledge regarding this minefield of JIA."



NRAS staff and guests at the launch

Have car will travel: driving tips for people with rheumatoid arthritis (RA)

Having a car and being able to drive can provide a great deal of independence. However, pain, weakness and stiff joints can make it difficult to get in to and out of a car and use the controls. Sitting in the same position for a long period of time can also lead to backache and tiredness.

Automatic transmission and power-assisted steering make it easier to drive if you don't have much strength in your shoulders, hands or arms. Other helpful options, such as height adjustable seats and steering, are now found on a wide range of cars too. The less a car has to be modified, the higher its resale value. However, if your arthritis means you have difficulty driving, you may need to consider adaptations that are available for primary and secondary car controls. To find out more, check out the Rica information on motoring with arthritis.

Rica, a national consumer research charity that focusses on work with older and disabled people, has a free guide available called *Motoring with Arthritis* www.rica.org.uk/content/motoring-arthritis that outlines key things to think about when choosing or adapting a vehicle if you have RA. The guide was compiled with input from arthritis charities including NRAS.

Rica's plan of action includes useful tips such as:

Think about how will you get in and out of your new car?

How comfortable will you be and can you reach the controls?

Make time to read specialist reviews for example from Disabled Motoring UK: www.disabledmotoring.org/dmuk/home which campaigns on behalf of disabled drivers and, of course, check out car review websites.

If you need more details about a car, then check out the online Rica car measurement search to find cars for example, with wide door widths, doors with low sills or boots with no sills: www.rica.org.uk/content/car-search

Over 1000 vehicle factsheets are available with the car measurements and photos.

Advice from drivers with arthritis worth considering:

- Try out a car and any adaptations on one of your worst days, not when you're feeling well
- Get plenty of practice if you are using adaptations or a new car
- Make sure the seat is comfortable and provides good support - adjust it and the steering wheel to suit you. Cushioning, electrically adjustable seats and heated seats all help
- Take plenty of breaks to avoid getting stiff. Leave enough time for this
- Make sure any painkillers you use when driving do not cause drowsiness or otherwise affect your ability to drive
- If you wear splints to support your joints, ask your occupational therapist (OT) if it's appropriate to wear them when driving. If they make driving difficult, the OT may adapt them
- If you have recently had surgery, ask your doctor to advise you when it will be safe to drive again

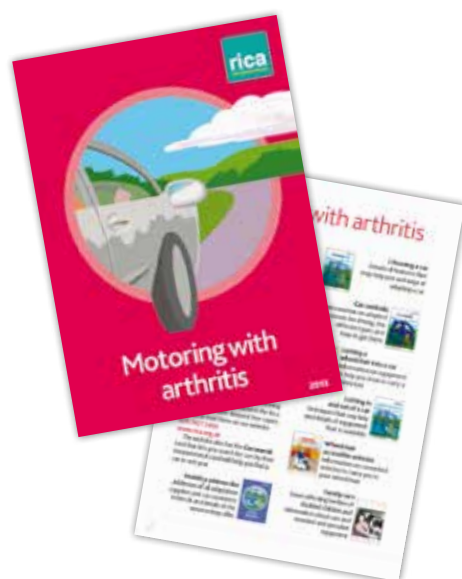
If you are unable to use foot pedals at all, there are different types of hand controls that can be fitted on an automatic car. Rica has information on car controls on its website and a print guide is available: www.rica.org.uk/content/car-controls If you feel you need an assessment, then find your local Mobility Centre from this website: www.mobility-centres.org.uk.

Rica is a national research charity dedicated to providing independent information of value to disabled and older consumers. It researches and publishes consumer reports, based

on rigorous research, and provides practical information for disabled and older consumers. It also works with manufacturers, service providers, regulators and policymakers to improve products and services. Rica's aim is to increase their awareness of the needs of disabled and older consumers through specialist research.

Rica is carrying out a survey asking drivers aged over 55 years about their knowledge and experience of new in-car safety technologies like automatic emergency braking and automatic parking assistance. The survey will help influence future consumer research and information. If you are over 55 and would like to help with this research go to the Rica website: www.rica.org.uk or phone Rica on 020 7427 2460.

To get a free print copy of the Rica guide, *Motoring with arthritis*, **please send a large (A4) self-addressed envelope with 73p in stamps to:** Rica, G03, The Wenlock, 50-52 Wharf Road, London N1 7EU



Motoring with arthritis guide

Members Top Tips...

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

Making everyday tasks easier

Kate Spires, a recent graduate from Manchester School of Art, has created Hackcessible, aiming to promote how everyday objects should be designed to truly include the diverse needs and abilities of a varied and ageing population. Speaking to people who live with rheumatoid arthritis it is apparent that many of the everyday tasks found difficult are actually things that could be made easier for a majority of people, with some simple adaptations. For example, extracting a plug from a low down socket, opening a jar, opening a heavy fridge door, holding keys to open a door and even trying to use the buttons on a TV remote. By encouraging people to create their own self-initiated 'hacks' using readily available materials, it can provide an inexpensive and creative alternative to assistive disability aids which can also empower the user to feel in control of their designed environment.

To find out more, visit: www.hackcessible.co.uk



Off road scooters

Countryside Mobility is an organisation which covers the South West area of the UK from Gloucestershire to Cornwall. It arranges for Trampers (off road scooters) to be available at a number of sites which would otherwise be inaccessible.

I never thought I would be able to 'walk' through the woods again or do a stretch of a coastal path until I came across this.

Creaky – Health Unlocked

Share your ideas...

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

NRAS Annual Conference 2014

As this magazine goes to press, we will be welcoming Members, supporters and their families from all over the UK to our 3rd Annual Conference, being held this year at Gomersal Park Hotel, West Yorkshire. We are delighted to have an array of guest speakers including Dr Maya Buch, National Institute of Health Research (NIHR) Clinician Scientist, Senior Lecturer at Leeds University and Honorary Consultant Rheumatologist at Chapel Allerton Hospital. We also have a number of health professionals holding workshops on topics such as fatigue, cooking with RA and exercise. We are looking forward to an enjoyable and successful day and we look forward to meeting more of you at our 4th Annual Conference next year!

Government Affairs

There has been mixed news on the welfare front during the last quarter. A Judicial Review on the 20 metre rule within the new Personal Independence Payment (PIP) found in favour of the Government.

Although the judge noted serious problems with the way proposals were consulted upon, it was deemed legal. The upshot is it will continue to be difficult for people with rheumatoid arthritis (RA) to claim the higher rate mobility component of the PIP. NRAS continues to campaign hard for improvements to the PIP and we have attended several stakeholder forums organised by the Department for Work and Pensions, Atos and Capita. In addition to this, our Government Affairs Officer, Laura Wetherly, has recently been appointed to DWP's PIP Improvements Working Group.

However, there has been more positive news in relation to the Employment and Support Allowance (ESA). A report by the Work and Pensions Select Committee called for extensive reform of the benefit and agreed with many of NRAS's campaigning asks. Among their recommendations, the Committee called for those with conditions unlikely to improve not to be placed in the Work Related Activity Group (WRAG), for the amount of time to be extended between reassessments for those with degenerative conditions, and for assessors to be given more information and training about disease areas. The report also mentioned case study material from NRAS about the experience of a person with RA being told during an assessment that it was 'irrelevant' if they could not write their name several times due to pain, as long as they could do it once.

In addition to this, working with Parkinson's UK and the MS Society, NRAS has continued to table further parliamentary questions and meet with politicians to put forward the case for better treatment of people with progressive conditions within the ESA assessment and re-assessment processes. The NRAS government affairs team met with Paul Maynard MP, Glenda Jackson MP and a representative from Dr Paul Litchfield's Independent

Review team to discuss this and has also been working with the Arthritis and Musculoskeletal Alliance to encourage member organisations to produce an online survey to ask people with a range of musculoskeletal conditions about their experiences of claiming benefits.

To coincide with the launch of the new service for people with Juvenile Idiopathic Arthritis (JIA) we managed to get several parliamentary motions tabled in England, Scotland and Wales as well as political endorsements from Ministers in England and Scotland. Prior to this we also wrote to all the Local Health Boards in Wales to invite meetings to discuss the state of Welsh paediatric rheumatology services. We also responded to several JIA-related consultations, including one by NHS England on the contents of an interim biologics statement for JIA, the National

Voices coalition's narrative of care for young people, NICE's draft scope for transition from children's to adult services social care guideline, and NHS England's Clinical Reference Group consultation on transition.

NRAS has responded to a number of consultations relating to medicines, including a consultation by the National Institute for Health and Care Excellence on Value Based Assessment (VBA) on their proposal to revise the way that the value of medicines in the NHS is determined. In respect of this consultation, NRAS argued for greater consideration of the importance of societal benefits and work outcomes. We also provided a wide ranging response to a consultation by NICE on the introduction of biosimilar medicines into the NHS.



Paul Maynard MP



Glenda Jackson MP



Work and Pensions Select Committee

Scotland campaigns update

The Scottish NRAS Ambassadors have been busy conducting local hospital site visits in Scotland, providing materials to rheumatology units for newly diagnosed patients. The latest visits completed, include Gartnavel Hospital where Sheila MacLeod and Sheila Terry had a very productive meeting with Dr Duncan Porter, whilst Anne Kakouris met with the rheumatology team at NHS Highland.



Duncan McNeil MSP

In May, the NRAS government affairs team, Sheila MacLeod, Chair of the Scottish Campaigns Network, and NRAS medical adviser, Stefan Siebert, also met with Chair of the Health and Sport Committee, Duncan McNeil MSP. At the meeting, problems with RA services, the lack of a comprehensive Scottish Government response to the Scottish Public Health Network's Needs Assessment of Services for Adults with Rheumatoid Arthritis (2012) and potential opportunities for further

engagement with the Health and Sport Committee were discussed. McNeil also kindly offered to sponsor a constituent drop-in session in the Scottish Parliament.

We are very pleased to announce that Professor Iain McInnes, Muirhead Chair of Medicine and Director of Institute (Immunology) at the University of Glasgow, has agreed to become our Patron in Scotland. He is much respected within the medical and rheumatology community and we are delighted to have his invaluable support.



Professor Iain McInnes

Ailsa, our CEO, and Scottish Ambassador, John Paton, attended the launch of the new Rheumatoid Arthritis Pathogenesis Centre of Excellence in Glasgow, a project sponsored by Arthritis Research UK, The University of Glasgow, University of Birmingham and the University of Newcastle. The centre aims to undertake research to understand why RA occurs and persists and whether any new treatments can be developed.

Scottish Ambassador, Matilda Tumim, presented to EULAR, where she talked about her first hand experience of using telemedicine in rheumatology.

At the beginning of July, John Paton went along as a representative of NRAS to a committee meeting of the Scottish Medicines Consortium (SMC) at which the subcutaneous version of tocilizumab was discussed. NRAS hopes to be represented at further SMC meetings in the future.



Nanette Milne MSP with Dr Alan Macdonald, Honorary President of the Scottish Society for Rheumatology, and Sheila MacLeod, Chair of the NRAS Scottish Campaigns Network

Wales campaigns update

At the beginning of March NRAS met with Chair of the Health and Social Care Committee, David Rees AM, to discuss challenges facing RA services in Wales.

Rees offered to sponsor a 'Meet the Patients' event for RA Awareness Week (which subsequently took place in June) and to write to the Minister for Health and Social Services, Mark Drakeford AM, to clarify Welsh Government plans to review the 2007 MSK Directive.



Mark Drakeford AM, Minister for Health and Social Services

NRAS subsequently received a response from Drakeford which confirmed that an informal consultation by the Welsh Government on whether to review the MSK Directive was underway. NRAS responded to the consultation and made a number of recommendations, including a suggestion that a new MSK Directive be published, which contains a more detailed list of 'key actions' for Local Health Boards to be independently audited against.

My experience as an NRAS Welsh Ambassador

By Cynthia Rees

I have really enjoyed becoming a Welsh Ambassador for NRAS. Although the new Welsh Campaigns Network has only been launched within the last few months, I already feel we have achieved a great deal.

My first activity as a Welsh Ambassador was to undergo a one day training programme in Cardiff on the Welsh policy making process, where I also had the opportunity to go on a tour to the Welsh Assembly and meet the Welsh Conservative Health Spokesperson, Darren Millar.

I was then very excited to take part in a recent 'Meet the Patients' event at the Welsh Assembly in Cardiff during RA Awareness Week in June. Prior to attending, the event, I emailed a number of local Assembly Members and invited them to come along and meet myself and other constituents who have RA and live in the Swansea area.

I was not sure what to expect on the day but it turned out to be a very positive experience as we were able to meet several Assembly Members and explain our concerns about rheumatology services in Wales. One of the local Assembly Members, Peter Black, agreed to take up the issues and wrote to the Chair of the Local Health Board about our concerns

over staffing issues and local service provision, and we have since received a copy of the letter sent out by his office.

In addition to this, Mr Black put us in contact with the Leader of the Welsh Liberal Democrats, Kirsty Williams AM, to try and seek support for a Welsh Government review of the Musculoskeletal Directive, which sets the vision for the quality of local service. I am delighted to say that Ms Williams recently supported a Statement of Opinion in the Welsh Assembly calling for the Musculoskeletal Directive to be updated and for better treatment and management of chronic fatigue for RA patients.

Most recently, I attended a two day training programme at NRAS's new offices in Maidenhead and was very impressed by their professionalism, their approach to the training and the people who make NRAS what it is – an excellent organisation offering support to individuals who suffer with RA and professionals in the field of rheumatology. It was also an opportunity

to meet three of the newer NRAS Scottish Ambassadors and to hear about their experiences.

Overall, I am amazed by the amount of background work that is put into making NRAS a leading charity in the field and the 'Voice for People with RA'.

I am very excited to be an NRAS Ambassador and extremely keen to help raise the profile of RA and NRAS, and to help improve services for the people of Wales.



Cynthia Rees and Brian at Swansea Marina Tesco

Launch of the Welsh Campaigns Network

Following the successful launch of the Scottish Campaigns Network in February 2012, NRAS has launched an equivalent programme for our members in Wales.

The aim of the Network is to empower people with RA to undertake campaigning and influence policy. In a similar fashion to Scotland, the initiative aims to develop NRAS's voice in Wales and ensure that we have a consistent campaigning presence.

Telephone interviews were conducted with potential Ambassadors during February and March, followed by a one day training session in Cardiff in early June, which featured an overview presentation about NRAS and an introduction to NRAS's approach to campaigning. The remainder of the day's training focused on building the Ambassadors' knowledge of developments in Welsh public policy and campaigning tactics which included specific sessions on the relationship between Wales and Westminster, the devolution agenda, elections, health structures and legislation.



Nerys Evans of Deryn Consulting talks to NRAS Ambassadors about health policy in Wales

The training in Cardiff, which was run in conjunction with public affairs agency, Deryn, was rounded off with a short tour of the Welsh Assembly. During the tour the new Ambassadors had the opportunity to meet with the Welsh Conservative Health Spokesperson, Darren Millar AM, and to discuss with him some of the issues affecting Welsh health services. Following the meeting, Mr Millar offered to table questions about the issue of RA and rheumatology services in Wales.

Eager to get the Ambassadors involved in campaigning, NRAS organised its first 'Meet the Patients' event in Wales during RA Awareness Week. The event

was advertised to all NRAS Members from across Wales as an opportunity to talk about their local concerns about rheumatology services and to participate in a photo opportunity with their Assembly Members to help draw attention to RA with local media.



Chair of the Health and Social Care Committee, David Rees AM, met with NRAS and also sponsored our Meet the Patients event in the Welsh Assembly

The event was very successful, with 18 politicians attending on the day, including Chair of the Health and Social Care Committee, David Rees AM, who kindly sponsored the event; former Minister for Health and Social Services, Jane Hutt AM; Chair of the Cross Party Group on Older People & Ageing, Mike Hedges AM, and the Deputy Presiding Officer of the National Assembly, David Melding AM.



All the new NRAS Ambassadors attended the Meet the Patients event at the Welsh Assembly

A number of politicians took to social media and issued local press releases to inform constituents about their attendance at the event. Several politicians also offered to undertake further follow up work, such as tabling questions in the Welsh Assembly and offering NRAS the opportunity to present at a future session of a Cross Party Group.

The new Welsh NRAS Ambassadors are:

- Jean Bailey-Dering
- Nia Blackwell
- Rich Flowerdew
- Cynthia Rees
- Vanessa Phillips
- Huw Roberts

Following the 'Meet the Patients' event, the second one and a half day training session took place at NRAS's office in Maidenhead in July, held jointly with four recent recruits to the Scottish Campaigns Network. This was an opportunity for all the new Ambassadors to meet each other and for each NRAS team to explain in more detail their work within the charity. On the second day, a session was held specifically to give the Ambassadors an opportunity to discuss and agree some campaigning priorities for their respective networks during the next 12 months.

Social Care and the Care Act 2014: a short introduction

By Laura Wetherley and Ben Clubbs Coldron

Earlier this year, the Care Bill received royal assent and became the Care Act 2014. The regulations and guidance to accompany this legislation are currently under consultation and NRAS has been working via its membership of the Care and Support Alliance (CSA) to stay informed of the changes.

The Care Act 2014 represents the biggest reform of social care arrangements in 60 years, enacting major changes to the provision and funding of social care. But what exactly is social care and what difference will the new legislation make?

What is social care?

Social care provides assistance with personal care and social support to people of all ages in order to deal with needs arising from illness, disability, old age or poverty. It also encompasses services which deal with supporting the families and/or carers of people who receive such assistance and support.

The aim of social care is to allow recipients to maintain their independence and quality of life. So in addition to residential care, reablement services are also available to help people regain the ability to look after themselves following illness or injury and stay in their own homes. Other related services include home adaptations and equipment to make life easier, as well as alert systems to enable people to cope with emergencies at home.

However, there are a range of other services that also fall within the remit of social care, which are less well known. These include social support of those with alcohol and substance misuse problems, prevention of abuse or neglect, preventative family support and child protection services, fostering, adoption, all the way through to working with young offenders, the homeless, children and young people who have learning or physical disabilities.

Who pays for social care?

Who pays for a person's social care varies from case to case and individual to individual. Most people will have to contribute something towards their care costs and some will have to pay the whole bill. Depending on their level of need and financial situation, some people are eligible to have some or all of their social care bill paid for by their local authority. This is determined by assessment of their care and support needs. These needs may be deemed less substantial if the individual has much of their care needs met by family or friends and potentially even because they have significant assets. The Care Act 2014 has the potential to radically change the eligibility criteria and has made changes to the way social care is funded.

The Care Act 2014

The Act sets out several changes to the way social care and support is provided, many of which are welcome. But there are still concerns about the impact of the legislation, particularly around the proposed eligibility criteria and whether,

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in the context of chronic underfunding of the social care system as a whole, these changes in law will have real life benefits for social care recipients.

Eligibility

The Act aims to implement a new national eligibility threshold which determines whether the Local Authority will have an obligation to provide social care to a person who reaches that threshold. This is welcome as it means that people will not be treated as eligible in one area of the country and ineligible in another.

Whilst the Act contains measures intended to reduce the financial burden on the individual, such as implementing an absolute cap on the financial contribution that local authorities can expect from the individual (specified as £72,000), the minimum eligibility criteria are not contained in the Act and will be set by regulations yet to be written.





The proposed draft regulations are unfortunately at least as tough as those which already exist, meaning those with moderate or low level needs will not be eligible for support. This means that the end result is maintaining the status quo. This is a contradiction of the expressed aims of the Act; to increase the provision of preventative social care preventing people from reaching substantial and critical levels of need.

Care plans and guidance

If an individual is eligible for social care provision, then the local authority will now be obliged to involve them in decisions about how their needs should be met and to prepare a care and support plan which satisfies the

individual's needs. This is a much more personalised approach which should allow people to tailor their care plans to the needs they identify themselves as having rather than relying on the Local Authority assessment.

Councils will now also have to provide guidance and advice to those who do not reach the eligibility threshold as to how to manage their moderate or low level needs. This means that there is at least some help extended to those with low or moderate needs allowing them to reclaim their independence, and they are not neglected, resulting in them reaching the threshold of need a few months or years down the line.

Carers

Carers, who since 1999 have received limited support for social care provision in their own personal capacity, have had their rights to care and support reinforced. The Act, for the first time, will require local authorities to meet carers' eligible needs.

Carers also have to be assessed and meet an eligibility threshold. The criteria

proposed includes considerations of the effect of caring duties on things such as educational and work related opportunities, recreational and social activities, and health and wellbeing, including mental health.

NRAS has concerns about the high eligibility threshold for government support, which excludes many individuals who have clear care and support needs. Many people with RA may be deemed to have 'moderate' or 'low' needs which, if met, would improve their quality of life immeasurably. A small amount of support and care for people could also prevent a deterioration of the condition and an escalation of need in the future. More fundamentally, the admirable sentiments of the Act may be impossible to deliver if the funding for services continues to decrease whilst demand increases.

We will continue to push for access to social care for all those with RA who need it.

RA Awareness Week site visit with Nanette Milne MSP

By Margaret Fiskin, NRAS Member

I was delighted to be invited to take part in the NRAS RA Awareness Week site visit at the Rheumatology Department in Aberdeen. It was the first time I had met Laura and Jamie and it was lovely to put faces to names. The Rheumatology Department has waited some considerable time for new facilities and it seemed appropriate that one of the first events of RA Awareness Week took place there. Nanette Milne MSP was down to earth, easy to speak to and had a very good sense of humour. She appeared to be really interested in the new department and also the current research being undertaken with regard to chronic fatigue.

The round table discussion was particularly beneficial with different points of view regarding the problem of fatigue being put forward by consultants, health professionals, NRAS representatives and last, but by no means least, patients. Sheila MacLeod, Chair of the Scottish Campaigns Network, who is a lovely lady, and I, gave our personal experiences as sufferers of RA. Nanette Milne listened intently to everyone and asked pertinent questions. She was disappointed that there had not been more input from the Scottish

Government regarding implementation of the Scottish Public Health Network Needs Assessment on RA, especially since this report was produced in 2012, and stated that she would certainly be following this up. She also agreed to do further work with NRAS and to table questions and motions within the Scottish Government. The discussion was so successful that it ran past the allotted time and it was good to speak to someone within the Scottish Government who, hopefully, can make a difference for RA sufferers in Scotland.



Margaret Fiskin with Nanette Milne MSP and Dr Neil Basu

Teresa Blee Dance School Summer Show

A big thank you to Teresa Blee Dance School in Helston, Cornwall, which chose to raise funds for NRAS at their summer show. They raised the fantastic total of £1180 from ticket sales, an impromptu cake auction and a retiring collection. The three shows were a sell out with around 100 performers of all ages taking part.



Teresa Blee Dance School Summer Show

One grandparent commented, "What a wonderful evening of very professional entertainment. All the children were a credit to the school and the costumes were amazing and they all looked immaculate."

How winning the NRAS Lottery has helped me follow my passion

With the NRAS Lottery now reaching its first anniversary we thought it was an opportune time to introduce you to one of our many winners.

'My name is Philippa Armstrong and I was lucky enough to win the NRAS Lottery at the beginning of April by matching five of my six numbers. This could not have come at a better time for me, but hey, when wouldn't it be a good time to win £1,000? I too have Rheumatoid Arthritis and am currently saving for an All Terrain Wheelchair to enable me to continue with my passion, competing in Open Dog Agility. I had never heard of NRAS before, but one of the many contacts I made on my fundraising journey mentioned them to me. So I searched online and was interested to see the wealth of information on their website and thought I'd give the lottery a go, never expecting to win, anyway it was for a good cause. So I was both surprised and delighted when the letter arrived with the cheque in it. Smiling broadly, I knew exactly what the money would go toward.'

'I have been competing in Dog Agility for 10 years and have been fortunate to have had two exceptional dogs, Zippy who is unique in reaching Kennel Club Grade four (of seven) and Binky who could beat running handlers' dogs by six seconds, making me the UK's leading wheelchair competitor. However, the ravages of my condition mean I am now unable to compete with my young dog Boogie until I have a specialist wheelchair. I find it hard being sidelined by the lack of the right equipment. I have saved 60% of the £14,000 I need to date, and the NRAS Lottery has helped me take a big step in the right direction.'

'I think NRAS is a great organisation that helps people like me to live the lives we want to; they are one of the smaller charities that really make a big difference and I think are totally worthy of my support.'

You too can sign up to play the NRAS Lottery and play for a chance to be one of our, six on average, weekly winners. It costs £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 the fundraising team at fundraising@nras.org.uk or call 0845 458 3969, alternatively please visit www.nras.org.uk/nras-lottery.



1. Philippa and Zippy 2. Philippa and Binky 3. Binky

Super Heroes take to the park for NRAS

12 NRAS supporters braved the extremely hot weather on 18th May and donned their super hero outfits to run either 5k or 10k around Regent's Park.

The day was scorching and the park was full of heroes, including Batman and Robin, the Mario Brothers and Superman to name but a few! Everyone was there to raise money for their chosen charities and our team did us proud by completing the race and raising almost £5000 for NRAS – well done team and thank you!

We have already signed up for next year's run, so if you fancy becoming your favourite super hero for the day contact fundraising@nras.org.uk or call Val on 01628 501547 who will be happy to reserve a place for you.



Super Heroes take to the park for NRAS

Wishaw Golf Club in full swing for NRAS

Over the last year we have been incredibly grateful to Nigel Fincher who chose to support NRAS during his captaincy at the beautiful Wishaw Golf Club in Sutton Coldfield. Nigel chose to support NRAS, a cause close to his heart, as his wife Marie has RA and helps to coordinate the Sutton Coldfield NRAS Group. Nigel held numerous events throughout the year to support NRAS, all of which culminated in his Captain's Day when NRAS had a stand and there was an evening meal with an incredibly well stocked raffle.

Nigel raised a fantastic £2,000 and Marie kindly accepted the cheque on behalf of NRAS on 5th April. A special thanks goes to Nigel as we are extremely grateful for his support throughout his captaincy, and also thanks to Wishaw Golf Club and Marie for their support.



The beautiful Wishaw Golf Club

If you, or someone you know, are about to become Captain of your local golf club, why not consider supporting NRAS throughout your term? We have a wealth of experience and can help you make the most of your year. Get in touch with Oli on 01628 823 524 or email oliver@nras.org.uk.

Our brave skydivers do it again for NRAS

On a glorious Saturday afternoon another successful skydive was held at Hinton Airfield in Northampton in aid of NRAS.



10 brave souls donned their jumpsuits on the afternoon of 17th May and prepared themselves to jump from an aeroplane at 13,000 feet (some had to be pushed!) Everyone thoroughly enjoyed their jump, even those who were slightly nervous before going up, whilst family and friends who had come along to support, watched nervously from the ground as the parachutes opened and the skydivers glided safely down to the ground.

Over £5,500 was raised by our team of skydivers, and thank you everyone who took part and raised such a wonderful amount. This year it has been so popular we have added another opportunity to jump on 4th October. If you would like join us, visit our website at www.nras.org.uk/skydive or email fundraising@nras.org.uk for more information. It's a great day and one you won't forget for a long time!

Alternatively, you can organise your own skydive. Denise decided to take part in a skydive to celebrate her 60th birthday, and it was also in memory of her mum who battled with RA for many years. Chantal and Graeme took part in a skydive in March; they were inspired by Chantal's gran who lived with RA for many years and her friend who now lives with RA. Katie, who has RA, decided she would like to organise a skydive and chose to support NRAS. Between them they raised over £2,000 – a fantastic amount, thank you.



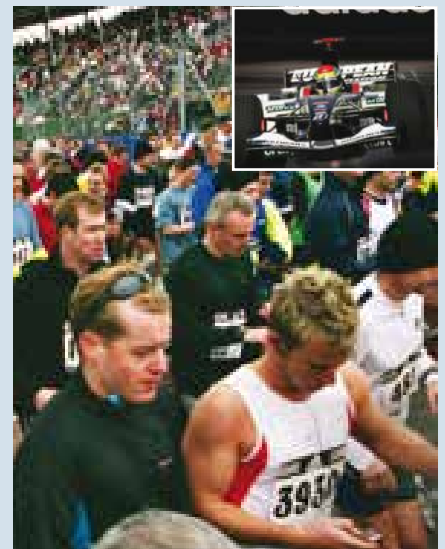
Katie Baker skydiving

New for 2015 - BUPA 10k and Silverstone Half Marathon

For the first time NRAS has places in the Silverstone Half Marathon and the BUPA London 10k, both organised by the team which runs the London Marathon.

The Silverstone Half Marathon is on 25th March and is a great training run if you have been lucky enough to get a place in the London or Brighton Marathon. It takes place at the iconic Silverstone motor racing track.

The BUPA London 10k starts and finishes in St James's Park, with runners passing many of London's famous sights, including Westminster Abbey, The Houses of Parliament, Big Ben and the London Eye. Buckingham Palace acts as the backdrop to the start and finish of this great race.



The Silverstone Half Marathon

For more information on either race please email fundraising@nras.org.uk or call Val on 01628 501 547

Caught in Time

I'm Lorna Anton, I'm 55 years old and work part time in schools supporting children with special needs. I have had RA for 6½ years. I had my diagnosis confirmed on 13th December 2007. In the five weeks up until I was diagnosed I was bedridden and on 14 painkillers a day and still in so much pain. I was unable to do very much at all. I had to be helped up to get up and I had to be fed tea or drinks as I could not hold anything.

My hands were swollen and didn't work. Every joint in my body except my knees were affected, so movement was very difficult. RA has now totally affected my life. I really thought at this point I was dying.

I had numerous blood tests and no one could tell me anything, other than raised inflammatory markers. By the fifth week I was getting desperate; I could not turn my head or move my right arm, I was bent over (hunched) as I was too sore to straighten. My hands were decoration, they didn't work at all.

My doctor on this visit said she would have me hospitalized or have me seen by my now rheumatologist, who did something which I will never forget: She put her hand on my arm and said, *"You will not walk out of here as bad as you have just walked in."*

I was told at this time she thought I had RA but a blood test would prove it. We would know in two weeks.

I knew I could not get any worse so I took the tablets in the hope of beating this RA. I kept diaries and took notes on how I felt, filled in my blood sheets myself and called to check on progress. I was in control now, not the RA, so I could see myself getting better.

It was a really hard time back then and when my youngest daughter cried wanting her mum back as she was, I cried with her and told her I would beat this.

When I look back now I am glad I had a name to what was wrong with me and know that I wasn't going to die. What that does to your head is beyond belief. At that point I was steadily getting worse, no answers and two weeks to Christmas. It was hell.

I could not have managed without my husband; he did so much to help me to do even the simplest things. I was a believer before this that you had to see pain for it to be real.

Boy, was I in for a change of attitude! I had great relief when I was in the shower, in my mind it washed the pain away. I managed personal care myself although it took a long time and I was determined. Looking in the mirror afterwards I looked good but was dying on the inside.

We all pulled together to help me. I sat each morning with my youngest having breakfast as normality for her. I was in agony sitting in that chair and I had to get my elder daughter up to do her sister's hair as I could not hold a brush, or anything for that matter. I have always done what I can manage and do not worry about what I cannot manage. I was bothered by fatigue lots in the beginning but only now if I do too much, which I do from time to time if I am busy doing something and I want it finished.

I now have my life back again and I am pain free, thanks to the triple therapy and my doctor's quick recognition of the RA symptoms, for which I will be eternally grateful.



Lorna Anton

I was asked by AbbVie to attend the Eular Conference workshop in Paris, where I met lots of new people including Dr Tom Sheeran from Cannock Chase Hospital, with whom I was paired to work on the workshop.

I was also asked by AbbVie to take part in an art initiative which involved working with an artist; in my case Lynsey Ewan, a local artist who lives near me. We met and chatted about myself and RA. We met a few times and over a number of weeks this masterpiece was created.

AbbVie is currently working to try and bring the European section of this art exhibition, Perspectives, to the UK in 2015 to coincide with the British Society of Rheumatology annual conference in Manchester in late April. We will keep you updated on this and hope that many of you will be able to see the art created from such personal and inspirational stories.

The hour-glass represents time.

The hand, inflammation and joints are self-explanatory.

The blue and lilac swirls represent the shower which gave me relief.

The sun and my garden flowers were my escape.

Artist Lynsey Ewan
Designed by Lorna Anton
Copyright AbbVie Pharmaceutical Group



Thank you for making RA visible! RA Awareness Week 2014

We were delighted by the support we received in raising the profile of RA during this year's awareness week which took place on 16th – 22nd June. Thank you so much for your efforts to make RA better understood by the general public, we can't make a difference without you!

Media

We received 80 pieces of media coverage and our poster was published in the Metro on the first day of the week. We had celebrity support from Claire King, Jenny Agutter, Jo Whiley, Craig Revel Horwood, Hazel O'Connor and political support from David Cameron, Nick Clegg and Ed Milliband.

The response to our social media activity was immense and this helped us reach out to thousands of people online.

Groups and Fundraisers

We had a successful group launch in Gloucester and a great turn out for The RAmbles, our first walking event, in Worcester. Many of you held information stands and raised awareness in your local area as well as fundraising through tea parties, RAmbles and even wing walking! We'll be showcasing all the amazing things you did during the week in our next magazine so keep an eye out!

Fatigue Report

As part of RA Awareness Week in June, NRAS published new research in collaboration with 2020health on the impact of chronic fatigue on RA. The report included an extensive literature review, which reviewed the clinical



impacts of chronic fatigue and the policy frameworks that inform treatment of this symptom. We began by running a focus group with NRAS Members in March and then worked with several academics and researchers to produce the online survey. The online survey attracted almost 2,000 responses and uncovered significant problems.

83% of respondents felt the public was not at all aware of the impact that chronic fatigue had on people with RA, while 79% said their healthcare professional had never tried to measure their levels of fatigue, and 47% had never spoken to their specialist nurse or rheumatologist about it.

To help launch the report and publicise RA Awareness Week, the Government

Affairs team organised a site visit with a member of the Health and Sport Committee, Nanette Milne MSP, to visit her local rheumatology service in Aberdeen. We also held a Meet the Patients event in the Welsh Assembly so that people with RA could meet their local politicians and raise concerns. Motions were also tabled by friendly politicians in England, Scotland and Wales offering their support and we worked with Linda Riordan to get a post published on a leading political blogging website.

Thank you to those who took part in the research. You can read the report and find out more about the RA Awareness Week 2014 at www.nras.org.uk/RAweek.

The Jeremy Vine Show

Following on from the awareness week Ailsa was invited to discuss RA on BBC Radio 2's Jeremy Vine show, along with Dr Sarah Jarvis on Tuesday 8th July. The show has an audience of 15 million so it was a fantastic opportunity to raise awareness of the condition. The programme is no longer on BBC iPlayer but we have published a recording on our website at www.nras.org.uk/publications/nras-ceo-ailsa-bosworth-on-bbc-radio-2s-jeremy-vine-show



RAmblers rally to the challenge

On a hot day in June over 100 supporters joined NRAS for our first ever RAMble in the grounds of Spetchley Park in Worcester.

We were incredibly lucky to have been given the use of the beautiful grounds in Spetchley Park where you could choose from 1 or 5 mile routes and a wheelchair friendly route around the landscaped gardens, dogs being very welcome on the 1 and 5 mile walks. We were so pleased to see so many of you helping us to raise awareness of RA, and together we raised over £1000 on the day!

Our Worcester group was out in force giving information on their group meetings and encouraging people to take part in their raffle and tombola.

The NRAS fundraising team were on hand to make sure that walkers had enough water before embarking on their chosen routes and that everyone was given a goody bag once they crossed the finish line. Our thanks go to the following who very kindly supported our walk:

- Spetchley Park
- Mars in the Community
- Mars Drinks
- Primafruit Limited
- Asda Supermarket
- Tesco Supermarket

We hope our RAMble will become an annual event during RA Awareness Week and that more of you will get involved and consider holding your own RAMbles. We will be putting together a RAMble pack which will be full of information on how to organise your own event, so watch out for this next year.

A huge thank you goes to Donna and Michael from our Worcester group, whose support ensured we had a fantastic day.



Please see page 20-21 for a selection of the photos that have been taken throughout RA Week 2014

ss Week 2014

ork that goes into RA Awareness week. Thank you to all!



Becoming a Patient Research Partner

By Carol Simpson

Background

My involvement at King's College Hospital NHS Foundation Trust Rheumatology Department unfolded when my rheumatoid arthritis (RA) really began to take hold in 1999. I decided that although the body had become somewhat feeble, the brain was still in good working order and needed to be engaged in something positive. I was unable to physically commit my time to a fixed schedule, so flexible hospital work suited me very well. Expenses are paid and the human interaction is invaluable as RA can be isolating.

How did I get started?

Looking back, one activity led to another: I began to volunteer with my Rheumatology Nurse Specialist – the late, great Cathy Morrison – who asked me to attend a visit with her to a pharmaceutical company and lecture/inform research pharmacists about the impact RA can have on patients' lifestyle and emphasise the importance of their work in developing drugs that would help alleviate the symptoms. These teaching sessions gave me confidence to talk to undergraduate medical students about the realities of life with RA and for them to understand better what the diagnosis means to patients. I was then invited to participate in various focus groups about patient experiences living with a long-term condition; psychological interventions in RA and general group discussions on how best to self-manage the disease. I also play 'patient' for medical students' end-of-year objective structured clinical examinations.

Further involvement

From 2005 I began working closely with the lead of patient involvement in research in the Rheumatology Department (Heidi Lempp). Together with another patient and the Nurse Specialist, we wrote an article for the British Medical Journal Series 'Patient Journey' in 2005, where I highlighted the impact of my diagnosis on my life and the changes and adaptations I had to make to accommodate the disease. Subsequently I continued to be involved in research and pioneered patient involvement in research for studies that related to RA within King's College Hospital and Guy's and St Thomas' Hospital NHS Foundation Trust. For example, I



Carol Simpson

participated in the creation of a Patient Handbook (for a study about intensive treatment for patients with intermediate RA), gave tutorials/questions sessions to small groups of medical students and have been interviewed by researchers from various departments at King's College Hospital in relation to my RA.

Through all these activities I became known as someone who was willing to play my part in research projects and contributed enthusiastically to the wider acceptance of patient involvement throughout both Hospital Trusts. Consequently I have chaired project management meetings as a patient representative and been asked to read/comment on ongoing studies to ensure that the required information is both understandable and relevant to patients and not just 'scientific-speak'.

Recently, along with another Patient Expert, I have been heavily involved in

an Independent Patient Group looking into best practice within the King's College Hospital outpatient clinic, e.g. seating arrangements in the waiting area, delivery of treatment to patients' homes, appropriateness of clinic appointments, etc. In addition, through the patient group, we organised three monthly educational evening meetings for the newly diagnosed patients who live with long-term musculoskeletal conditions. Important topics such as emotional support, adaptation and management of RA with allied health professionals and clinic staff were discussed, followed by a question and answer session, to help newly diagnosed patients understand their disease better. In addition, I attend bi-monthly meetings with consultants/other departmental heads/researchers to feed back about the outcomes of these meetings to the monthly independent patient group (four-six attendees). Also under discussion is a new web platform

for the use of patients/consultants/GPs concerned with Rheumatology, to give greater access to information across all aspects of patients' care, treatment and management, e.g., test results, consultant letters, prescriptions, disease activity charts plus up to date research information and accredited, trustworthy web links.

On reflection

Although I have been involved with research now for a long time (psychological interventions, intensive treatment for intermediate RA) my main focus remains with the patient experience. It is important on the one hand that patients understand their disease and on the other hand that the medical profession appreciates the impact a diagnosis has on the individual. In addition I pay close attention to best practice across the board to ensure both patients and professionals get positive clinical outcomes and personal satisfaction.

King's College Hospital has moved on in leaps and bounds in the area of patient involvement over the last 10 years. When I first started my volunteering I was greeted with a good deal of scepticism and raised eyebrows by doctors in particular. I and other recruited expert patients and carers had to work hard with persistence and humour to gain gradual acceptance and recognition for our contributions in the outpatient clinic and academic team. This collaboration in my view is essential when living with a long-term condition. I now have an Honorary Contract with King's College London and King's College Hospital Foundation Trust. This bureaucratic process took far too long, but it has been helpful to attain acceptance from the less enthusiastic in the medical world!

I would encourage both NRAS Members and others who live with long-term diseases to become proactively engaged with their local hospital. What I have learnt over the last 10 years is: if we don't speak up and offer our help where possible, then overall improvements to the service cannot be truly achieved.

EULAR Edgar Stene Prize Competition 2015



NRAS is pleased to support the Edgar Stene Prize Competition 2015. At the opening ceremony of the forthcoming European Congress of Rheumatology in Rome, Italy on 10th June 2015, the Edgar Stene Prize will be awarded for the essay topic:

"Taking control of my life, working together with health professionals to achieve my personal goals."

EULAR would like to invite people with rheumatic and musculoskeletal diseases (RMDs) to write about their personal experiences and the role that health professionals have played in supporting them to live as independently as possible, achieve important personal goals and to take control of their lives. What have you been able to achieve and how? Each small step counts and we look forward to hearing your inspirational stories. In this context, health professionals may include your nurse, GP, rheumatologist, physiotherapist, occupational therapist or podiatrist - in brief any of the health care team around you. EULAR would also like to hear about what could be improved in your country and if you have access to all the health professionals you need. What should an ideal relationship between health professionals and people with RMDs look like?

Entrants must be age 16 years or over to participate and each national jury

will nominate the best entry from their country. A EULAR jury will select the 2015 overall Stene Prize winner and this will be announced by 15 March 2015. In addition to the prize of €2,000, EULAR provides the recipient with travel to Rome and hotel accommodation for up to four nights as well as an invitation to attend the opening ceremony and the gala dinner at the EULAR Congress (10-13 June 2015).

Entrants should submit an essay, not exceeding two A4 pages, to NRAS by 31 December 2014. Entries can be emailed to emma@nras.org.uk or by post to:

NRAS, Ground Floor, 4 The Switchback Gardner Road, Maidenhead SL6 7RJ

Last year, NRAS Member Liz Buckley was chosen as the UK entry. Although she was not the overall winner, as a finalist her essay was included in Stene Prize Booklet 2014. The booklet and a more detailed outline of the rules can be found on the EULAR website www.eular.org

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



Liz Buckley (right) with her daughters

The use of Stem Cell Therapy in rheumatoid arthritis

Belgian company Tigenix has announced a randomized phase II trial of its adipose(fat)-derived stem cell product Cx611 to start in 2015 for patients with rheumatoid arthritis (RA). Patients who have active RA, despite being treated with methotrexate and steroids, will be enrolled provided that they have not been treated with biologics.

Stem cell therapy is the use of stem cells to treat or prevent a disease or condition. Bone marrow transplant is a form of stem cell therapy that has been used for many years.

The primary endpoint will be remission, defined as a Disease Activity Score in 28 joints (DAS28) below 2.6.

Frank Luten MD, chairman of rheumatology at the University Hospital of Leuven, said in a press release *"There is a need for a treatment with an alternative mechanism of action that could increase the proportion of patients brought into remission and reduce the need to progress to chronic, sequential, and expensive biological therapies."*

The final results of the proposed study could be available in the first half of 2017, according to the company.

Predicting response to anti-TNF – a possible biomarker?

A new study by researchers at the University of Manchester has revealed a potential way of allowing doctors to predict which arthritis patients are most likely to respond to anti-TNF therapy.

At the European League Against Rheumatism (EULAR) annual congress, the researchers presented the findings of their study in which they observed that DNA methylation, is a potential biomarker of response to etanercept and adalimumab therapy in patients with rheumatoid arthritis (RA).

DNA methylation is an important mechanism which controls the gene expression (whether it is "on" or "off"). The team believes that observing changes of this kind can be used to identify which RA patients would benefit most from anti-TNF therapies.

They looked at patients on anti-TNF therapies, who had experienced an extreme response after three months treatment with etanercept or adalimumab. DNA samples were taken before and after therapy started.

The team was able to identify a number of specific genes and processes that appeared to be associated with a better chance of responding well to anti-TNFs. This could be used in the future as the basis for producing diagnostic tests and screening processes.

Since not all patients achieve a good response to anti-TNF therapies, it would be very useful to be able to personalise treatments accordingly.

3D printed wrist splints for people with arthritis

Doctors may soon be able to make custom designed wrist splints for people with rheumatoid arthritis due to a recent innovation in Computer Aided Design (CAD) technology from Loughborough University.

Dr Abby Paterson, from the Design School said, *"I wanted to give clinicians the ability to make splints they have not been able to make before."*

Wrist splints can be designed and made by doctors with little or no experience of CAD. The splints are lighter, less bulky, fit better, and look aesthetically more pleasing. Multiple materials can be used in a single splint and cushioning features can be included. The 3D printed splints are potentially cheaper than current ones and have the added benefit of being more comfortable.

The splints are made by scanning a patient's arm in the position required. Then, based on this scan, a 3D model splint is designed and a computer model generated. A 3D printer can then produce any number of splints, when needed, in a variety of

different styles and colours. They can be made with a lattice effect which can aid with breathability, so reducing sweating when worn, making them more likely to be used by patients.

Dr Paterson was supervised during her PhD by Dr Richard Bibb and Dr Ian Campbell. Dr Bibb came up with the idea for the tailored wrist splints in the late 1990s. He thinks that the 3D splints could be cheaper than the current ones, because the design and manufacture stages have been separated and so could provide savings for the NHS.

NRAS comment: 3D printing is a fascinating evolving technology. It is good to see that this new technology is being used to benefit people with RA and hopefully in future it can be used on other areas of the body such as the ankle.

Chronotherapy: The science of timing drugs to our body clock

Patients with rheumatoid arthritis commonly find that their symptoms are worse in the morning. Doctors are now beginning to think that this is not simply because the joints stiffen up overnight through lack of use.

"Rheumatoid arthritis is driven by cells in the immune system such as T-lymphocytes. These cells each have their own clock and their inflammatory response varies depending on the time of day," says David Ray, Professor of Medicine at the University of Manchester. *"Even when we remove them from the body and look at them in a dish they still keep a day/night rhythm."* The production of hormones are also known to vary throughout the day [this is known as diurnal variation].

Some of the drug therapies for treating rheumatoid arthritis are very strong and there are possible side effects. Professor Ray says, *"The processes that drive the disease are only active for part of the 24 hour cycle – so if we get our potent drug in at the right time we can avoid exposing patients to toxic drugs throughout the day."*

A trial being carried out at the University of Manchester is trying to determine the best

time to deliver drugs. In this way they will only work to dampen the immune system when needed.

Although the concept of timing medical treatment to fit in with our natural rhythms is still unusual, it is one that is gaining ground with more doctors as they realise the importance of our body clocks.

We do have some examples of this in drug therapy already. The slow release of some Non Steroidal Anti-Inflammatory Drugs (NSAIDS) allows better relief of morning stiffness. Recently a delayed release preparation of Prednisolone (Lodotra) was produced to have its maximum action in the early hours of the morning, when the body's own release of cortisone is at its lowest. A lower dose of this Prednisolone was more effective and had less side effects than conventional doses of Prednisolone taken in the morning.

EULAR, Paris

In mid June, Ailsa, Clare, Tracey and Oli travelled to Paris for the annual EULAR (European League Against Rheumatism) conference. EULAR represents patients, health professionals and scientific societies of rheumatology from all European nations and attracts over 14,000 delegates each year.

Arriving in Paris on a very hot Wednesday afternoon to find there was a taxi strike we eventually arrived at the Paris Congress Centre, a huge and not particularly disabled friendly venue! However, over the next two days we each attended a wide variety of interesting and informative sessions on topics including: patient decision making & personalised medicine; self assessment of DAS; building successful alliances with other stakeholders in chronic diseases; self management in healthcare; improving the education and training of future physicians using patients with RA; and a session on care for young people with inflammatory arthritis.

We were fortunate to have Oli, Fundraising Manager, present on the outcomes of the

first RA Awareness Week held by NRAS in 2013, one of our Scottish Ambassadors, Matilda Tumim present on Telemedicine and Ailsa chaired a PARE session entitled 'What's New: latest advances in management and treatment'.

Di Skingle, an NRAS Trustee, who is currently chair of the EULAR Standing Committee of PARE (People with Arthritis/ Rheumatism in Europe) was also very busy ensuring all PARE sessions ran well.

It was a very busy but productive few days and it is always interesting to hear what our European counterparts are achieving and to learn from each other to ensure we are all working towards the best possible outcomes for those living with inflammatory arthritis.



Join the



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



But we need more

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

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

A week in the life of...

Specialist Podiatrists



Dr Lindsey Cherry – NIHR Clinical Lecturer in Podiatric Rheumatology, Solent NHS Trust and University of Southampton

Lucy: I trained as a Podiatrist and began a two month internship in a Rheumatology facility, working within both research and clinical settings. It was here that I first met my colleague Lindsey. My role in Dorset as a podiatrist within the rheumatology department is really interesting and I see patients in hospital and community settings. Recently I started working as a Practitioner one day per week, where I work alongside the consultant in managing patients' disease. Aside from patient contact I recently completed a Masters in Clinical Research and I enjoy speaking at conferences to highlight the importance of foot involvement in rheumatologic conditions.

Lindsey: After qualifying as a podiatrist, I completed a rheumatology research internship. I loved this and continued to work both clinically and as a lecturer from that point on. After gaining some experience, I completed a PhD whilst continuing a clinical role in rheumatology. I was lucky enough to be one of the first podiatrists to receive funding from the Department of Health to continue working in this combined role of researcher and clinician for Solent NHS Trust and the University of Southampton. To me this is the best job in the world. Ultimately, the work that we do helps to improve treatments for patients all over the world!



Lucy Sanders – Specialist Podiatrist in Rheumatology and Extended Scope Rheumatology Practitioner, Dorset HealthCare University Foundation Trust

1. Monday

Lucy: I start at 8.30am to set up my clinic and look over my notes for the morning. Within our hospital clinics, I am placed along the corridor with the rheumatology consultants and practitioners. This works really well. If I am concerned about a patient, I can ask the consultant to speak with my patient briefly or I can provide my patients with prescriptions for antibiotics if they have an infected foot wound. I also often get a knock on the door from another member of the team that would like my opinion on a patient! At lunch time I drive to a clinic that is based out in the community. These clinics are easier for patients to access and often mean that I work a lot more independently. These clinics are varied and I see new patients, as well as patients on a regular basis or those for annual reviews. An example of this would include patients with a past history of foot ulceration, so I would see them to maintain good foot health and keep people as comfortable as possible. This may include issuing items to protect prominent toes, making insoles to deflect vulnerable areas on the bottoms of feet and of course providing advice and education.

2. Tuesday

Lucy: On a Tuesday I take off my 'podiatrist hat' and work as a rheumatology practitioner. This new role is challenging but very rewarding. I am set in a clinical environment with another very experienced practitioner, a GP with an interest in rheumatology, and the consultant. Sometimes, patients are doing really well with no painful joints and we can leave their medications as they are. For others, problems experienced can be very varied. Examples are arranging for X-rays of the neck and spine for someone who has numbness in their arms, altering medications for someone who has active disease, removing fluid from a swollen knee joint or providing advice on pain relief - and of course letting patients know about local NRAS groups!

3. Wednesday

Lucy: Lindsey and I are both part of a specialist interest group for podiatrists working in the south of the country. At the time of writing, we are working on developing guidelines about performing nail surgery for our clinical colleagues to use.

Lucy: Today is our monthly departmental meeting. We review case histories and images such as MRI and X-rays. It is a time that we can get advice from colleagues with a wide range of differing experiences regarding patients where their treatments are more complicated. This meeting is open to any staff that work within rheumatology and is usually attended by consultants, practitioners, podiatrists, physiotherapists, occupational therapists and back fitness practitioners.

4. Thursday

Lindsey: Today, I start setting up our podiatry rheumatology clinics. I also have a responsibility for managing the overall running of the clinics so this means that I look at all the referrals that have come in to the hospital and work with our admin staff to book patients into the next available clinics.

In the clinic we often see patients who have lots of things going on at one time, so we like to go through the patient notes before we start so that we are as fully informed as possible. This means talking to the doctors, nurses, physiotherapists, occupational therapists or community based specialists to make sure that we have a rounded view of what is happening for our patients. Our clinic takes place in the rheumatology department so that the whole team and the patient can be involved in decisions about how best to manage a problem – sometimes it does seem as though we need a bigger room to fit everyone in though!

I have lunch on the run and head over to a different site for the afternoon. Some weeks, like Lucy, I complete a community clinic seeing all kinds of patients. Other weeks I support members of the team to complete evaluations of their service which can include a range of topics. This week I am helping some team members evaluate the impact that rapid antibiotic supply has had for patient care. This is a really interesting part of my role, where I get to share skills that I have learned from research previously to help our clinicians improve their services.

5. Friday

Lindsey: This morning I arrive for 8am so that I can get ready to see patients in the research clinic at 9am. These are really great patients who have volunteered to come and take part in our various foot research projects. At the moment we are looking at what problems they may or may not have with their feet when they start to receive biologic therapy. In this clinic, I ultrasound the joints and

tissues of the foot and then accompany patients when they go for an MRI scan. I have a brilliant team of research nurses that I work with in this role who help make sure that the clinic runs smoothly and that all our volunteers have a great experience.

In the afternoon, I supervise a group of students including those studying for a PhD. This is always great fun, hearing about how the students are getting on and helping them to problem solve situations. It is one of the most rewarding parts of my role when I see my students working with their patients and other researchers to improve care and make meaningful differences in clinic.

6. Saturday

Lindsey: I am usually at the yard riding my horse called Bea.

Lucy: I am either out running or walking along the seafront!



This is us with our respective husbands celebrating with cocktails having successfully done our presentations at EULAR

Group News Autumn 2014

The first six months of 2014 have been very busy with NRAS group launches. Colchester was the first to launch on 27th March and the information evening was hosted by Gill and Kim. NRAS was very lucky to have Dr Richard Watts, NRAS Medical Advisor, present to the group on the advances of treatment in RA and four very keen people came forward to coordinate the group.

They had their first meeting on 3rd July which was organised with the support of Dr Tom Walton from Colchester Hospital and was well attended. The group have already planned the rest of their 2014 meetings!



Dr Richard Watts, NRAS Medical Advisor

April 23rd saw the re-launch of the Great Yarmouth NRAS group. Gill and Kim hosted the evening with the support of the James Paget Hospital rheumatology team, with special thanks to Sarah Small (Occupational Therapist) who was a great driver in getting the group up and running again. Four people have already joined Kim and Gill for a planning meeting (via our first video conference!) and have lots of ideas to take the group forward – keep an eye on the NRAS website for details of their future meetings.



Some of the rheumatology team from James Paget Hospital

The new group in Banbury launched on 21st May. This had been in the planning for some time with Maureen Cox (Advanced Nurse Practitioner, Rheumatology) and three very motivated NRAS Members - John Bone, Lesley Nell and Elizabeth Mueck. The planning most certainly paid off as there were over 70 people who attended the information evening hosted by Gill, Kim and Tammy from NRAS. Professor Nigel Arden

from Oxford University kindly came straight from clinic to present to the group, which was very well received. From the launch a further five people came forward to volunteer their time to ensure the Banbury group succeeds. They held their first group meeting in June with a talk entitled 'Understanding Medications'. The group coordinators are currently scheduling in dates for the remainder of 2014.



Professor Nigel Arden

The most recent launch was held in Gloucester on 18th June, during RA Awareness Week, with Gill, Kim and Nicky from NRAS facilitating the evening. This event was really well attended with in excess of 100 people turning up on the night! Local NRAS Member/Volunteer Sharon Branagh was the driving force behind this new group and spent much of her time on the lead up to the event promoting the launch, with local information stands and even a radio interview. The information evening was well supported by the rheumatology teams from Gloucester Royal and Cheltenham General Hospitals. 17 people showed interest on the night in helping to coordinate the group with Sharon. 2014 meetings have already been organised with the first taking place on 13th August.



An enthusiastic Sharon shares her vision for the NRAS Gloucestershire group

NRAS would like to thank all the Volunteers and the rheumatology healthcare professionals who made these group launches such a success. Kim and Gill are very positive that these are strong new NRAS groups and we wish them every success!



Gill & Kim

But there is no resting on our laurels, during July and August Kim and Gill will be busy planning for the five new groups due to launch in autumn and winter this year:

- NRAS Gwent (South Wales) on 15th September
- Derbyshire NRAS (Chesterfield) on 7th October
- NRAS East London (Mile End) on 13th October
- Salford/Manchester proposed date 20th October (TBC)
- Truro (Cornwall) proposed date 12th November (TBC)

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

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

NRAS Roadshows 2014

Following on from the success of last year's training Roadshows for Members and Volunteers Clare, Gill and Kim took the NRAS Roadshows to Elstree in North London, Bristol, Leamington Spa and York. 67 Members and Volunteers joined in the activities and workshops to inspire them to get actively involved with the work of NRAS and services in their local area.

At each event there was a representative from the local Healthwatch who presented to the delegates on the work of Healthwatch England as well as the work of local Healthwatch teams. Many of the Members and Volunteers had not heard of Healthwatch so these presentations were very well received and timely, during such a time of change within health and social care delivery throughout the UK. If you would like to find out about Healthwatch in your area, please go to www.healthwatch.co.uk.

At the Bristol and Leamington Spa Roadshows we previewed the new exercise section of the NRAS website which you can find at www.nras.org.uk/exercise. Attendees got to try out some of the exercises and gave very constructive feedback on the new online resource.

At Elstree we were joined by Faeza Keshavjee, an experienced Tai Chi and Qigong tutor, who took the group through

meditation and gentle exercise which all seemed to enjoy. In York, Pilates instructor Fran Haggerty, who runs classes locally specifically for people with reduced mobility, took the group through a full body exercise routine, all of which can be done from seated position. If you are thinking of joining an exercise class please make sure it is suitable for your level of mobility and ensure your tutor is aware that you have RA.

A choice of two sessions was offered at the Roadshows during the afternoon. Attendees could take part in a focus group to help with the design and content of a new NRAS publication or, for those currently running NRAS groups or planning to start one, there was a workshop on sharing the challenges and successes of being part of a patient group. There were many great ideas shared in all sessions, so we thank everyone for their contribution.

In their feedback from the Roadshows Members answered that they most highly valued the opportunity to network with each other, share ideas and best practice on running local groups and participate in other aspects of the work of the society.

Kim, Gill and Clare would also like to say a big thank you to Beverley and Sally from the NRAS Helpline who helped to facilitate a couple of the Roadshows. Our thanks also go to Daniela and Ruth from NRAS Media Team for facilitating a session on utilising all forms of media to get the NRAS message out there!

Thank you to all who attended the Roadshows for showing your dedication and commitment to your Society. We hope to see some of you again and hopefully many more of you at the Annual Conference in Yorkshire on 19th September.



1. NRAS Roadshow Bristol 2. NRAS Roadshow Elstree 3. NRAS Roadshow Leamington Spa 4. NRAS Roadshow York

Biosimilar medications - Uncharted Waters, a stakeholder event

Biological medicines have revolutionised the treatment of many immune-mediated inflammatory diseases (IMIDs). However, the escalating burden of chronic disease amid cost constraints means that not all patients have access to them. Biosimilar medicines are an important and relatively new category of biopharmaceuticals, which may be defined as medicines made, using or derived from, living organisms using biotechnology. There are more than 200 such products on the market today. Some 300 more are being investigated in clinical trials. When relevant patents have expired, biopharmaceuticals can also be marketed by companies other than the company that originally marketed the product. This novel subclass of biotechnological medicines is most commonly known as 'biosimilar medicines'. Biosimilars have comparable quality, efficacy and safety to that of the originator biological medicine. Biosimilar medicines have the potential to increase availability of effective treatment on a global basis but, with that opportunity, comes a large degree of uncertainty, creating a vast expanse of uncharted territory for all involved.



Royal College of Physicians building

In collaboration with NASS, CCUK & Psoriasis Association, NRAS co-hosted a stakeholder meeting in April at the Royal College of Physicians. NRAS has worked with these other patient organisations representing those living with IMIDs before and it was important to collaborate to gather the varying viewpoints of patients, physicians, pharmaceutical industry and regulators as we have a common need for information, clarification, debate and discussion.

This event took the important first step in gathering views and concerns around this new development in the sector. Presentations from representatives of industry, academic research, the British Rheumatology Society for Rheumatology Biologics' Registry and regulatory bodies set out to explode some of the myths, identify common themes and isolate areas of uncertainty that need further clarification.

The event was made possible by an unrestricted educational grant from the Association of British Pharmaceutical Industry (ABPI) Biosimilars Taskforce.

The entire meeting was filmed and is available to view on the website www.nras.org.uk/biosimilars as is the



Panel of speakers Matt Regan, Ailsa Bosworth, Professor Peter Taylor and Bill Richardson

report on the evening's presentations and discussions. The report summarises the main topics covered and questions raised. It represents a first attempt to scan the landscape and identify a navigable path that will ensure that the patients with Immune Mediated Inflammatory Diseases, and indeed the wider public, are correctly informed about these new therapies.

The NRAS position paper on biosimilars is available on the NRAS website to download. NRAS Members will be kept updated and informed of any future developments as the world of rheumatology enters this new territory of biosimilar therapies. If you are currently on a biologic or about to commence biologic treatment and have any questions or concerns about biosimilar medicines do ask your rheumatology team for their views and what their department's position is on utilising this new generation of therapies.

How reliable is RA information on the internet?

As a group of five physiotherapy students from the University of the West of England, in our final year we embarked on the challenging task of researching and writing an 8000 word literature review. It was identified early on that we all had an interest in rheumatology and with the help of lecturer, Rachel Thomas, we decided to tackle the important issue of the quality of online educational resources for individuals with Rheumatoid Arthritis (RA).

So why was this research necessary? RA is a chronic condition affecting around 690,000 individuals in the UK alone making it a very relevant topic in today's society. Due to the nature of RA it is well established that individuals with the disease regularly access information regarding their condition, with more and more turning to the internet to do so. A recent study found that 80% of internet users are accessing health information online, with a third of those reporting it was easier than accessing information from healthcare professionals (Gordon, Capell and Madhok, 2002).

Furthermore, the chronicity of the disease means that individuals with RA must engage in self-management to improve health outcomes. Education about the disease forms a big part of this and with more people choosing to turn to the internet we must ensure that the information provided is both accurate and beneficial. Currently there is limited research into the quality of such online resources.

The aims of this research project were to establish the quality of online education resources available for adults with RA, and discuss the implications for clinical practice and future research. A number of online databases were searched to highlight articles of interest and a final three were included in our systematic review.

Overall the quality of the articles and how they measured quality varied, making it difficult to make comparisons between them and draw relevant conclusions. Due to the constantly changing nature of the internet the research becomes quickly dated and so more up to date research was indicated.

Despite the lack of quality in the articles found our generalised findings were

that firstly non-profit, university and government organisations provide the highest quality information compared to those with a financial interest.

Secondly, as physiotherapists it is important to be aware of the clinical implications this research has highlighted. We must understand the potential dangers of our patients accessing poor healthcare information and be aware of high quality sites to sign post patients to, such as the National Rheumatoid Arthritis Society and Arthritis Research UK.

Thirdly, our research highlighted the need for a validated tool or measure to assess the quality of the information on these websites. We found that more articles could have included patient involvement and whether they can distinguish between high and low quality sources of information. As well as this it was apparent that quality is a very subjective measurement and was measured differently between studies. The term quality should be constituted in further studies to make the findings more specific, for example the accessibility or accuracy of online educational resources should be searched.

Finally, the Information Standard, a scheme promoted by the Department of Health to regulate health information published online, is being utilised by a few organisations including the National Rheumatoid Arthritis Society. However more needs to be done to improve its awareness and promote its use on a variety of health websites.

The findings from our research were presented on 4th June 2014 to Clare Jacklin from the National Rheumatoid Arthritis Society and other post graduate researchers and again at the Allied Healthcare Professions conference. The literature review was undertaken by Sophie George, Pippa Harley, Martha Moore, Stephanie Murray and Alice Watts.

For any further information please contact Martha Moore at martha2.moore@live.uwe.ac.uk

*Full reference for the journal cited is:
Gordon, M., Chappell, H. and Madhok, R. (2002) The use of the Internet as a resource for health information among patients attending a rheumatology clinic. Rheumatology [online]. 41 (12), pp. 1402-1405. [Accessed 15 July 2014].*



Our dissertation group

Harnessing the power of technology

Robin Christopherson, Head of Digital Inclusion at national computing and disability charity, AbilityNet, looks at how we can harness the power of technology to help disabled people in the workplace.



Did you know that over 80% of disabled people acquire or develop their condition during their working lives? And sadly, up to 40% of those with rheumatoid arthritis leave their jobs within five years because of their diagnosis.

At AbilityNet we believe strongly that this shouldn't be the case and that disabled people can continue to make a valuable contribution in the workplace and in many cases, continue to do their jobs just as productively as they did before.

The Equality Act (2010) stipulates that employers are legally responsible for ensuring that their employees are adequately equipped to do their job. This includes making 'reasonable adjustments' to their workstation, their working conditions and other environmental factors in order to make them as comfortable as possible.

As we know ignorance is no defence in the Law and so, not having systems in place to discover whether staff members need help is not a viable excuse. It is therefore the employer's responsibility to take reasonable steps to find out whether adjustments are needed by building checks and measures into employment policies and practices at recruitment and within regular line management processes.

Reasonable adjustments can apply to almost any aspect of an individual's working situation. They may need to move location because of specific environmental conditions and their potential negative impacts on their health. Differences in levels of natural light, cold, heat, draughts, etc, can have profound effects on some people and their comfort can be improved radically simply by changing office.

Flexible working patterns can also qualify as a reasonable adjustment for someone with a progressive or fluctuating condition. In a chronic and relapsing disease like rheumatoid arthritis, characterised by 'flare ups' and periods of feeling better, an adaptable approach to working hours is a reasonable response.

But it is perhaps in the arena of workstation adjustments that we can make the greatest improvements to an employee's wellbeing. If we consider that over 90% of jobs involve IT and that 77% of administrative and clerical jobs are still occupied by women (who are three times more likely to suffer from RA), issues around desk-bound comfort and productivity become paramount.



Barbara

How does a workplace assessment work?

Every person's situation is different and an assessment by a qualified professional is the first stage in identifying individual needs and recommending adjustments. It involves:

- Close observation of the client at work and their direct environment
- Confidential discussions focusing on the client's job remit, relevant history and current circumstances
- An understanding of what is required and what the client would like to achieve
- An opportunity to try out recommended hardware and software solutions
- An in-depth discussion of the assessor's conclusions

How much does it cost to make a reasonable adjustment?

- Physical adjustments might include new computer hardware or software, ergonomic furniture or specialist office equipment

- Non-physical recommendations may involve changes to hours or conditions, a phased return to work or re-allocation of duties; job sharing or home-working

Whilst the cost of recruiting and training a clerical grade member of staff is nearly £8,000 (CIPD), the average cost of a workplace adjustment – in the experience of our clients – is just over £700. It simply makes good business sense to retain good staff. By ignoring the needs of a valued employee, an organisation risks losing their expertise and experience as well as their loyalty, also enhancing the possibility of litigation down the line.

Staff with disabilities can be a major asset to any organisation as we have found in our on-going relationship with one of the UK's largest providers of financial services, which has been using our Workplace Disability Assessment Service for over two years. It was amongst the first major employers in the country to introduce a formal inclusion strategy and their example demonstrates graphically that, supplied with the right workplace adjustments, disabled employees can be as productive as their colleagues, they take less sick leave and stay longer in their jobs.



Anne Marie

Our work with them began when an in-house survey revealed staff with disabilities to be less engaged than their 'able-bodied' colleagues due to lack of support and inadequate provision of appropriate workplace adjustments.

The company, recognising that immediate action was required, put an effective

workplace disability management process in place based on a commitment to attracting, nurturing and retaining the best talent. They understood that the situation needed a mainstream 'best practice' solution, not simply a legal compliance measure. As a senior director observed at the time: *"The new process was to help colleagues perform at their best – not merely what a court might deem to be 'reasonable.'"*

With help from AbilityNet, the company was able to develop a streamlined 'one-stop shop' approach, which increased the speed and reduced the complexity of the processes involved in supplying employees with the adjustments they require.



Mike Miller

In 90% of cases, a full AbilityNet workplace assessment is required either face-to-face or remotely using telephone and remote viewing technology to identify the appropriate workplace adjustments needed.

Says P, an executive assistant: *"I have rheumatoid arthritis and every time I've needed to change something, I've always had support to do that. I recently requested another workplace adjustment because my health has deteriorated. The last time I asked for a piece of equipment – a footrest – it arrived within a week."*

Says A, an HR project manager: *"I am registered blind and have quite a bit of assistive technology to do my job. As far as I'm concerned the playing field is absolutely level because of this equipment. Without these adaptations, I wouldn't have a job."*

AbilityNet offers free advice and support at www.abilitynet.org.uk or call Freephone: 0800 269545. Our IT Can Help service helps disabled people with IT at home for free.

Arthritis Research UK Rheumatoid Arthritis Pathogenesis Centre of Excellence launches

The Centre was launched on Friday 6th June by Olympic gold medallist, Dr Katherine Grainger, in the opulent surroundings of the Banqueting Hall of Glasgow City Chambers.

The project, a partnership between the universities of Glasgow, Birmingham and Newcastle, aims to find out more about the causes of rheumatoid arthritis, a serious, inflammatory, auto-immune condition that affects the joints and the body's internal organs leading to chronic pain and fatigue.

Arthritis Research UK is contributing £2.5 million to the project with the three universities contributing an additional £4 million. Part of the funding allows for the recruitment of PhD students and post-doctoral researchers. They will spend time based with at least two of the partners, enhancing communication between the three centre hubs.

The event, which was attended by around 200 guests including researchers from the three partners and sponsors, and patients, schoolchildren and clinicians from the Glasgow area, was compered by sports presenter, Alison Walker. The High School of Glasgow Chamber Choir entertained the guests with pieces from their award-winning repertoire.



L: RACE launch (L-R) Dr Stephen Simpson and Chris Buckley from AR UK, Katherine Grainger, Professor Iain McInnes and Professor John Isaacs
R: Ailsa at the launch of the new Arthritis Research UK Rheumatoid Arthritis Pathogenesis Centre of Excellence

Posters were prepared by rheumatology researchers to explain the disease and the Glasgow Science Centre was there with a number of their touring exhibits.

Professor Iain McInnes, Director of the Institute of Infection, Inflammation and Immunity at the University of Glasgow, will lead the new centre. He said: "This new centre aims to address the unmet needs of more than 400,000 people in the UK who suffer from the crippling condition of rheumatoid arthritis. It will help us learn more about the mechanisms behind this disease and how we can use this knowledge to develop more effective treatments, and maybe even, one day, a cure.

"What we hope this new centre will enable us to do is to take a much more personalised approach to rheumatoid arthritis, so that patients can benefit from treatments more attuned to their own experience of the condition and their own physiology."

My Story... *By Sally Merrey*

I always thought of myself as a high flier! You're never too old for cartwheels, so at 37, on holiday with friends in Scotland I took to the boards next to the waterfront and started my run up. 30 seconds later I'm collapsed in a heap on the floor, my hands and wrists give way on me. Umm, maybe I am too old for this?

Not once did I think that there might be a problem with my hands – why would I? But now I know that was my first trigger, that I would soon be getting more and more “symptoms”, but what for? It took me three years to eventually be diagnosed with rheumatoid arthritis (RA). Having now read more and more on my disease, a long diagnosis period appears to be a common theme. Sore hands, swollen joints, sore feet, stiff hips were met with “it’s your age” or “it’s wear and tear”. Thankfully after blood tests, scans, prodding and poking here I am. I felt a bit of a fraud at my specialist appointments, I was the youngest one there by about 30 years but it’s only through education that I now appreciate it affects young and old, men and women and children of all ages.

RA affects many people in different ways and thankfully I have only had three major flare ups in my hips and shoulders which meant I couldn’t even get out of bed and the pain was pretty unbearable, but mainly my day to day problems are gripping things, not being able to put pressure on my hands or wrists which affects cutting food, holding saucepans, etc. I had to learn to do basic things around the house in different ways so as not to make my condition worse. My job is in financial services and it is 95% admin based so carrying files and even writing can be hard some days as I can’t even grip a pen. For me, it’s learning that if you ask for help it’s there and remembering that you can’t always do the things you used to but you don’t have to feel useless – it’s all about adapting.

I don’t feel alone though – local NRAS groups, media information and awareness, magazines, radio and television are all being used to spread the word that there is help, support and care for all of us. It’s not just a 6 monthly trip to talk to my specialist – I can learn so much more and gain help and tips for coping on a day to day basis.

There is so much more I need to know though and I think I have spent the last nine years in slight denial and probably haven’t taken my condition as seriously as I should. RA doesn’t just affect your joints, it can affect major organs, skin and your eyes. Fatigue is also a major hindrance and is not fully appreciated. There are so many things to think about and not just for sufferers but for those who care for us too.

That’s why when I heard of the NRAS RA Awareness Week I wanted to do something to help raise funds and

awareness in my own circle of family and friends. If I don’t fully understand the implications of living with RA, will they? So, whilst I am still able to, I went one better than a cartwheel – A WING WALK!! Kindly sponsored by my employer, Kingsley Financial Planning Ltd, in Leamington Spa, I planned my daring challenge. Many people wondered how with RA I could even get up on the wing and I can tell you, it wasn’t easy but I did it; I flew in the air on a Stearman plane up at 500 ft and 130 mph for 10 minutes (thanks to the marvellous pilots and staff at Aerobatic Tactics Ltd) and with the help of my family and wonderfully supportive husband, recovered from the after effects to see my target of £1,000 surpassed and I have raised £1,215 in total. So many kind donations were given by friends, family and people I didn’t even know – so you know... THE SKY’S THE LIMIT!



Sally after completing her wing walk

“Thanks to the marvellous pilots and staff at Aerobatic Tactics Ltd”



Sally ready to go!

Dear Helpline...

I have been told that I will be changing from my Metoject syringe to a Metoject pen. What can you tell me about this?

From 1st July the Metoject syringe was discontinued and the new Metoject PEN introduced. However, some hospitals and pharmacies may still have a stock pile of the Metoject syringes so will run these down before introducing the PEN, therefore you may not have been switched to the PEN yet. Eventually though everyone will be moved over to the PEN version.

The main difference between the syringe and pen is that the PEN is an auto injector, which means it is a spring loaded, push button device. It also has an automatic shield that slides over the needle following injection, to prevent the possibility of a needlestick injury.

It is a single use device and will deliver only one dose. You should dispose of the PEN in exactly the same way as you did the syringe – into a sharps bin.

Just like the syringe version, the PEN will be available in a range of doses. The body of the PEN and outer carton are colour coded so that the various strengths are easily identifiable.



Instructions for storing the PEN are the same for the syringe version. It can be stored at room temperature (less than 25

degrees centigrade). It can also be kept in the fridge (minimum temperature 2 degrees centigrade) but should be allowed to warm to room temperature before it is used. It can be stored for up to two years from date of manufacture.

If you usually receive your Metoject syringe via a homecare company such as BUPA or Healthcare at Home this will continue with your PEN. Medac, the company who produce Metoject, have provided patient information literature for the homecare companies to distribute to you, and likewise have produced literature for pharmacists, consultants and nurses so they can inform patients on how to use the PEN.

If you have any queries or concerns regarding the pen, please contact your pharmacist, rheumatology nurse specialist or GP.

Further information and a video link that takes you through the self injection process step by step can be found at www.metoject.co.uk

I have read in the papers recently about a new treatment for rheumatoid arthritis using stem cell therapy. Could you tell me more about this and when it is likely to be available?

Stem cell therapy is the use of stem cells to treat or prevent a disease or condition. Stem cells are the original cells in human tissue (the body's "raw materials") that can make exact copies of themselves indefinitely. They have the ability to modify or differentiate into specialized cells for various tissues in the body, such as heart muscle, brain tissue, and liver tissue. No other cell in the body has the natural ability to do this. Embryonic cells in the foetus are the classical stem cells, and cells from the bone marrow are stem cells used in bone marrow transplantation, a treatment for leukaemias that has been used for many years.

Researchers have discovered several sources of stem cells. Embryonic stem cells – these come from embryos that are three to five days old and Adult stem cells – these are found in small numbers in most adult tissues, such as bone marrow, liver or fat. Embryonic stem cells can divide into more stem cells or they can become any other type of cell in the body. Adult stem cells are more limited as to what they can become, usually only the tissue they are derived from.

Much research is being done into the use of stem cells to treat a variety of diseases but recently a Belgian company called TiGenix has announced the

clinical development of its adipose (fat)-derived stem cell product Cx611 for treating rheumatoid arthritis. This will begin with a randomized phase II trial scheduled to begin in 2015.

The study will enrol patients who have active rheumatoid arthritis (RA) despite treatment with steroids and methotrexate, but who have not received any biologic therapies. The final results could be available in 2017 which will help to determine if this is may be a viable treatment for RA.

I've recently read online about some new drugs for treating rheumatoid arthritis called "biosimilars." What are they and how do they differ from the biologic drug treatments that are currently available? When will they be available in the UK?

To understand what biosimilars are and how they differ from the current biologic drugs it is necessary to know a little bit about what biologic drugs are and how they are made. Unlike the more common standard disease modifying anti-rheumatic drugs (DMARDs), such as methotrexate and hydroxychloroquine which are small molecules and can be reproduced exactly, biologics are large molecules. They are manufactured in a different way from the standard DMARDs as they are produced from a living organism that contains proteins from living cells. Because they are much larger and more complex than typical small molecule drugs, the manufacturing process for them is highly complicated and they are difficult to produce commercially.

Biosimilar is the term given to describe officially approved, subsequent versions

of biologics made by a different company following the expiration of the patent on the original drug. The new manufacturer does not have access to the original living cells that the original drug was made from, and the exact production process will be different, so they will not be exactly the same as the original biologic. Biosimilars are permitted to have small, structural differences from the original but, these must not alter how well the drug works, how safe it is or how the drug reacts with the body's immune system.

The following biosimilars have recently been licensed for use in the UK: Inflectra, marketed by Hospira, and Remsima, manufactured by Celltrion, which are essentially the infliximab (Remicade) biosimilar. They have been approved by the European Medicines Agency (EMA) for the treatment of inflammatory conditions

including rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis. Although Inflectra and Remsima have been approved, a last minute extension of the original patent on Remicade means that they are now unlikely to be available in the UK before February 2015.

To read more about biosimilars and the work NRAS has been doing in regard to the advent of biosimilar medicines, please go to the NRAS website.

The EMA have also produced a very helpful information sheet which you can view on this link – www.ema.europa.eu/docs/en_GB/document_library/Medicine_QA/2009/12/WC500020062.pdf



NEWS &

Christmas Cards – FREE postage & 2013 prices!

We have a brand new range of Christmas Cards for you to choose from this year, which you can now purchase online at www.nras.org.uk/shop, by returning the enclosed flyer in this copy of your magazine or by calling 01628 823524 and speaking to a member of the fundraising team. Once again we are offering FREE postage on your order and we have frozen our prices at £4 per pack.

A few remaining cards from last year are also available on our shop and can be purchased for £2.50 per pack, again postage is free.

Be sure to get your orders in early and beat the Christmas rush!

All proceeds from the sale of cards go directly to supporting our work so please do consider supporting us by buying our cards.

Calling all Health Professionals

One of our core activities and goals is to work as closely as possible with Allied Health Professionals. This year we are undertaking a survey of health professionals (to include anyone who comes into contact with RA patients such as pharmacists, GPs, community nurses) to find out what you think of the services we provide and what you would like us to do in the future.

- Are there any topics that our publications do not currently cover?
- Have you ever attended one of our NRAS group meetings?
- Are you aware that NRAS runs a self management programme?
- Have you ever called the NRAS Helpline on behalf of a patient?

We value all your comments and want the future direction of the work we do to reflect the needs of health professionals to ensure we are doing everything we can to assist you in improving patient information and education. The link to this short survey can be found on our website <http://www.nras.org.uk/surveys> and should only take 5-10 minutes to complete, so please do take part and help us to help you. Thank you in advance.



Join us for our Annual Christmas Carol Concert

Singing voices at the ready, as we will once again be holding our annual Christmas Carol Concert, on Friday 12th December at All Saints Church in Maidenhead. We would love you to join us so please put the date in your diaries.

For more information or to register please visit our website at www.nras.org.uk/events or email fundraising@nras.org.uk. Once again the event will be free with a retiring collection at the end of the evening.

We hope to see you there!

EVENTS

Nearly new NRAS website!

You will hopefully have seen our new website which went live in April 2014. We've had some great feedback and hope you've found it easier to navigate around and find the information you are looking for.

The integrated shop and groups map have now been added and we also have an updated Members' forum. The archive from the old forum has now been restored and can be accessed through the new version. Do log in and have a look around! It's a great space to find lots of information and to talk to other people with RA.

NRAS Gwent (South Wales) on 15th September

**NRAS Gwent
Rheumatoid Arthritis Information Evening**
Lecture Theatre in the Education Centre
Ysbyty Ystrad Fawr Hospital
Hengoed, Caerphilly CF82 7EP
6:30pm – 8:30pm

Derbyshire NRAS (Chesterfield) on 7th October

**NRAS Chesterfield
Rheumatoid Arthritis Information Evening**
Bridge Street Methodist Church,
(also known as Pilsley Methodist Church)
Bridge Street, Pilsley, Chesterfield, S45 8HE
6.30pm – 8:00pm

NRAS East London (Mile End) on 13th October

Look out for more details coming soon!



Attention Health Professionals

Many of our health professionals order our publications in bulk, which can be costly to send. However, have you considered ordering just one copy of each of our main publications as reference copies? We can then give you handy order forms that are quick and easy for patients to complete and send back to us. Patients can also see the full list of publications we offer and they have the option to download them from our website if they'd prefer. This means more space in your rheumatology units, less wasted out of date copies and valuable funds saved for NRAS! Email enquiries@nras.org.uk or call 0845 458 3969 to request some order forms and/or reference copies of publications.

medac launch Metoject® PEN

medac GmbH announces the introduction of Metoject® PEN, a pre-filled methotrexate auto injector. From 1 July 2014, Metoject® PEN will replace the Metoject® range of syringes which will be discontinued.

The main difference between the Metoject® PEN and the Metoject® syringe is that the PEN is an auto injector. It has a different administration process and an automatic shield which slides over the needle following injection to prevent the possibility of a needlestick injury. The PEN is a single use device which delivers only one dose and is disposed of following administration. The same colour coding as the syringes has been applied to make the various doses easily identifiable for patients and this is visible on the body of the pen and on the outer carton. Storage is at room temperature and the shelf life is two years from date of manufacture.

Key features of Metoject® PEN:

- Easy to handle
- One button activation
- Automatic needle shield protection
- Single use

For further patient information on Metoject® PEN, please contact your pharmacist, nurse specialist or GP or visit www.metoject.co.uk



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To see what is happening
on Helpline follow them

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information follow

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

giftaid it

Tweets

Ben2Ben @Ben2BenUK · Jun 22
Lochnagar longest day sleepover, 1st #munros for some with RA.
[@NRAS_UK](#) #RAAW14 #lookdeeper



1 4 View more photos and videos

Wendy Hardwick @Wendy_Hardwick · Jun 23
[@NRAS_UK](#) and thank you for all you do! Keep up the great work NRAS!

1 View conversation

Thérèse Humphrey @TerezHumphrey · Jun 23
[@chroniccurve](#) [@NRAS_UK](#) Yes I so agree! "#LookDeeper" My favorite hashtag by far next to #Rheum. Gr8 job at promoting true #Awareness!

1 View conversation

Sally-Anne Hunter @SallyAnneHunter · Jun 22
A big thank you to [@NRAS_UK](#) for their inspired #Lookdeeper campaign raising awareness of the "invisible disease" rheumatoid arthritis

Please Remember NRAS in your Will

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

A Gift in Your Will Supports Our Future



nras
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Arthritis Society

National Rheumatoid Arthritis Society
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