

Members'

MAGAZINE

WINTER 2016



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National Rheumatoid
Arthritis Society



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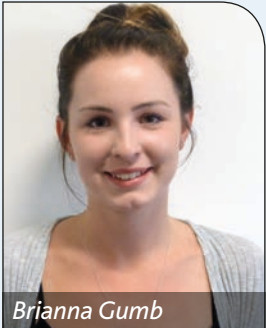
GET IN TOUCH

www.nras.org.uk
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By Ailsa Bosworth, MBE

Chief Executive



Brianna Gumb

A hearty welcome to Brianna

We are delighted to welcome Brianna to the team who joins us as Fundraising Administrator. Brianna's key responsibilities are acting as front of house for Membership and Fundraising Team as well as responsibility for our Payroll Givers and e-fundraising income streams, she is also on hand to process all last-minute Christmas card orders. (It's not too late to put your order in for your NRAS cards).

Brianna joins us with a wealth of exceptional administrative experience, having worked most recently with Virgin Experience Days managing the Shard Experience. Looking to now embark on her career in the charity sector we are delighted to have her on board; she is already a key member of the team fitting in perfectly and learning about all aspects of NRAS membership and fundraising. Welcome Brianna.

Winter 2016

Dear Members



Ailsa with his Honour The Deputy Lord Lieutenant, Charles Elly to her right and Deputy Mayor of the Royal Borough of Windsor and Maidenhead, Councillor John Lenton and His Escort the Deputy Mayoress, Margaret Lenton

We have just celebrated our 15th birthday (October 20th). I can't believe how rapidly 15 years seems to have gone by and how much I have learnt over that period of time. If only I had known what I know now when I was diagnosed all those years ago, many things might have been different!

We had a lovely celebration with friends and supporters here in the office and some of the very kind messages which people sent on video can be viewed at bit.ly/nras15years. There are a lot of people to thank for helping us to get from zero to where we are today and I can't name them all as they would fill this magazine but I would like to single out a few who have been unstinting in their support for us over many years. Professor Gabriel Panayi encouraged me to start the charity and has been a staunch ally since before we launched in October, 2001. He was President of the British Society for Rheumatology at that time and helped us to appoint Medical Advisor Rheumatologists all over the UK which was a very solid foundation of access to specialists as we started to build the NRAS resources. As an evidence-based health charity, it was always important that we have the medical evidence base backing our information and support from the get go.

When Gabriel retired from the NHS and became a Patron, Professor David G.I. Scott took over as Chief Medical Advisor and served in this role for many years until he retired from the NHS. Following in his footsteps as Chief Medical Advisor was Professor Peter Taylor, the Norman Collison Professor of Musculoskeletal Medicine at Oxford; no matter

where he is in the world, he always responds to our emails, often within minutes, which never ceases to impress us. We can't thank them all enough for everything they have done and continue to do for NRAS. Sue Oliver, retired Nurse Consultant who got a much deserved OBE for services to rheumatology a few years ago is another health professional I'd like to thank. Sue and I have done many projects together over the years when she was our Chief Nurse Advisor and helped us to start our volunteer network back in 2003! She and I were joint Chairs of the Rheumatology Futures Group which commissioned the King's Fund report into RA Services across England, published in 2009. The Group also produced the 'S' factor posters you may be familiar with raising awareness of RA symptoms.

I think this year has probably been the busiest year I can recall and we have some very exciting projects in the making so I think next year will be an important one in furthering the aim of NRAS which is to be there at the start of everyone's journey with RA and whenever you need us along the way.

So, to all our brilliant staff and trustees (past and present), Members, Volunteers, health professionals, friends and supporters, thank you all for your contributions. You have helped to make NRAS the organisation it is today. Here's to the next 15!!

In the meantime, we wish you a wonderful Christmas and all the very best for a Happy and Healthy New Year from everyone here at NRAS.

Members' MAGAZINE

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To comment on this issue or to submit a story or article for a future issue please email editor@nras.org.uk

Editors of this issue:
Clare Jacklin, Director of External Affairs
and **Sally Wright**, Head of Marketing and Communications

Meet the Team

Conn on Anne

After the very generous write up Anne gave me in the last magazine, I am somewhat obliged to be complimentary but that is in no way a chore.

Anne joined NRAS just before me in May 2015. She has many years (I won't say how many or I'll be in trouble!) experience supporting children and young people in a variety of settings so she is the perfect fit to manage the services we provide to children with JIA and their families. She organises fantastic events all across the country as well as delivering some expert insight and signposting over the phone to parents. She also produces dynamic new publications for the JIA wing of the charity.

With two teenage sons and a dog that devours everything he sets eyes on, there is never a dull moment in Anne's life. Always ready with a funny story, Anne keeps us all entertained.



Anne Gilbert

NRAS Youth and Family
Services Manager

Victoria on Alison

Alison joined the helpline team in April 2016, and six months on she is an established member of the team, and we can't imagine not having her here. Ali brought a unique perspective to this role, having previously worked as a nurse, dealing with patients with MS. Though she has had to learn about two new conditions from scratch (RA and JIA), her knowledge of the healthcare system and her experience with learning about healthcare conditions have meant that she has had no problems taking this on and we found quite quickly that we could learn as much from her as she could from us.

There are skills needed for helpline that you just can't teach. Ali is a very warm, bubbly person and easy to talk to. She is also a very good, empathetic listener and I'm sure anyone who has spoken to her on the helpline would have found her very reassuring to talk to.

Outside of work, Ali likes spending time with her husband, two children and the family dog. She also enjoys reading, writing, singing, swimming, going to see West End shows and socialising with her family and friends.



Alison Cini

Information and Support
Coordinator





Denise Pointon



Nicky Freemantle



Oli Hoare

Farewell to NRAS colleagues

By Clare Jacklin

The NRAS office team is a close knit bunch of folks and it is therefore never easy when one of our merry band leave for pastures new...

...so you can imagine how sad we are to be saying farewell to 3 of our buddies. Denise Pointon, the NRAS Finance Director is retiring this month and is looking forward to spending more time with her husband who has been retired for some time now. Denise has been a real "asset" (financial pun definitely intended) to the NRAS team. Both Ailsa and I are particularly grateful to her for her steadying hand on the tiller that has guided NRAS from being in deficit in 2014 to turning a healthy surplus in 2016. All at NRAS wish her and Bill a very happy retirement together and hope they can now both enjoy the fruits of their labours.

Nicky Freemantle, Ailsa's PA, moved onto pastures new in October, but Lorraine Price will be joining us in November; managing Ailsa's diary is not for the faint hearted! Nicky has been a key team player in the NRAS family supporting all areas of the charity in particular the RA Self-Management programme and the JIA family events. We wish Nicky all the

very best in her new role as she returns to her roots in event planning and management.

Last but by no means least, we say so long and farewell to Oli, NRAS Head of Fundraising. I remember very clearly over five years ago this fresh faced, handsome young man joining NRAS in the post of Trust & Grant Fundraiser. It wasn't long before Oli proved himself to be indispensable to the fundraising team, and in a relatively short time, due to his hard work and dedication, he has risen to the dizzying heights of Head of Fundraising. It is with great pride that we have watched Oli grow in confidence and ability, so whilst we are sad to see him leave, we fully understand that it is time for him to spread his wings and take on new challenges. We are only a little jealous, as Oli will be moving to beautiful Cornwall with his equally beautiful wife Jemma to start a new chapter in their lives. What he doesn't realise is we are all planning holidays in Cornwall now! We will find you Oli!

To all three of our lovely colleagues Denise, Nicky and Oli, we all sincerely wish you the very best in your future ventures and will miss you all.



Dr Anne McEntegart



Group listening to Sheila MacLeod

The Gathering

An informal day of learning more about living well with RA

In planning activities for 2016, the Ambassadors were keen to organise a day for those with RA from all corners of Scotland, to get together and learn more about the disease in an informal setting. 'The Gathering', held at the Forth Valley College in Stirling, exceeded all expectations. Local consultant, Dr Sara Else began proceedings by updating us on developments in care over the last 10 – 15 years followed by Nurse Specialist, Liz McIvor and Specialist Physiotherapist, Kirsty Bell, who spoke on how to live well with your RA. The day closed with a superb keynote speech from Dr Anne McEntegart, a Consultant Rheumatologist in Glasgow, which focused on the future of RA where prospects look more promising than ever before both for the newly diagnosed and those with established disease.

Sheila Macleod, Chair of Scottish Ambassadors, is also delighted to report that, at Holyrood, the Cross-Party Group on Arthritis and Musculoskeletal Conditions has been reregistered for the new parliamentary session. There is a completely new line up of MSPs under the convenorship of Brian Whittle MSP. A full programme of business begins

on Wednesday 16th November when the group will examine the impact of social deprivation across the range of inflammatory and musculoskeletal conditions which it covers.

Huge thanks go to Sheila MacLeod, Sheila Terry and John Paton – the Ambassadors who organised this event.

If you feel you might be interested in contributing as a volunteer to the NRAS campaign in Scotland alongside the current five volunteer Ambassadors, please get in touch with Conn O'Neill who would be happy to explain what is involved and level of commitment required etc. conn@nras.org.uk

Whilst we can all agree good things are on the horizon, we know from our recent 'Who Cares?' report that there is a huge variation in access to health and social care across Scotland. We look forward to the challenge of 2017 and beyond in campaigning for the best quality care for people with RA wherever they may live.

NRAS Rheum for you 2016



An excellent afternoon for patients and healthcare professionals

Not much 'room' at Rheum for You

In late September we held the second Rheum for You conference in Nottingham. It was an excellent afternoon for patients and healthcare professionals, who found it both educational and sociable in equal measure.

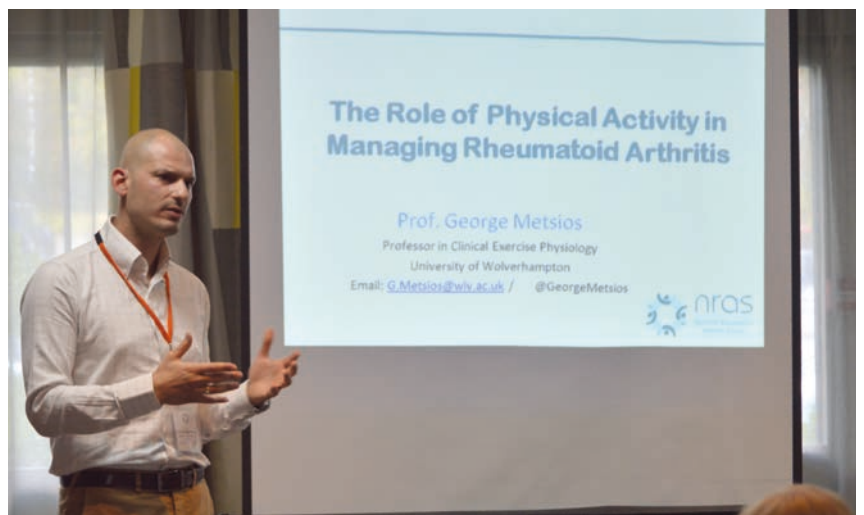
We were privileged to have NRAS Medical Advisor, Dr Chris Deighton, speak about the past, present and future of rheumatoid arthritis treatment. Dr Deighton is now semi-retired but he shared his expert knowledge as a Consultant Rheumatologist at Derby Royal hospital, with some very entertaining slides which brought humour to the afternoon. This was then followed by a presentation from Clare Jacklin, Director of External Affairs, giving an update on all the various projects NRAS is currently working on.

Finally Professor George Metsios, Professor in Clinical Exercise Physiology at the University of Wolverhampton, explained how physical activity has been proven to reduce inflammation therefore reducing RA disease activity.

The feedback from those who attended has been excellent, with one Member telling us, "well worth the two-hour drive. Informative, entertaining and sociable. I'd thoroughly recommend similar events." We look forward to bringing you the dates and locations of the 2017 conferences early in the New Year.



Chris Deighton sharing his views of what semi-retirement is like!



Professor George Metsios



By Fiona Greenfield

Centre Director
Relate Mid Thames &
Buckinghamshire

General Article

Love sometimes hurts

Relate Mid Thames and Bucks understand how issues like rheumatoid arthritis can affect relationships



relate
the relationship people

Our vision is a future in which healthy relationships are actively promoted as the heart of a thriving society.

When relationships feel like a lot of work it's easy to feel disillusioned. This is particularly true if you're having to manage something like rheumatoid arthritis. Stressors arise in every partnership and when you care deeply for someone, disagreements and problems matter. The more you care about someone the more you will mind when things between you go wrong. Problems can test your love.

When tensions, misunderstandings and miscommunication are present, our relationship can feel baffling and difficult. We may think it's quite obvious what we do and don't need and can't understand our partner's behaviour. At Relate we help many people in this situation.

Looking at 'the problem as the problem' rather than individuals, we provide a neutral setting to sort through the thoughts and feelings that inform our behaviours and look behind these to support you both in finding new skills and patterns to help with future difficulties.

We understand that relationships are not static - they change and evolve throughout our lives and these changes can sometimes trigger feelings of loss, fear or disappointment. If both partners are willing and committed to each other, these challenges can add to their relationship and increase their love - working through problems together has a transforming effect on love.

We're also able to consider the physical changes in the relationship which might be stopping you doing things which in the past had given you pleasure together as a couple - from difficulties sitting for long periods engaging in a joint activity, to the impact on your romantic, physical relationship. It's important to think about how else you could connect with each other if these things have been impacted and to appreciate there are many ways to show and feel love, care and support.

We often find that partners show and feel love very differently - words, touch, time spent together, actions or gifts can all vary in their level of importance to ourselves and our partner. Discussing the impact of these from a condition like rheumatoid arthritis can help you both talk about what may substitute some of the things you've lost.



In such times when things get difficult, you or your partner may need some space to relieve the tension or recharge your batteries

The pain from any physical condition can also make us irritable and snappy. Don't be too hard on yourself when this happens but consider in advance what you may and may not need from your partner in future. Open communication to educate (not criticise) each other on how to deal with these moments before they arise can really help, as does acknowledging what your partner gets right. We all like to feel appreciated and sometimes when things are particularly difficult we can find ourselves only saying what's wrong or what we don't like and assuming our partner should know what to do instinctively.

In such times when things get difficult, you or your partner may need some space to relieve the tension or recharge your batteries. The proximity we need to our partner can vary in individuals (and at different times) and this is another area where talking can help to find constructive ways forward.

Our relationship can also be affected by our self-esteem which can be profoundly impacted by our physical appearance and the visible signs of rheumatoid arthritis (from swollen joints to difficulties managing hair and make-up). How we feel as a man or woman can be tied into our appearance so try to keep up other things that make you feel good about yourself. This can be something as simple as being friendly to someone new or helping a neighbour with something simple. It can be validating to know how much we can brighten another person's day.

If you've done everything you've needed to do to support yourself – eating well, getting enough sleep etc., and are still struggling, it can feel very lonely. We're here if you need us at Relate Mid Thames and Bucks and we know that every person and relationship is unique. We'll explore yours and your partners' individual needs and help you put a voice to those needs and find strategies and resources going forward.

Some tips to keeping your relationship healthy:

- commit to spending time together regularly (without TV, laptops etc.)
- do things which boost your self-esteem (helping others/spending time with a friend)
- use the resources available to you which are soothing and nurturing
- remember to vocalise the things that you appreciate about your partner
- choose a good time to talk about the things that are bothering you (i.e. not late at night, when either of you are stressed, etc.)
- imagine you're educating each other about what's bothering you and importantly, what you'd like instead
- respect your partner's opinions and feelings even when they're different to our own
- and take those opportunities when you can bring humour and fun into your relationship!

If you think you might benefit from speaking to us at Relate Mid Thames and Bucks, we'll provide a safe setting to help contain those difficult issues and explore how the problem manifests itself. We're a nationwide counselling service and available to anyone facing relationship difficulties (cohabiting, married, separated, older, younger, LGBT, black, white). We work with individuals, couples and families. Our services include family counselling, relationship counselling, sex therapy and telephone counselling. We'd be happy to talk with you about the problem, no matter how big or small it may be.

To find out more, contact: **01628 625320**
www.relatemtbc.co.uk



By Sally Wright

My Story

Crooked Hands strike a chord!

Richard Welsh chats to Sally Wright about his love of music and the challenge of RA.



Richard Welsh

I had to rebuild my mental image of myself and decide what my strengths were, all over again.

I first came across Richard from an article Ailsa forwarded to me. My brief; 'can you track him down, it would make a really interesting story, he lives in Durham'. Sure I said. However, I soon found out that whilst Richard did indeed live in Durham, it was Durham, North Carolina, USA!

The power of social media prevailed and following a series of emails and Facebook messages Richard very kindly agreed for me to call him for an interview.

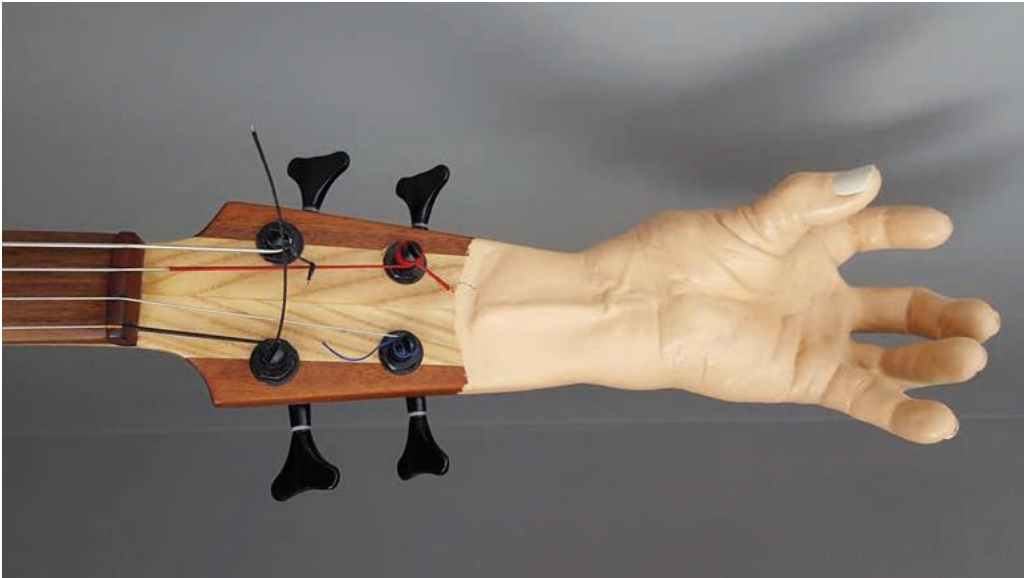
SW Thanks Richard for agreeing to take this call, I really appreciate your time. So can you tell me a little bit about your RA, when you were diagnosed and how that was for you?

RW Sure, I was 33 yrs old, diagnosed in 1993, but I didn't know what it was. I was working as a general contractor at the time (construction and carpentry), I thought if I ignored it long enough it would go away. I was having minor problems in my joints, symmetrical problems, my hands would swell but I

put this down to wear and tear through my work. I left it for about 6 months and by the time I went to the doctor, I was in pretty bad shape, it was really aggressive and there was lots of damage in my hands, knees and feet. In the back of my mind I thought it was arthritis, my joints were big and red and swollen. I went skiing with friends and that's when it really kicked in; my feet were so bad and I don't really remember the month after that. I was in so much pain I could hardly get out of bed. Because I'd left it so long, it then took a while to get in to see a doctor as there weren't many rheumatologists around.

SW What about adaptations or compromises you've had to make?

RW I was a working musician, a guitar player, and after 5 years I could no longer play guitar. When I became 'disabled' I started to play a lap style guitar called a Dobro. I pretty much decided that music wasn't going to be part of my life in the way it was, so learning to play the Dobro was a real step forward for me. Getting some of my carpentry skills back and making these instruments has really



I look at a container and it'll call out to me, 'I wanna be a banjo!'

helped – it's the little victories! I've had to learn not to be such a hard head and listen to my body when it's yelling at me. I have a lot of problems with fatigue, but I'm a napper now!

SW What would you say were your biggest challenges?

RW My attitude was the biggest problem I had at first; I was just so depressed about it. I had to rebuild my mental image of myself and decide what my strengths were all over again. You know you have this picture of yourself and then you have a chronic illness, you have to rebuild the mental picture that works with your new situation. Not being able to play music was hard. I was also pretty athletic so giving all that up and trying to stay in shape was hard. I'm lucky with my metabolism though, but the doctor said early on 'watch your weight and don't smoke'.

SW So tell me about Crooked Hand Instruments.

RW It was my birthday, I was on the internet and found this site where they were building instruments out of cigar boxes. I happened to have a workshop and I thought, 'I could do that'. It quickly became an addiction but it was a way to get my carpentry skills back. I had a lot of time on my hands!

There's lots of sanding and filing but I've modified a few tools that make it easier for me to hold onto as my hands are pretty bad. It takes me a long time, but that's ok. I first started getting the cigar boxes from a cigar store in Wilmington, North Carolina. They were all nice and new and clean but, after a year or so, I started buying old used and vintage ones on eBay - a little bit more expensive, but a hell of a lot more character. The older cigar boxes are so well made, really strong and make decent resonators, but I use old cookie tins or tins from candies. It's hard to say where the inspiration comes from but it's hard to walk past an antique store now! I look at a container and it'll call out to me 'I wanna be a banjo!'

The first 20 or so I made you couldn't play as an instrument but the ones I'm turning out now are pretty viable, especially the ukuleles and the 4 string guitars.

SW So tell me about the handle/fret board – what do you call the guitar handle?

RW Oh you mean the hand at the top? Yeah, so I've made a mould of my left hand – I've done this on two so far. One's an upright bass I made out of a gas tank, that was the first large instrument I made and I used the mould at the top of the headstock from alginate. I put one on the top of a cello too. On the smaller instruments I inlay a little wood carving of my hand.

It takes me about 30 hours to make an instrument. I usually build 2-3 at a time and that takes me about 2-3 weeks.

SW So how are you now?

RW My RA is very much under control right now. I'm dealing with old damage; my problems tend to be tendonitis in my right wrist and shoulder. I've had to become ambidextrous because of the damage. I'm pretty mobile and most people don't even notice I have RA until they see my hands.

SW If you could look back on your younger self, what advice would you give?

RW Well I would certainly say 'go to the doctor as quickly as possible!' Then try not to worry too much about how your life's going to change. Your life will change anyway as you age, everyone has their health issues. I try not to dwell too much on my RA, I tend to live in the moment. Stress is the worst thing. I'm fortunate that I don't have much to worry about now. My wife, Leah (Kraus), is the reason I'm able to do these things. ■

Richard doesn't have a website, but you can take a look at his instruments on his Facebook page www.facebook.com/crookedhand.instruments



Crooked Hand cellos made by Richard

To read the full article, please visit our website here www.nras.org.uk/stories/crooked-hands-strike-a-chord



By Ailsa Bosworth, MBE
Chief Executive

General Article

New NRAS patient portal

Coming to a screen near you soon!

Everything we do as a charity and the resources we create and develop for people with RA and children and adults with JIA relate to equipping them to understand and self-manage their disease to the best of their ability. We know, and the research demonstrates, that patients who are knowledgeable about their condition and take proactive steps to modify their behaviours and lifestyle to maximise their ability to self-manage well, do better, are less likely to suffer from other health problems such as anxiety and depression, and have better long term outcomes.

Our goal as an organisation is to be there at the start of everyone's journey with RA (and families affected by JIA) and to support them whenever they need us throughout their life. Therefore,

partnering with Patients Know Best (PKB), having investigated a number of platforms for patient held records over a period of time, was a step we could take with confidence, which would fulfil our above aim. Having access to correspondence from your healthcare providers, your blood and imaging results, being able to email your consultant or nurse specialist and having your own care plan with the ability to set goals for example, are all things which we believe will put patients in the driving seat. Whilst this kind of facility might seem a bit new and innovative now, I strongly believe that in a few years time, we will wonder how on earth we managed our own long term conditions without it, just like the impact of mobile phones and the internet. Could you imagine not having the ability to interrogate the internet to find information on whatever subject you want, when you need it today? I can't!

We are currently in the process of working with PKB to develop and incorporate a tailored care plan for people with RA which will be included within our portal. On our home page, we will also have direct links to resources such as the NRAS helpline team, NRAS online peer support forum, NRAS downloadable DAS App and our publications so that units who commission this great resource for their patients will give existing and new patients immediate access to NRAS and all that we can do to support people which we know does make a difference.

In order to be able to access our portal, it will be necessary for an NHS Rheumatology Unit or Clinical Commissioning Group (CCG) to commission the NRAS portal, either specifically for their RA patients or for their rheumatology patients more widely where people with other rheumatic conditions will be able to access the standard PKB portal, but with RA patients having access to the specially developed NRAS front end. We're really excited about the potential to improve patient care, give clinicians access to a host of data they currently don't have access to, including the collection of baseline patient reported outcomes and reduce costs of healthcare delivery at the same time. For health professionals wanting more information, please email Phil@nras.org.uk. Note: It's important to mention that neither NRAS or PKB are able to access any patient data which is entirely confidential to the patient and the health professionals and others (family members) they choose to share the data with.

The screenshot shows the NRAS patient portal interface. At the top, there is a navigation bar with 'Settings', 'Help', and 'Log out' options. The main header area says 'Home' and 'Welcome John Desmond'. Below this, there is a welcome message from Ailsa Bosworth, MBE, Chief Executive of NRAS, expressing the organization's commitment to supporting patients with RA and JIA. The central part of the page features a grid of interactive tiles: 'Discussions', 'Health', 'Treatments', 'Diary', 'Files', 'Apps', and 'Sharing'. To the right of the welcome message, there are four action buttons: 'Send message', 'Audit log', 'Invite professional', and 'Start consultation'. Below the grid, there is a 'Notifications' section showing two messages from August 11, 2016. At the bottom, there are four footer tiles: 'Connect with others with RA', 'Speak to the NRAS Helpline team', 'Download our Know your DAS app', and 'Information and Support'.

General Article

Patients Know Best

Like NRAS, Patients Know Best was founded with a clear vision and mission



By Dr Mohammad Al-Ubaydli

Founder and CEO of Patients Know Best

At PKB, our mission is our name – that patients genuinely know best about their health and their care. We do this by putting patients in control of their medical records because when this happens, medical professionals are better able look after their patients and patients are better able to look after themselves.

We know that by putting the patient at the centre of their healthcare management, safety improves, quality goes up and costs come down.

Our rapid growth over the last few years is testament to the fact that our approach works and that patients and organisations trust our technology.

We're now live in over 60 hospitals across the UK and in seven countries and some of our customers include Great Ormond Street Hospital, St Marks, Luton and Dunstable and Chelsea and Westminster – to name just a few.

Our patient-controlled approach is now being adopted on a far larger scale.

Every month PKB delivers over 10 million test results to patients, including appointments, clinic letters and care plans. Patients Know Best is already being deployed organisation and trust wide and we have customers rolling out across whole populations of patients.

Patient groups and charities are critical partners in putting patients in control. By working together, we can spread the message that this is the right way to deliver care. It's these groups who speak on behalf of the patient, fight their corner and in many cases, know the patient the best. We're delighted that NRAS has become the latest patient group and charity to partner with us.

We also know that rheumatic conditions impact large numbers of people across the UK and we believe that our patient-controlled approach can have a significant impact on the health and wellbeing of these patients.

Through the new NRAS portal, powered by PKB, rheumatology health professionals will receive more information and be kept better informed about the health of their patient – meaning they can provide better, more rounded care.

At Patients Know Best we want to work with patient organisations like NRAS – proactive, dedicated teams of people who want to move things forward and make positive change happen for patients across the country.

NRAS is embarking on pioneering work with us and we hope it will inspire other patient organisations to do the same for their patients. We're delighted to be working with NRAS and look forward to supporting them now and in the future.

Every month PKB delivers over 10 million test results to patients



By Trina Rule

General Article

Singing for Lung Health

My career as a secondary school teacher was always enjoyable and fulfilling but, in combination with the debilitating effects of almost 30 years of RA and with a growing family, it left me with little energy for much else in my life. So, when I took early retirement two years ago, I was excited to have the time to pursue some hobbies that I had not had time for previously. I had always loved singing and so I joined a couple of choirs and thoroughly enjoyed not only the singing but the social aspect of a communal activity as well.



Trina Rule pictured seated, far right.

“I overcame my scepticism because the results have been remarkable.”

However, I encountered a problem relating to RA. I frequently experienced discomfort when breathing and I found that the long breaths required for singing were causing me problems. I ploughed on though, determined to continue with this enjoyable past-time. However, last August, I had surgery on my neck and my restricted movement caused a slight problem with the anaesthetic. This left me with some swallowing issues and, more annoyingly, problems with singing.

I was beginning to think that maybe it was going to be too difficult for me to pursue this hobby when a friend told me about a group that had set up locally, called 'Singing for Lung Health'. So, I went along – perhaps a little sceptically - to see if it could be of any help. I am so glad I overcame my scepticism because the results have been remarkable.

The group is run by local musicians, Kate Barfield and Greg Stephens. Having run community choirs

since 2003, Kate had a great awareness of the many benefits that the singers seemed to gain from belonging to a choir. She took this further by training with the British Lung Foundation which runs courses for this very purpose. This training enabled Kate to teach specific breathing techniques through singing to improve lung health. To put the theory into practice, in November 2015 she set up Village Voices, a community choir specifically for people with breathing difficulties.

The group itself is run weekly and although we meet in a retirement village in Stoke, there is a wide range of ages from young adults to older people, both men and women. The group is open to anyone, regardless of their musical ability, but who have some kind of breathing difficulty. For some, the breathing problems might be very severe, whereas for others, it might be mild asthma. There are a number of people, like me, who have other medical problems that have caused breathing difficulties.

Each session starts with relaxation exercises, the practising of breathing techniques, followed by some vocal warm ups. We learn to breathe in a certain way which is now becoming second nature to me and is certainly easing the discomfort I felt previously.

The benefits of singing are proven to be many and they are not all medical. Research has shown that singing can help us to feel more in control of our breathing, encouraging us to breathe more deeply and more slowly. It improves muscle strength which is very good news for those RA sufferers whose muscles are affected. It improves posture which, again, is something often adversely affecting RA patients. In addition to these physical benefits, singing can improve voice projection which, in turn, may improve confidence. Perhaps most importantly though, is the wonderful sense of well-being that results from singing, particularly with other people. There is no medicine like it! RA can sap your energy, your enthusiasm and your mood but the simple act of joining voices with a group of friends every week, can counteract all that negativity.

These groups are springing up all over the country now as more people like Kate train to run them. It isn't really about the sound; many of the people who attend would probably admit that they have never really sung before – it's about the benefits to health and wellbeing. Having said that, I think



together we make a good sound and we have even performed in public to a very enthusiastic reception!

I am so pleased that I found this group and I really want others like me to reap the benefits of a good sing.

To find your local group, visit www.blf.org.uk/support-for-you/singing-for-lung-health

General Article

RA Awareness Week 2017

19th-25th June 2017



Deciding on a theme for any awareness week can be tricky, it's the first step to a whole heap of planning. We decided to poll our communities on Facebook and Health Unlocked to see what the most popular would be and here are the results;

There was resounding support for 'invisible illness' and following the release of our collaborative film with Eli Lilly, *'Behind The Smile'*, this will sit perfectly for RAAW 2017.

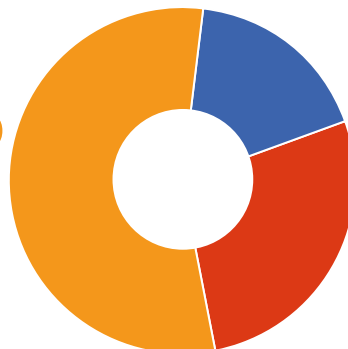
We will shortly be putting a plan together so if you have any ideas you'd like to put forward or if you'd like to be involved in any way either by fundraising, hosting an event or telling us your 'behind the smile' story then please do get in touch with us here at media@nras.org.uk

Dates for your calendars for RAAW 2017:
19th-25th June 2017!

 **281 Voters**

55%

Invisible effects of Rheumatoid Arthritis (RA)



17.5%

Differences between Osteoarthritis (OA) and Rheumatoid Arthritis (RA)

27.5%

Impact of Rheumatoid Arthritis (RA) on life – relationships, hobbies and work



Fundraising

Nicky's on top of the world!

Nicky made the huge decision to climb Mount Kilimanjaro for NRAS, even though she has RA. Here is her story...



There was no way I was going to let my RA stop me from giving it a go.

My story starts 8 years ago. I had pain and swelling in my hands and feet, resulting in numerous visits to my doctor. After months of painkillers and being told to 'keep an eye on it' I was finally diagnosed with RA.

I had been so active and outgoing, loved to travel, play netball and lived for my winter sports. I was devastated; there were days when I could hardly walk, let alone do anything more strenuous. I quit the netball team and thought my active days were over.

I started on methotrexate and slowly started to feel less pain, even though I had lots of inflammation in my joints. After a couple of years, I followed my dream to live and work in Canada. Although the odd extra cold day meant my joints ached more than normal they didn't stop me from having the time of my life! I moved to London in 2012, had the odd flare but over the years have been able to overcome the aches and pains and live an active life. I have now been pain free for 2 years thanks to medication and positive thinking!

This September I took on the biggest challenge of my life reaching the summit of Mount Kilimanjaro. It's not easy, even for the fittest of climbers! I didn't know how it would affect me, whether I would struggle with 7 days of hiking, Kili has always been on my bucket list and there was no way I was going to let my RA stop me from giving it a go.

I'm pleased to say that I made it to the summit! It certainly was the biggest challenge of my life, at times I really struggled. Thanks to my medication and some extra painkillers, I got through it with no sign of the RA in sight. It was an incredible experience and I'm so pleased that I can say I conquered the mountain, not only that, but I raised over £400 for NRAS too.

I hope that sharing my story shows that having RA doesn't mean you will have to stop leading an active lifestyle, with the right medication you can control the pain and eventually start to cross off those life achievements; for me it was learning to snowboard, running 10k and summiting Kilimanjaro!

A massive well done to Nicky for ticking something off her bucket list, such a great achievement. Thank you for choosing to support us and raising so much money, whatever will you do next?

If climbing Kilimanjaro is on your bucket list why not make 2017 the year to tick it off? Visit our website at www.nras.org.uk/walk-and-trek or email fundraising@nras.org.uk or give Val, our events fundraiser, a call for more information.

Fundraising

Team NRAS does it again!

Fundraisers take part in the annual Great North Run in Newcastle and the Royal Parks Half Marathon in London



Some of our Great North Run team

13 of our fantastic fundraisers took to the streets of Newcastle on the 11th September to take part in the annual Great North Run, the most famous of all the half marathons. Val and Oli were there to meet them as they crossed the finish line in South Shields with the sun shining down on them.

Val said *"the team were absolutely amazing and it was good to meet so many of them and thank them personally for all the hard work they had put into not only running the race but raising sponsorship, we even had one runner who had to help resuscitate another runner who collapsed in front of him – simply amazing!"*

The team raised over £6000 between them, well done to everyone who took part, same again next year?

A team of 17 runners took part in the Royal Parks Half Marathon on the 9th October. It was a lovely sunny day, an ideal temperature for runners to take on the 13.1 mile course, taking in four of our stunning London Parks.

Our NRAS runners finished with flying colours with our fastest runner completing the course in 1 hour 48 mins! Val and Bronwen were on hand to meet the team on the finish line, along with their families and friends. One runner went above and beyond and ran with an injury from a rugby match a couple of weeks before – a fracture to his skull! The team have raised over £10,000 with more still to come, a fantastic effort by all.

If this makes you want to put your best foot forward and run for NRAS we have guaranteed places in several running events next year, including the Great North Run and the Royal Parks Half Marathon, all the information is on our website at www.nras.org.uk/runs to book your place – make 2017 the year you get to strut your stuff in an NRAS running vest!



James and Josh at the Royal Parks Half Marathon





By **Yasmin Kafei Shirmanesh**

Student in Pharmacy Practice with the support of

Matthew D. Jones

Lecturer in Pharmacy Practice

General Article

RA and Inhalers – do they go hand in hand?

Comparison of the ease of use of four typical inhaler devices in people with and without rheumatoid arthritis

One in six people with rheumatoid arthritis (RA) also have a lung disease such as asthma or COPD. Many of these people will need to use an inhaler for this. Hand problems caused by RA could make using an inhaler difficult. Some people with RA also have their lungs affected by the disease and this might prevent them breathing in fast enough to use inhalers. This had not been researched before so this project aimed to find which inhalers were best suited for people living with RA and how to improve the design of inhalers.



Pressurised metered dose inhaler (pMDI) and HandiHaler



Turbohaler and Easi-Breathe inhaler

The National Rheumatoid Arthritis Society helped identify groups of people with RA to take part in this study. For each person with RA that took part, someone else without RA, but of the same sex and similar age also took part. This was done to see if there was a difference between people with and without RA. The people with RA completed two questionnaires to measure how severe their RA was and how bad the symptoms in their hands were. The people without RA just completed the questionnaire on their hand function and dexterity.

Four of the most common inhalers were used, these were the pressurised metered dose inhaler (pMDI), Easi-Breathe inhaler, HandiHaler and Turbohaler. The researcher observed members of each group to establish the following;

- with what ease or level of difficulty they were able to complete each step to set up the inhaler
- could they breathe in fast enough to use inhalers, a measurement device called an In-Check Dial was used for this

The Turbohaler was found to be the easiest for people with RA to use, as 85% could use this inhaler. The Easi-Breathe could be used by 77% of the people with RA while the pMDI and HandiHaler both appeared more difficult for people with RA to use. Only half of those with RA could use the pMDI. The main problem with the pMDI was being able to press the button. The Handihaler was the most difficult of the 4 inhalers for those with RA to

use with only 15% of people being able to operate the Handihaler. The main problems were being able to take the capsule of medicine out of the foil packaging to put in the inhaler and pressing the button on the inhaler to pierce the capsule.

Out of the 34 people with RA who participated in the project only one could not breathe in fast enough to use the inhalers, so this is not such an issue for the majority of people. This project found that the best inhalers to give to someone with RA are the Easi-Breathe inhaler and the Turbohaler. It is a recommendation from this study that the pMDI and the HandiHaler should not be prescribed to people with RA if possible. In future, new inhalers should ideally be designed to have fewer steps to set up the device ready for use. People with RA should be trained to use inhalers and have a check that they are able to use them before they are prescribed.

Note from NRAS to pharmacists – During the annual Medicine Use Review for someone living with RA ask if they use an inhaler and ask them to show you how they use it.

Note from NRAS to individuals – if you are having difficulties using your current inhaler ask your pharmacist for advice and perhaps recommendations to your GP for a different type of inhaler.

General Article

Behind The Smile

NRAS collaborates with Eli Lilly to produce touching yet powerful film on what it's like to live with RA



Earlier this year we partnered with Lilly pharmaceuticals to produce a film for World Arthritis Day 2016. The purpose of the film was to create a campaign that raises awareness around rheumatoid arthritis. We spent two days filming to produce the main film featuring a character called Jane and then some further filming to do a piece to camera with Donna Saunders, one of our Members and Professor Iain McInnes, Consultant Rheumatologist, University of Glasgow.

All three films were released on World Arthritis Day (WAD) 2016 and have provoked an overwhelming response across the world, with some heartfelt comments and words of thanks for putting this 'out there'! With over 24,000 views in the first 24hrs and 46,000 views to date, the film certainly struck a chord and here are some of the wonderful comments;

That's me!! Actually brought a tear to my eye. I never tell anyone how I truly feel, just keep going and believing 'I'm fine' x

That hit home – from having taps with handles you can push, using 2 hands to put toothpaste on your brush to picking up bags on your arms because you don't trust your hands to have the strength – and yes we tell everyone we're fine x

This stuck a chord that it had me blubbing. Well done all involved for making such a fantastic video about the things most of us with RA go through daily. Keep spreading awareness xx

Wow! That is not how I expected to react to this. I'm in floods of tears because this is exactly what I do. However, I do tell my rheumatologist how I feel and they don't necessarily listen and they think 'I'm fine'.

Very true! After watching this and crying, my son says "mom, you ok?" First words out of my mouth is 'I'm fine'.

Wow what a powerful film and tough to watch! Definitely struck a chord! When I see my rheumatologist she always says 'hello, how are you?' And I always say 'fine'. Once we are in her room she then says 'now tell me how you really are'. I think this is a great approach as we are all so used to saying 'fine'.

If you have yet to see the films, you can view them here on our YouTube channel;

bit.ly/invisibleRA - Jane

bit.ly/invisibleRAonna - Donna

bit.ly/invisibhleRAMcInnes - Professor McInnes

I never tell anyone how I truly feel, just keep going and believing 'I'm fine'.

Now have your say about what is behind your "I'm fine" by completing the "Unmet Needs Survey" at bit.ly/ramatters



By Shivam Arora

Web and Digital Media
Officer

Remember:
if something
seems too
good to
be true, it
usually is!



General Article

Internet Safety Tips

We've all no doubt noticed a huge rise in the number of dodgy emails dropping into our inboxes recently with often nothing more than a link or an attachment (many times an invoice). We thought we'd share with you some good advice about keeping your emails and PCs as safe as possible.

Email attachments are especially dangerous because they can contain viruses and other malware. When you open the attachment, the malware can be automatically installed on your computer and you may not even realise anything has happened. Malware can damage files on your computer, steal your passwords, or spy on you, so it's important to be extra careful when you receive attachments. Many times these are also linked with "ransom" software, i.e. you get an offer to buy some expensive bit of software to unlock your files so they in effect HOLD YOU TO RANSOM.

Malwarebytes Anti-Malware is a useful programme that helps to protect your PC from such files. It can be downloaded for free from www.malwarebytes.org. There is also a paid version that offers increased protection and security.

Tips for dealing with attachments:

- **Don't open any attachment you were not expecting.** Even if an email looks like it's from someone you know, it may have been automatically sent to you by a virus on their computer. This is how many email viruses are spread. If you receive an attachment from NRAS that you weren't expecting, please feel free to call or email us to verify that the email was meant for you on 0845458 3969 or enquiries@nras.org.uk
- **Keep your antivirus software updated.** Viruses can spread quickly and if your antivirus software isn't up to date it may not be able to block new viruses. (Think of it as a flu jab for your PC). This type of software can be quite costly, but it is definitely worth investing in. There is also free anti-virus software available, like Avira, which offer reasonable protection from viruses.



Telephone Safety Tips

Are you fed up of those pesky cold calls interrupting your dinner or your favourite TV programme? Well there is a way to stop them. The Telephone Preference Service (TPS) is a central opt out register whereby individuals can register their wish not to receive unsolicited sales and marketing telephone calls. It is a legal requirement that companies do not make such calls to numbers registered on the TPS. The original legislation was introduced in May 1999. It has subsequently been updated and now the relevant legislation is the Privacy and Electronic (EC Directive) Regulations 2003.

Who can register?

The term individual includes consumers at their residential address, sole traders and, except in Scotland, partnerships.

How long will it take to become effective?

Once a number has been registered it will become effective within 28 days.

Is there any charge for registering?

No, it's free to register on the TPS.

To register your telephone number or make a complaint: The quickest and easiest way is to do this online www.tpsonline.org.uk or call 0345 070 0707 there is also a Mail Preference Service (MPS) available call 0845 7034599 for more information.

My Story

Galloping Grandma begins blogging at 70!

I was 70 this year and to celebrate, I decided to write a blog about travelling with my Rheumatoid Arthritis which was actually diagnosed in 2000, although looking back I probably had it much longer.

Every joint was feeling terrible, all aches and pains and entering that phase when you convince yourself that it is all psychosomatic and even my GP looked rather disappointed when his gout diagnosis proved negative! Me - who only drinks about a glass of wine a week with Gout? Un-deterred, the GP took another armful of blood and tested me for everything. This brought about an instant diagnoses of RA - I was so relieved, I laughed out loud! Now at long last I had something solid to get hold of, to 'Google', to join NRAS, etc. etc. My smile was somewhat diminished by learning that it was incurable, but there were lots of new drugs to keep it in check. For those that are in the know, I am on Humira (anti-TNF) as well as methotrexate.

Stage one was to get a rheumatologist and my first one was a sweetie, but was too old. He retired after taking care of me for about 8 years and then there followed a sorry list of not so good ones. Eventually after a number of operations, such as a new hip, having my gall-bladder out, which proved to be unnecessary! They had done the gall-bladder op and failed to notice that I had RA - despite the fact that I always give each doctor I see a large sheet of paper with rheumatoid arthritis written in large capital letters on it! Although I did have a few small stones in my gall bladder, what was making me ill was something called costochondritis that can affect people with RA, so I then had to go back to hospital for another week and be massaged twice a day by a real hunky physio!!

Next I was given a cream by another private skin doctor for my skin cancer that made my entire face swell up and upon reading the accompanying literature, it said quite clearly 'Do not give to RA patients'. And yes, she too had been given the letter stating I had RA! Where did the skin cancer come from I hear you ask - well not from the RA I can assure you. Anybody of my age will know that protective sun creams were not invented when we were children. You got a good dollop of olive oil plastered all over you and were sent out to play (and cook) in the sunshine!!

Next came the knee replacement - never go here if you don't absolutely have to! Mine was done by a doctor who had never done one before (I didn't find out that until afterwards) and **over 2 painful years later** I found out it had been put in crookedly. The pain was excruciating and if it hadn't been for my excellent GP and my husband, I really think I might have died at that point. And how did I find out it was crooked? By first my left foot breaking followed by the right one! Having talked it over with my husband, after 18 months with a broken left foot, we decided to go to the top person for feet in Ireland and, at the same time, change my rheumatologist to the top one in Ireland too, both of whom were up in Dublin. What a good decision that was! As my foot had been broken for so long, it needed titanium plates putting in and, he told me the right one was on the verge of breaking too! So, I eventually got home after the first operation with both feet in walking boots to keep my stance as even as possible. I was so delighted not to have a broken left foot, that I promptly tripped over my booted feet and broke my left wrist and my right shoulder. It was hard not to be very, very depressed!

The right foot broke on the second day of a trip to Greece to celebrate our 40th Wedding Anniversary! My surgeon had warned me that this would be worse than the left one, and he wasn't joking. Not from a pain point of view, but this foot was plated and wired together and it meant I couldn't put it on the ground at all for 3 months. My first prolonged wheelchair experience followed, of course, by a blood clot in the leg! But in fact I was lucky. My eldest son is a joiner so he put in ramps all over the house and, as the oil industry that my husband had worked in suddenly bottomed out, he was at home to look after me and became my live-in cook/housekeeper!

I had the operation on my right foot in March 2015 and I am just about better, with only swollen feet in the evenings now, but I am able to walk a little more each day. I know I probably face a few more operations yet, but I refuse to give up and try to walk the dogs every day - except when it rains too much - this is beautiful south west Ireland after all! You are probably wondering how on earth, if you have read my blog, how I have managed to travel so much but you will just have to keep reading my blog, www.thegallopinggrandma.com to find out as my adventures certainly haven't stopped yet!



By Sally Borst

I probably face a few more operations yet, but I refuse to give up and try to walk the dogs every day.



On my morning walk in summer

Healthcare Champions

On 2nd November, NRAS held its 5th Healthcare Champion awards ceremony in Portcullis House, Westminster with the kind permission of the Prime Minister and NRAS Founding Patron, the Rt. Hon Theresa May. The event was a resounding success with over 80 NRAS Members, healthcare professionals, MPs and special guests attending.

The awards provide the opportunity to celebrate the dedication, professionalism and excellent care given by those healthcare professionals that go 'the extra mile' to provide the best possible outcomes for the many people living with RA and JIA, whilst also working in a challenging environment of NHS reforms and financial cuts.

This year we asked our Members and parents of children with JIA to nominate their choices for the awards. From over 60 nominations the judging panel, including some NRAS Medical Advisors and Trustees selected 10 RA and 3 JIA champions. Those selected best demonstrated a commitment to

meeting the needs of their patients, treating them in a holistic and inclusive manner. The champions demonstrate how to truly include people in decisions about their care, by listening to their concerns and educating individuals about their condition, their options and their next steps in their treatment pathway.

And the winners of the 2016 NRAS Healthcare Champion Awards are...



Dr James Galloway – Consultant at Kings College Hospital, London



Dr Viren Mehta – GP at Cheadle Medical Practice, Cheshire



Dr Martin Lee - Consultant and Karl Nicholl – Specialist Nurse at Freeman Hospital, Newcastle



Sharon Pearson, Alex Greengrass and Fidelma Gordon – Specialist Nurses at Lister Hospital, Hertfordshire



Whole Rheumatology Team at Queen Alexandra Hospital, Portsmouth



Janice Booth and Geoff Dodd - Rheumatology Nurses at Clifton Hospital, Lytham St Annes



Baz Jambor - Senior Physiotherapist at Derriford Hospital, Plymouth



Harpal Tiwana representing Professor Chris Buckley - Consultant and Alison Deeming - Specialist Nurse at City Hospital, Birmingham



Dr Margaret-Mary Gordon - Consultant at Gartnavel Hospital, Glasgow; unable to attend



Paul Amlani-Hatcher accepting the award on behalf of Dr Vispi Parekh - GP at St Albans Medical Centre, Kingston-upon-Thames



Catherine Tranter - Specialist Rheumatology Nurse at Norfolk & Norwich University Hospital



Whole Paediatric Team at Evelina London Children's Hospital



Keynote speaker, Dr Peter Lanyon, President of the BSR with Ailsa



Dr Jeremy Camilleri - Consultant Rheumatologist at University Hospital of Wales, Cardiff



All the Champions





By Lorraine Pulford

My Story

Just go for it!



Leader of the pack – Lorraine



Lorraine doing Tai Chi

I can hardly believe it was over 20 years ago when I stood in our small office. 'My turn to make the drinks' I announced to the girls. I looked down and noticed my knee had 'ballooned', it was sore and stiff.

I spoke to my mum and said I thought I had rheumatoid arthritis but she said it wasn't possible and not to be silly. Really, I think she was a bit shocked as she'd cared for dad with this disease for many years.

Because of the family history, my GP was very understanding, when the blood test results came back confirming I had RA. My GP actually apologised and said he was hoping it was only gout. Medication was duly ordered which helped for a while, but the side effects were worse than the RA pain so I was afraid to go back to my GP. Eventually I had to give in; unfortunately, as I'd left it so long, the RA had progressed as it had damaged the joints – if only I had gone back sooner!

I was sent for an appointment with the rheumatologist and we tried other medication but to no avail. Eventually I was offered a trial scheme which had been successful in America. Feeling at the point of no return I decided to take part and I'm so glad I did. There were 3 trials, of which no-one knew the brand names – one of the 3 was a placebo. At the end of the trial I was told I was on leflunomide and I have used it ever since; the

other was methotrexate, which I have tried without success over the years.

During this time my home life was very up and down with the family trying to accept the situation and I was trying to carry on working. Mum passed away and my daughter married, leaving hubby, myself and Sam the dog. After 10 years my hubby decided he wanted 'some space' but it turned out he had found himself a 'newer model'.

Obviously I was devastated and also worried how I was going to look after Sam and myself. No need though as I looped his lead onto my mobility scooter and went 'walkabout'. I met other dog walkers at the local park, some of which I had previously known. A couple of them invited me for coffee and asked me if I would be interested in joining a local friends group.

To cut a long story short, two ankle replacements later, I am now involved in a lot of local community activities. I swim weekly and do Tai Chi to help keep healthy. There is a lot going on in our local communities, it just needs us to go out there and find it. All this has kept me busy over the last ten years and I also have social interaction with friends that I have made within these groups. Having recently retired from work, I am looking forward to many more activities and meeting new people!

Just go for it – no excuses!

Commissioning

'New2RA' shows great promise in year one.

NRAS' aim is to be considered as part of the multi-disciplinary rheumatology team and for our services, programmes and interventions to be considered as much a part of the patients' treatment pathway as the drugs and clinical medical services.



'New2RA', as the name suggests, is a short (2 hours) lay-led workshop tailored specifically for people newly diagnosed, usually provided within 3-4 months of getting a confirmed diagnosis of RA. We know that the impact of a diagnosis of rheumatoid arthritis with all its implications, together with the need to take regular powerful medication, can leave people in shock and with a range of feelings from disbelief to anger and often with a strong sense of isolation. The workshop is a supplement to the information and guidance provided by the rheumatology team and is intended as a key step on a 'pathway' of support for self-management to accompany and augment the traditional medical/treatment pathway. The success of this intervention will rely in no small part on the regular sign-posting and direct referral by health care professionals and other partners.

The key aims for the workshop are:

- to enable people to express their feelings and to 'normalise' these within the group.
- to facilitate the sharing of experiences and views of the diagnostic and treatment process compared to national standards and guidelines, so that we can feed back to the local rheumatology team (anonymously) the experiences of individuals (both good and not

so good) so as to enable the team to address any issues which have been highlighted.

- to increase awareness and knowledge by highlighting areas such as the importance of compliance with medication, the need to maintain or introduce exercise and encourage smoking cessation.
- to impart the concept and practice of better self-management and encourage the initial setting of simple goals
- to help people identify areas for improvement in the services they get, encouraging them to be more assertive in discussion and decision-making.
- to locate NRAS as a constant 'ally' and supporter.

With the help of Senior Research Fellow at Manchester University, Dr Suzanne Verstappen, we have developed and refined a 3-part evaluation process for the workshop – pre and post course questionnaires and a 2-month follow-up to test individual progress. The results from participants so far, in pilot and full delivery phase, have been really encouraging, especially for a short intervention of this kind. Deliveries are underway or planned in Croydon, Oldham, Sussex and Newcastle, with the possibility of other locations in 2017.



By Phil Baker

NRAS Director of
Commissioned Services

The workshop is intended as a key step on a 'pathway' of support for self-management to accompany the traditional treatment pathway.



Ask the helpline

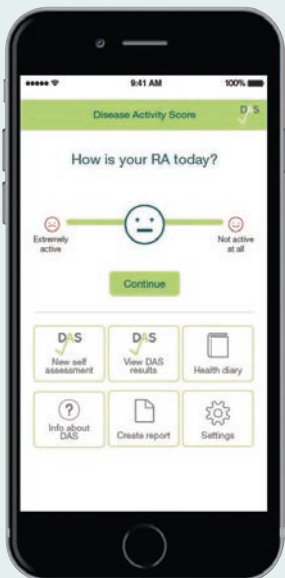
Hydrotherapy and RA

I have heard hydrotherapy can help with RA. Why is this and how can I access it?



Download the NRAS DAS App

www.nras.org.uk/publications/know-your-das



Hydrotherapy is conducted by a physiotherapist in a pool which is normally a lot warmer than a leisure centre pool. The warmth of the water can soothe and relax your muscles and make it easier for you to carry out certain exercises.

A number of the people we have spoken to with rheumatoid arthritis have said that when in a hydrotherapy pool, their pain is eased quite dramatically and this allows them to carry out exercises that otherwise would not be possible to do outside of the water. The reason behind this is that the water supports your body making it easier for you to carry out different movements. Water resistance training can be used to gradually gain strength and flexibility.

Hydrotherapy has been used for hundreds of years as far back as the Ancient Greek and Roman times, and has been recognised for its healing benefits in a wide range of health conditions. The general consensus is that warm water increases blood flow and improves oxygen supply to cells in various organs and the skin. This then improves lymph drainage and helps release toxins from the body, which in turn may boost the immune system.

To access hydrotherapy, you could ask your GP or rheumatology nurse to refer you to a physiotherapist to see if this treatment would suit you. Many hospitals have a hydrotherapy pool, however some areas may not and you may have to travel to the neighbouring hospital for treatment. You would normally have an initial assessment with your physiotherapist to see what sort of exercise would be suitable for you to carry out. Then you would be prescribed a block of 5 or 6 sessions, around 30 minutes each.

Once you have finished your prescribed course your physiotherapist may suggest carrying on with the exercises in your local pool or joining an aqua aerobics class. General swimming is also an excellent way to maintain muscle strength and improve cardio-vascular health.

Ask the helpline

Finding helpful products

My mum has rheumatoid arthritis, and I wanted to buy her some products to help her around the house, but there are so many websites around, I don't know who to trust and what to look for.

This is a question we get asked a lot on the helpline. There are large numbers of websites out there that offer various aids and gadgets for disabled people, and it can be hard to find websites that you can trust. The prices between these websites can also vary greatly.

Recognising the difficulties with finding sites that are reliable with a good range of products, NRAS recently teamed up with 'Spring Chicken', as you may have read in the previous issue of this magazine. Spring Chicken offer a range of products aimed at making life easier:



www.springchicken.co.uk/nras

There are also a number of other websites that members have successfully used in the past, such as NRS Healthcare and Betterlife (previously called 'Better Life Healthcare, now run through Lloyds pharmacy). You can also get a number of products to help around the home, not always aimed specifically at people with disability from large, well-known companies such as Lakeland, Argos, Boots etc. and going with brands/organisations you know of and feel you can trust gives you reassurance when making your purchase. The Disabled Living Foundation also offers useful advice and factsheets on various aids.

Some of the hardest questions to answer are questions such as 'what product would help someone with RA?' or 'what mattress would NRAS recommend for someone with RA?' RA is a very variable condition, in terms of the range of symptoms, severity and which joints are affected, so it is more about finding a product to meet someone's individual needs than finding the best 'X' for someone with RA. Having said that, of course it can be useful to get tips and experience from other people with RA and to see what they found helpful.

Some of these tips can be found in our 'Useful Tips' article, www.nras.org.uk/useful-tips

Putting a post asking for suggestions for a product on the NRAS HealthUnlocked forum has also proved successful in the past: www.healthunlocked.com/nras

Hopefully the above tips and websites will give you some good ideas on where to purchase products, but first you will need to see if the product you want exists. The NRAS Helpline Team are aware of a lot of different products and are always happy to help, but if you wanted to find something yourself, here are some tips that might help.

Start by searching for some key words explaining what your mum might be struggling with, for example 'lift kettle'. Adding the general term 'arthritis' will ensure that your search brings up products aimed at people with joint problems. In this case, you will soon start to see that one of the main solutions for this problem is a product called a 'kettle tipper'. Knowing the commonly used term for the product will then allow you to search for 'kettle tippers' and find a range of products. This will allow you to make your choice, depending on things like brand/company selling the product and what you know about them, price and quality. Reviews from customers can help you get an idea of the quality of the product, and whether they felt it was worth the money they paid!





Research Update

'Living' hip replacement

Development of a new "living hip" replacement using stem cell technology

The treatment of joint conditions could be revolutionised by advances in stem cell technology that have been used to create a new "living hip" replacement.

A new way to grow cartilage using the patient's own stem cells has been found by Washington School of Medicine in conjunction with Cytex Therapeutics. In addition, they have given this material the ability to release anti-inflammatory molecules which could help to combat all forms of arthritis. This could significantly advance hip replacement surgery.

The research, published in the Proceedings of the National Academy of Sciences describes how the new cartilage is grown on a 3D template shaped like the ball of a hip joint from reprogrammed stem cells.

The patient's own stem cells are taken from fat beneath the skin and are moulded onto the template in the precise shape of the individual's joint. It can then be implanted on to the surface of the patient's damaged arthritic hip. An added bonus is the introduction of a gene into the newly

grown cartilage that can be switched on with a drug to release anti-inflammatory molecules to help prevent the return of the arthritis that destroyed the cartilage originally. This gene can be switched off again simply by stopping the drug.

The benefits of this new type of hip replacement is that it has the potential to last longer and be more effective and safer than traditional hip surgery. This could be especially beneficial for younger patients as typical prosthetic (artificial) joints generally last for less than 20 years. Subsequent surgery to replace a worn out artificial joint is often difficult and can put the patient at further risk of infection.

Dr Farshid Guilak, Professor of orthopaedic surgery at Washington University said *"replacing a failed prosthetic joint is difficult surgery. We've developed a way to resurface an arthritic joint using the patient's own stem cells to grow new cartilage. Combined with gene therapy to release anti-inflammatory molecules to keep arthritis at bay."*

"Our hope is to prevent or at least delay a standard metal and plastic prosthetic joint replacement"



Lymphoma risk study

A new study shows that patients with RA who have taken anti-TNF treatments do not appear to be at any higher risk of lymphoma than patients who are treated on other medications.

Previously, patients with rheumatoid arthritis were thought to be at higher risk of developing lymphoma compared to the general population. It is important to know what effect potent anti-TNF drugs have on this risk.

Researchers used information from the BSR (British Society for Rheumatology) biologics register to compare the risk of lymphoma in people treated with anti-TNF drugs with those treated with standard disease modifying anti rheumatic drugs (DMARDs). 11,931 patients with RA treated with anti-TNF drugs were compared to, 3,367 RA patients on standard DMARDs. Other data was also

looked at such as smoking status, disease activity, previous cancers, the use of DMARDs, comorbidities and steroid use.

The average follow-up time was around 6 years for those on DMARDs and 8 years for those treated with anti-TNF drugs. During this time, 114 cases of lymphoma were found over all. 30 cases were found within the group of 3,367 patients who were on standard DMARDs. 84 cases were found within the larger anti-TNF group. When adjusted for the total number of people in each group, there was no significant difference between the risk of lymphoma in each group.

From these figures, the researchers have concluded that there is no significant increased risk of lymphoma in RA patients who have taken anti-TNF for up to 5 years after treatment was started.

Research Update

Nerve stimulation study shows potential

Vagus nerve stimulation device may offer hope for relief from rheumatoid arthritis symptoms

A new study from the Academic Medical Centre at the University of Amsterdam, the Feinstein Institute for Medical Research and SetPoint Medical has shown that an implantable bioelectric device that electrically stimulates the vagus nerve could be used to help in controlling some of the symptoms of rheumatoid arthritis.

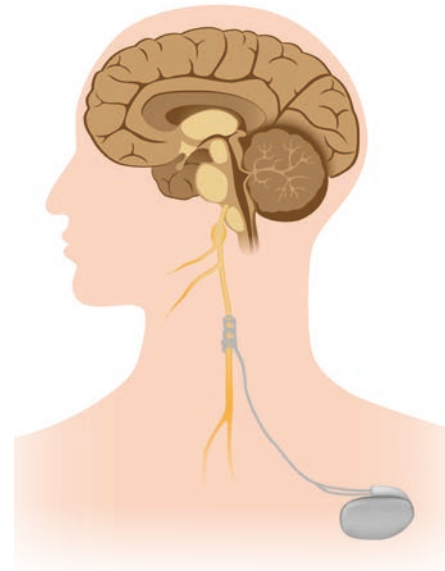
The vagus nerve connects the brain to the major organs of the body. The coin sized device works by sending bursts of electrical current to stimulate the vagus nerve for three minutes a day. This has been shown to reduce the activity of the spleen, so that it produces fewer chemicals and immune cells that cause the harmful and painful inflammation in the joints of people with rheumatoid arthritis, thus potentially being safer.

Just 17 people with RA were involved in the study, several of whom had tried multiple therapies,

including biologicals, with no real success in managing their RA. Stimulation of the vagus nerve in some of the patients inhibited the production of TNF thus reducing disease severity as a result. No serious side effects were reported.

Professor Peter-Paul Tak, principal investigator and lead author of the paper at the Academic Medical Centre said *“Even in patients who have not responded to the most modern pharmaceuticals, we have seen a clear trend of improvement. We may be able to achieve remission in 20 to 30 percent of patients, which would be a huge step forward in the treatment of rheumatoid arthritis”*

Using bioelectronics implants such as this show the potential to target conditions normally treated with drugs and may help people who do not respond to pharmaceutical treatments as well as reducing side effects associated with drugs, thus potentially being safer and potentially cheaper as well.



Why do we wake up achy and stiff?

Scientists have found in recent research that one reason people with RA feel sore and achy in the mornings may be because of anti-inflammatory proteins that our body clock uses to suppress inflammation at night. The proteins in question have been identified as cryptochromes.

A study was carried out on joint tissue in mice looking specifically at the cells involved in inflammatory arthritis. They found that inflammatory cells in joints had a 24-hour rhythm, with less inflammation during darkness, which was lost when mice were exposed to constant light. The researchers showed that the cryptochrome proteins decrease inflammation in these cells and when the cryptochrome gene is removed the inflammation levels are elevated. Further tests carried out to activate this protein proved that it could protect against inflammation.

Julie Gibbs, a leading researcher from the University of Manchester, has suggested that by understanding how our body clock regulates inflammation over 24 hours, we may be able to develop new

treatments in the future. She also goes on to explain that by altering the time of day we administer drugs, we may be able to make them more clinically effective at controlling inflammation and related symptoms.

This new found knowledge could help scientists identify new types of drugs for inflammatory arthritis.





Gill Weedon

External Projects & Groups Supervisor

Kim Fitchett

External Affairs Coordinator

External Affairs

NRAS Group Coordinators

Kim and Gill have been able to meet with many NRAS Group Coordinators this year whilst hosting Group Leaders networking lunches.



North West Coordinators



South West Group Leaders lunch

The role of Group Coordinator is integral to the successful running of the NRAS Groups.

Without shared leadership by these marvellous volunteers the groups simply wouldn't exist. The group leaders' (all of whom live with RA themselves) hard work and commitment to supporting others living with RA is truly amazing. The regional networking lunches were arranged to facilitate the sharing of best practice, solving problems, practical advice and to express our gratitude to these amazing Volunteers who help so many people to attend their group meetings. Each of the lunches have been fun and interesting with lots of ideas shared, leaving everyone feeling positive. Kim and Gill have very much enjoyed meeting so many hard working NRAS Volunteers and as always, we would like to send a huge thank you to each and everyone of them for their tireless efforts for those living with RA.

External Affairs

NRAS Groups' Update

The autumn has kicked off with two new group launches!

On a hot sunny day Clare and Kim travelled to Pembrokeshire to launch the West Wales NRAS group on 15th September. A social group in this area had run for many years but had lapsed over recent years. It was felt by the healthcare professionals at Withybush General Hospital that the time was right to launch an educational RA group and the team have committed to supporting the group going forward.

With the dedicated support of Suzanne Davies, Rheumatology Clinical Nurse Specialist, the event was arranged to take place in Narberth. An insight into the new biosimilar medications was given by Consultant Rheumatologist Dr Julie Barber. She was then joined by Dr Amanda Coulson, Consultant Rheumatologist, Suzanne Davies, Rheumatology Clinical Nurse Specialist, Eleanor Ireland, Rheumatology Nurse, Eirianydd Garrod, Rheumatology Nurse, Moira Wainwright, Rheumatology Occupational Therapist and Bridget Meiring, Rheumatology Therapy Assistant, for the Q&A session that followed.

An appeal was made for volunteers to come forward to help coordinate the new group and eight people have said that they want to be involved. A meet and greet and get-to-know-you meeting will be taking place in November to plan for meetings to start in 2017 with guest speakers on a variety of topics. More details can be found at: www.nras.org.uk/groups/nras-west-wales.

A huge thank you to all the healthcare professionals who were involved on the evening.



Suzanne Davies getting to grips with a tricky question from the assembled crowd.

Gill and Kim made the long, long journey to Grimsby on the 11th October for the launch of the North Lincolnshire and Goole NRAS Group. We were very grateful to have the help and full support of Susi Gaikwad, Clinical Specialist Physiotherapist, who helped to organise the whole evening. The event took place in the physiotherapy gym of Diana, Princess of Wales Hospital.

We were so overwhelmed with the turnout that it was necessary to trawl the hospital for more chairs as more and more people were arriving. It was certainly standing room only!

The keynote speaker was Dr Nick Dadiras, Consultant Rheumatologist, who gave a general overview of RA. This was followed by a presentation from Susi about her role in physiotherapy and how the department works together to provide the best patient care. The Q&A panel stimulated some excellent questions, several of which were answered by fellow patients themselves, really highlighting the benefits of an NRAS group in this area that can offer real peer to peer support and information..

Keep an eye on the NRAS website for 2017 meeting dates: www.nras.org.uk/groups/nras-north-lincs-goole.



The Grimsby launch

By the time you receive this magazine Kim and Gill will have also been to Stoke-on-Trent and Southend-on-Sea and Clare will have been to Torbay all in November to hopefully start three new groups in those areas. Details of all patient events can be found on the NRAS website.



Jim and Nicky Spurgeon



Kimberley Lowe and her Dad



Sophia Major



Joss Squire cycling for Grandma

Fundraising

Ain't no mountain high enough...

...ain't no valley low enough, ain't no river wide enough to keep you from raising funds for NRAS!

The latter half of the year has seen our community fundraisers signing up thick and fast for all sorts of events and challenges, with no end of talents and sheer determination shining through.

We have too many lovely fundraisers to mention all by name personally – so a big, heartfelt thank you to anyone who ran anything from a 5k to a marathon, who cycled around the UK or ventured further afield, to our terrific triathletes and to our very tough - Tough Mudder style challengers, or to anyone who selflessly asked friends and family for donations to NRAS instead of receiving gifts for birthdays, weddings or anniversaries. **Thank you.**

Just to give you a flavour of the real diversity of some of the fundraising challenges that have been completed here are just a handful of our truly dedicated supporters!



Jim Spurgeon - from Halstead in Essex completed, what he described as one of the most 'gruelling and toughest things' he had ever attempted with the mighty 'Man versus Mountain Challenge' on September 3rd on Snowdon Mountain, North Wales. Jim completed the 22 miles of mountainous terrain and obstacles, such as a quarry jump and

a 25 metre river swim under horrendous weather conditions; with winds of 60mph and zero visibility. Jim's finish time was a very credible 5 hrs 36 minutes, raising nearly £700 for NRAS. Jim chose NRAS, as his wife Nicky (both ran the Vitality 10K back in May) was diagnosed with RA in early 2015. Jim wanted to honour Nicky who has great strength and determination to overcome her disease. Well done Jim!

Walking is something most of us do during our day but for one young lady she decided to set herself a challenge to walk 1 million steps during the month of August. **Kimberley Lowe**, who lives in Tooting, needed to walk at least 32,500 steps every day – the recommended amount for us all is 10,000 steps per day; so you can see it was quite a challenge! Armed with her Fitbit, trainers and plenty of blister plasters, Kimberley walked to and from work and anywhere and everywhere she could over the month! Kimberley raised a truly amazing £1,330, never faltering with her challenge over the month. Her inspiration was her Dad, who in 2015 was diagnosed with RA. Kimberley wanted to highlight the fact RA is not just a disease that happens as you get older and that it can take years to get control of the pain which is faced daily.

Sophia Major – took on some 'major' challenges this year, pushing herself both physically and mentally with the Manchester Marathon, a 12K Tough Mudder and finishing up with a Skydive in August. Sophia wanted to show her support for her sister who has benefitted from NRAS services. Sophia, completed all three of her challenges, testing her abilities to the maximum and raised a wonderful £775 for NRAS.

Joss Squire one of our younger fundraisers wanted to do something for a charity and decided NRAS would be a good one to support. His Grandma has lived with RA for over 52 years since she was 26. Joss raised a fantastic £96 doing his cycle along the South Staffordshire Railway walk route.

NRAS

Christmas Carol Concert

The NRAS Christmas Carol Concert will be on the 9th December and for the first time will be held at St. Peter's Church in Maidenhead. All our favourites will be there again - the Cox Green Brass Band, White Waltham School choir and Noteworthy to name but a few.

We do hope you will be able to join us for what promises to be a lovely evening of music and verse, and please stay to join us for a glass of wine and a mince pie at the end of the evening. All the information is available on the website at www.nras.org.uk/other-events. If you have any further questions do please email us at fundraising@nras.org.uk or give Val a call on 01628 501547. Entry is free with a retiring collection at the end of the evening so just turn up on the night with your best singing voice at the ready!

Get up and running

in support of
NRAS and JIA

Nicola was determined her RA wouldn't stop her doing the things she wanted to do.

Will you join Team NRAS and run in the Brighton Marathon 2017?

Sign up at
www.nras.org.uk/runs

NRAS is Changing Minds, Changing Services,
Changing Lives for People with RA and JIA



nras
National Rheumatoid
Arthritis Society



Colyn Smith MSP and Sheila MacLeod, Chair of the Scottish Ambassadors Network



Dr Kathryn Martin at the Scottish Parliament

Policy and Public Affairs

Who Cares? Report

An opportunity to make the case for people living with RA or JIA



Speakers Liam McArthur MSP, Clare Jacklin, Dr K. Martin and Prof. Iain McInnes

Results show that:

89% indicated that RA limits their daily activities

97% of personal care is provided by family members

On 6th September, Conn, Clare and our Scottish Ambassadors welcomed NRAS members and healthcare professionals to the Scottish Parliament for the launch of our latest major report, 'Who Cares?' A long awaited report on the health and perceived social care needs of people living with rheumatoid arthritis in Scotland, was produced in collaboration with Dr Kathryn Martin from the University of Aberdeen.

Late last year, people living with RA in Scotland completed a survey with our highest ever survey response rate in the country. The report explores their care experiences and is further informed by the anecdotal evidence we collect in speaking to so many people living with RA.

Dr Martin addressed those presented a summary of the key findings and recommendations. There are nearly 40,000 people living with RA in Scotland. This is expected to rise to over 42,000 by 2020. With the new imperative to integrate health and social care across the UK, it was important for NRAS to explore the prevalence of co-morbidities; the impact of RA on work/occupation and how complex care needs were being met.

The findings showed that the most common additional health problem of people living with RA was depression. Worryingly, 44% of respondents felt unable to work because of their disability. Work is hugely important for the majority of those of working age. Loss of one's job may lead to mental health problems, financial difficulty, loss of pension provision (leading to greater reliance on the state in older age), and can have a significant impact on personal relationships with friends and family.

With the majority of social care being informal and provided by family members, many respondents felt they were a burden on their principal carer, which can add to anxiety and depression. Further to this, a worrying 89% were unaware of what types of circumstances make them eligible for help with care and support from their local council. Local councils should make access to information about help with formal social care easily accessible and ensure that health professionals know how best to sign-post people.

Liam McArthur MSP who kindly sponsored the event in Parliament and our Scottish patron, Professor Iain McInnes, also spoke at the reception. The Scottish Ambassadors and the Policy and Public Affairs team in Maidenhead will use this report to take forward our Scottish campaigns in 2017 and beyond.

Policy and Public Affairs

Benefit assessments

NRAS cautiously welcomes big changes



Conn at ESA Assessment Centre

You may have seen in the news that the Secretary of State for Work and Pensions, Damian Green, made an announcement at the Conservative party conference in Birmingham about changes to assessments for the Employment and Support Allowance (ESA).

ESA is an income replacement benefit for people with disabilities. Some adults with RA/JIA claim this benefit for people with disabilities and many have reported a less than pleasant experience of the assessment process. People with severe RA/JIA who sadly have no prospect of lessening symptoms in the near future or reversing extensive joint damage have been particularly frustrated at the need to regularly attend an assessment - the 'work capability assessment' - sometimes as often as every six months. We raise this and other issues with the government and with the private company who carry out these assessments, Maximus, on a regular basis. We welcome the announcement from Damian Green that if you have a lifelong condition that is not going to get better then you will no longer have to be repeatedly assessed in order to claim ESA.

We must be cautious however as we await the details. Please do not assume that a list of conditions will be created that passports you on to a lifetime award, it will most likely be at the

discretion of the health care professional carrying out the assessment, supported by evidence provided by your usual clinicians, that makes a judgement call on whether the claimant is likely to "get better". This is right and proper, given that with rapid diagnosis and a prompt start to effective treatment, many people diagnosed with RA/JIA today will hopefully never find themselves needing to claim a disability benefit, we would not want to confine RA to such a list.



Alongside colleagues in the Disability Benefits Consortium, we are working to ensure that these reforms work for people with fluctuating, long term conditions like RA and JIA. Equally, we will push for a similar approach to be adopted for the Personal Independence Payment (PIP) and continue to keep our fingers crossed for some joined up thinking whereby the assessments for ESA and PIP could be merged - wishful thinking?!



By **Conn O'Neill**

NRAS Policy & Public Affairs
Officer

We welcome the announcement from Damian Green that if you have a lifelong condition that is not going to get better then you will **no longer** have to be repeatedly assessed in order to claim ESA.

Arthur

By Alyson Hughes

25.8.16

If you liked Alyson's poem why not show your support by visiting her donation page at www.justgiving.com/fundraising/NRAS-Arthur

This gnarled man before me who's hunched into a ball,
 Was once a man who stood so proud and so tall.
 He hides his pain with a grimace and a grin,
 No one knows the toll of his skeleton within.
 His twisted frame contorts with disease,
 It ravages with no manners, no thank yous nor please.
 Each limb and joint feels broken in two,
 So swollen and knobby with a colourful hue.
 He needs help doing the simplest of things,
 From eating and dressing and tying shoe strings.
 Arthritic pain grips him day after day,
 But this has not always been the way.
 As a lad he'd climb trees and have lots of fun,
 And fool around in the midday sun.
 He did what he could for his kids and his wife,
 Providing them with a future for a wonderful life.
 But that man who stood so majestic at dawn,
 Has withered and faded and practically gone.
 His heart beats slower,
 his kidneys have shrunk,
 All this from the rheumatoid
 and medical junk.
 Yet despite all his anguish
 he does not whine,
 And when asked he'll reply
 with a grimace....'I'm fine!'



Share
 your story
 with us!

If you've been inspired by any of our Members' stories and have a great one of your own to tell, then please do get in touch with us at media@nras.org.uk

700,000 reasons to run Berlin 2017

That's approximately how many people live with RA and JIA in the UK.

Will you join Team NRAS and run in the Berlin Marathon 2017?
Sign up at www.nras.org.uk/runs

NRAS is Changing Minds, Changing Services, Changing Lives for People with RA and JIA

Thank You to those who donated to our Radio 4 Appeal

On the 16th October we broadcast our Radio 4 Appeal, which shared the story of Amy, who was diagnosed with RA shortly after the birth of her first child.

Amy's story covered the highs and lows of her journey and how an NRAS Telephone Support Volunteer 'came to her rescue'. Although we have gone to print before we know the final total has been tallied, you can find out how much was raised on our Facebook page and website. You can still support the Appeal as Amy's story is also our feature for the Christmas Appeal.

To support the Appeal and listen again to the broadcast, visit: www.nras.org.uk/amy



BBC RADIO



16

OCTOBER

A BBC RADIO 4 APPEAL



By Anne Gilbert

NRAS Youth and Family Services Manager

JIA & Me

Pretty in Purple

Producing Pennies for JIA!



Bronwen and Lilliah



Baking purple cakes would be a great way for families to get together and have some fun.

An exciting new project for the JIA team at NRAS to raise awareness of JIA and have some fundraising fun at the same time #wearpurpleforJIA.

Wear Purple is now an established event and was the idea of Lynette Haselip. They approached the JIA-at-NRAS team to be the recipients of the funds they raised this year and we helped them to promote 'WearpurpleforJIA'. We had a huge response and an amazing £6000+ was raised. Lynette wants us to make next year even bigger and better and to grow the purple challenge nationally, so that got us thinking about additional ways to both raise awareness as well as much needed funds.

Taking inspiration from the new series of 'Bake Off' we decided that baking purple cakes would be a great way for families to get together and have some fun. So, we filmed some baking fun in Bronwen and Val's kitchens (Bronwen and Val are part of the NRAS fundraising team). Bronwen's gorgeous grand-daughter Lilliah had a great time both helping and then eating the final result. Val's

daughter Victoria was definitely the star baker ably supported by Val's son Alex, both of whom feature in the second video creating some amazing dual coloured frosting. I was directing and it was all going well until the piping bag exploded and I ended up with more frosting in my hair than on the intended cupcake! It was quite a challenge for Alex from Visual Vibe who was shooting the videos to avoid getting purple frosting on his filming equipment!

Watch out for the videos which we will use next year to raise awareness of JIA and kick off the #wearpurpleforJIA challenge on June 9th.



A family affair



Harvey, Andrew and Terry

We met Charlotte Verity and her son Harvey at our JIA big family day in Yorkshire this year. Harvey is 6 and recently diagnosed with JIA. Since then Charlotte, Harvey and their extended family and friends have been pooling resources to raise awareness and share how JIA can impact children's lives. Harvey's school dedicated a whole month to JIA on their school notice board and his kidsclub, the Mayne Play Kidsclub in Grimsby got involved with lots of fundraising and raised a fantastic £359. Even Harvey's Great Grandma, June, took one of our NRAS collection boxes and collected £70 in loose change! To really make it a family affair Harvey's step Grandad, Andy Wright, contacted us to say he wanted to raise funds and ran in the Grimsby 10K, along with his friend Terry Axcell, the family supported with fun runs themselves and Harvey was amazing and ran a 2K fun run as well!!! We think they look great in their NRAS T shirts. Andy raised £477.52 and received £250 in matched funding from his employers, Youngs in Grimsby. A big well done to the Verity and all the extended family and friends for all your efforts over the summer months and thank you to Youngs of Grimsby.

Craig Weston took part in the RideLondon 100 mile cycling challenge. His long-suffering wife (cycling widow) gave him strict instructions that he could only take part on the proviso that he raise money for something that really meant something to them; so he rode for NRAS, specifically for juvenile arthritis (JIA).

Craig told us "at the beginning of 2015 our world was rocked when our daughter Sophia (then nearly 6 years old) was diagnosed with juvenile arthritis. To say we were shell shocked is an understatement... we didn't even know that children could get arthritis. Then began the seemingly endless hospital appointments, steroid injection operations, weekly drug injections, medicine to control nausea, stress and worry. 18 months on and Sophia is doing really well thanks to an amazing team from the Evelina children's hospital in London. Some days can still be difficult and, as there is currently no cure, who knows what the future holds, but to see the child who sometimes couldn't get down the stairs, crying as she was in so much pain, cycle up Box Hill with me makes me very proud of my strong, courageous, lovely girl!"



Craig with Sophia

Craig has raised £1,816 so far.

The whole family supported us with fun runs and Harvey was amazing running a 2k fun run himself!

Jumping for Joy! Amazing young fundraisers

Lauren Edmonds who is just 5 years old held a sponsored trampoline bounce with her friends during the summer holidays. They literally jumped the afternoon away to raise funds for JIA at NRAS. Lauren was diagnosed with JIA at just two years old and has endured numerous hospital visits, tests and operations, but despite everything Lauren is still full of life and laughter with lots of energy and a love of bouncing!!!

Lauren jumped with 23 other children, managing 2201 bounces between them and raising a whopping £2,250. If you want to help jump up this total you to reach new heights you can still support Lauren's Jumping For Jia by donating at uk.virginmoneygiving.com/team/LaurenAndFriends



Lauren Edmonds



Bradley Wiggins, eat your heart out!

We met Benjamin Chamberlain and his family at our fun-day event in Newmarket earlier this year and we are delighted to hear that he is taking part in the London to Brighton cycle ride in September 2017 to raise funds for JIA-at-NRAS.

This is what Benjamin said to us "so, I seem to have booked myself to do the London to Brighton Cycle ride! It's 54 miles of open roads so the chances of me being knocked off could be high! As I'm sure everyone is aware of Sienna's condition I will be riding for JIA - juvenile idiopathic arthritis. NRAS has supported us from the moment Sienna was diagnosed from 2yrs of age which, as a family, has been invaluable! 54 miles is a long way for someone who is as tall as he is wide, and weighs a fraction more than Sir Bradley Wiggins! Any donations would be gratefully received to help me raise awareness for this condition".



“Every child has the right to an adventure. Life is about grabbing opportunities. The prizes don't always go to the biggest, the best and the strongest – they go to those who persevere. These are simple life lessons that Scouting teaches.”

Bear Grylls



Tor's Centenary Challenge

Tor's centenary challenge is an inspiring story of a young scout who isn't letting his diagnosis stop his adventures. Every Cub Scout has their unique characteristics, and Tor is no different, but one thing that sets him apart is his diagnosis his diagnosis of JIA.

Despite all the hospital appointments, starting methotrexate and a biologic drug, Tor has managed to join in weekly meetings with his friends. He was excited to take part in the Cubs 100 celebration camp, and it was great to see him taking part in archery, climbing, crate stack and the assault course challenge.

Tor said "It was a brilliant camp, I had loads of fun

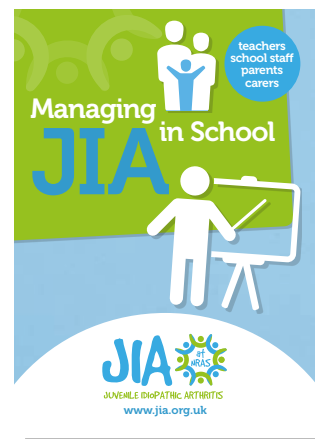
with my friends, I set myself a personal challenge to finish the assault course - and I did it! "

Tor's Scout leader remarked "You can see from Tor's face that he thoroughly enjoyed his weekend away. He challenged himself despite his juvenile arthritis, and got stuck into the range of adventurous activities and had so much fun doing it. "

This summer Tor turned 11, and has made the transition to Scouts, where he's continuing his adventures! But not before he gained the Chief Scout Silver, the highest award a Cub can achieve!

JIA & Me

JIA Schools booklet gets top marks



Have you got your free copy of "Managing JIA in Schools" yet? If not please email anne@nras.org.uk or visit www.jia.org.uk/publications/managing-jia-in-school to download

The JIA Schools' booklet is proving very popular and we have had some great feedback. Here are some of the comments from parents:

"I just received my copies of the 'Managing JIA in Schools' booklets - and cried. Currently facing many of the issues discussed in this book, I was overwhelmed with relief to see them in print, validating that these issues are very real, that they are faced universally through many families and that someone has taken the time to listen to those families, learn from them and then put together this constructive, informative booklet so that others can be better educated about how to support JIA families to face these challenges. I probably didn't realise until I opened this envelope how vulnerable I was feeling.

I am so grateful for the support JIA-at-NRAS is providing.

Thanks so much for the copies of the 'Managing JIA in Schools'. What a fantastic booklet!

I am so pleased to have something that just sums it up all in one place. So much so I want to give a copy to all of my daughter's teachers. With that in mind is it possible for you to send to me 10 more copies. I will of course pay for them and cover the postage, just let me know how much I owe you."

"Well done on a really useful booklet"

BSPAR Annual Conference

The British Society for Paediatric and Adolescent Rheumatology (BSPAR) conference will be held this month and Anne and a member of our helpline team will be attending. We will report back items of interest from this important conference in the spring 2017 NRAS Magazine issue. JIA at NRAS will have a stand at the conference displaying some of the artwork of winners of the "JIA and Me" art competitions. The "JIA Explained" booklet will be launched at the conference too as it is a great platform for us to make all the paediatric health professionals aware of this informative new resource. To pre-order your JIA Explained booklet email anne@nras.org.uk or keep an eye on social media and the website for when it is ready to be ordered online.





Competition

EULAR Edgar Stene Prize

Open for Entries!



The Edgar Stene Prize 2017 competition is open to people 16 years and over who are living with a Rheumatic and Musculoskeletal (RMD) disease. The 2017 prize will be awarded to the winning essay on the topic:

"Time is joint - Joints over time"

"Early diagnosis and access to care in rheumatic and musculoskeletal diseases (RMDs) – the ideal world and the reality – my personal story"

For many people with RMDs it can be a long journey to receive the right diagnosis and appropriate treatment for their condition. The competition invites entrants to write about their personal experience: How long did you wait until your diagnosis was confirmed and how did you cope with the uncertainty, pain and fear during that period? Would an early diagnosis have made a difference from how you are feeling now? Do you have access to care and optimal treatment and management of your disease? What would an ideal situation look like and what is your reality?

Please submit all completed essays to Emma at emma@nras.org.uk or by post by midday on Wednesday 21st December 2016. Each entry should not exceed two A4 pages. Full competition rules and further details can be found on the EULAR website: www.eular.org

Each national jury will nominate the best entry from their country and a EULAR jury will select the 2017 overall Stene Prize winner by 15th March 2017.

The Stene Prize winner will be awarded a prize of **€1,000 and will be invited to attend the Opening Plenary Session of the EULAR Congress in Madrid** (14th June 2017) with travel and accommodation covered. The runner up will be awarded €700 and third place awarded €300.

GOOD LUCK!



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