

Members' MAGAZINE

SUMMER 2017



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National Rheumatoid
Arthritis Society

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By Ailsa Bosworth, MBE

Chief Executive

Dear Members

As I write this, it is the first day of Wimbledon and we're all hoping Andy Murray is back on form and going to win. However, by the time the magazine lands on your doorstep, the tournament will be a distant memory and we'll be starting to think about Christmas and year end stuff! But for now, I'm focussing on the prospect of a lovely summer ahead, long evenings and having a summer holiday at the end of August to look forward to. I hope that you too have some nice summer events in your diaries.

Living with RA, as I have for more years than I care to remember, I find that it's very important to have something in the diary to look forward to but also to live in the here and now and focus on enjoying things in everyday life wherever I can. Like last night, sitting in the garden having a drink with my husband in the evening sunshine, feeling the grass underneath my bare feet, and savouring that feeling which doesn't happen that often as I can't walk without shoes!

Clare, Matt and I were at EULAR in Madrid in June, which was EULAR's 70th birthday. It was unbearably hot at over 40° so when we came out of the congress building it was like someone was holding a fan heater in your face. Thank goodness for air conditioning! It was our busiest EULAR ever – Clare and I did 6 presentations between us plus we had a poster. I was the patient voice at an evening symposium on the subject of biosimilars, a subject of huge importance to patients and clinicians alike currently. If you want to know more on this topic, can I recommend that you watch the video interview filmed with Professor Peter Taylor? www.nras.org.uk/biosimilars

investigation into the health and perceived social care needs of people with rheumatoid arthritis living in Scotland. Finally, the symposium on biosimilars. Phew! Our poster was on the subject of the 'Behind the Smile' video series, which many of you will be familiar with. In addition to presenting all this work, we had a number of meetings with other organisations and stakeholders we work with as well as being able to network with other patient organisations from across Europe, and we even managed to squeeze in the odd session on a variety of subjects which relate to RA and JIA. For Matt, who has only been in post for a couple of months, EULAR was a great experience and enabled him to learn a lot in a short space of time and also talk to other Policy and Public Affairs leads from large patient organisations in Europe.

EULAR's 70th birthday also saw the launch of a world-wide campaign called 'Don't Delay, Connect Today!'. This is all about the imperative to get a diagnosis as soon as possible after symptoms first appear and is a campaign we shall be wholeheartedly supporting in the UK. We will let you know more about this in due course and how you can get involved.

Our new, interactive educational video about cardiovascular disease risk assessment – **Love your Heart** is well on its way to be launched in September and we hope many of you will be participating in the programme. If and when you do, please do fill out the evaluation form at the end and also (when it comes further down the line) the 6-month questionnaire as these will be vital to help us evaluate the impact this new resource is having and help us to improve on future versions.

Sadly, we said farewell to Conn, our Policy and Public Affairs Manager who has left to take up a role in industry but we wish him well and we know that it's not goodbye because Conn has made it clear that he will continue to support NRAS in a voluntary capacity whenever he can. He's already been back since leaving in fact, to help with the training programme for some of our new Ambassadors from Scotland, Wales and Manchester and he helped at our JIA Family Day on 1st July in Ilkley, West Yorkshire. Thanks Conn and continued best wishes in your new role!



This video is not for the faint-hearted as it's 53 minutes long, however, it has chapter headings which you can skip between, and it is a useful resource for training health professionals as well!

Other subjects we presented on included: **'Can patient organisations help prevent co-morbidities?'**, a summary of lost working time from the **'Burden of RA; a Socioeconomic Study'**; this was a major European study across 10 different countries looking at the health economic costs associated with RA on which we collaborated with Chester University; **'RA Matters' survey** – another European collaborative survey, industry sponsored. The results of our **'DAS App'** use. **'Who Cares?'** – an

If you are receiving this magazine for the first time and are not yet an NRAS Member, sign up today and receive it on a regular basis.

Simply contact membership@nras.org.uk to find out more about joining.

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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

Editor of this issue;
Sally Wright, Head of Marketing and Communications

Greetings from the new Chairman of NRAS Gordon Taylor

Ailsa set up NRAS 16 years ago. It is still the only UK charity specifically devoted to supporting adults and their families living with Rheumatoid Arthritis (RA) and children, young people and their families affected by Juvenile Idiopathic Arthritis (JIA). Everyone working at the head office in Maidenhead, and all of our NRAS Members, Ambassadors, and Volunteers around the country are doing a fantastic job supporting, providing information and advice, and most of all, empowering all to have a voice and take control of their RA and JIA. NRAS is truly patient-led.



Gordon Taylor

Chairman, NRAS Board of Trustees

The importance of having someone you can call on for advice and support is so important. Married to my wife, Fiona, with 3 active teenage children, we have lived in many countries that my work in Healthcare and Pharmaceuticals has taken me to. In 2016, we came back to the UK after 17 years of living abroad, and we now live in the New Forest. I am originally from Newcastle, my Dad and brother still live there and I try to get back as often as I can. Members of my family have autoimmune diseases, and I am very familiar with what is needed in terms of the challenges and vital solutions necessary to enable them to continue doing the things they enjoy. Advice and help is not always easy to find, especially if you are far from home, or family members are not nearby.

When I came back to the UK, I wanted to use my management experience to help as a Trustee. NRAS were looking for new Trustees to strengthen their board, and after talking with Ailsa and the other Trustees, NRAS seemed a great fit for me. I have been a Trustee since January 2016 and Interim Chairman since January this year, being formally elected Chairman at our June 6th Annual General Meeting and Trustees' Board Meeting. That meeting was also a chance to meet and hear from Sheila MacLeod, Chair of Scottish Ambassadors, on their excellent work, which was also mentioned in the Spring Members' magazine. I am looking forward to learning more about all of the other great work done by our national and local initiatives around the UK.

As Chairman, together with the Board of Trustees, we are committed to continue working closely with Ailsa and her Management Team to ensure we maintain a solid, sustainable strategic plan, and regular review of our activities to ensure NRAS continues to do the best possible job to support everyone with RA or JIA to live life to the full.

Gordon Taylor,
 Chairman, NRAS Board of Trustees

“We are committed to continue working closely with Ailsa and the NRAS Management Team to ensure we maintain a solid, sustainable strategic plan, and regular review of our activities to ensure NRAS continues to do the best possible job to support everyone with RA or JIA to live life to the full”

Celebrating the many faces of Clare Jacklin

How long? 10 years already? Well, you know the old saying 'time flies when you're having fun'!

Clare joined NRAS in June 2007 as our Volunteer Network Manager: she hasn't changed a bit, has she? I looked back at our annual review for that year and we had 12 staff, less than half the number of staff we employ in 2017!

Clare has played a huge part in helping to grow and develop the organisation over the past 10 years and her dedication and commitment to improving the lives of those affected by RA and JIA is recognised, not just by me and the team here, but by rheumatology professionals and people with RA and JIA across the UK and beyond. Her relentless cheerfulness and being prone to make the odd pun, well a lot of really awful puns on a regular basis actually, is the cause for a lot of eye rolling, but her skills and achievements outweigh all the high jinks and giggles by a mile. She works hard and plays hard and here's the proof! OK, I've said the nice bits, now let's get down to the nitty gritty...



She's been a blond on occasions



She's fond of this dark Irish stuff



She'll dress up and pose at the drop of a hat



She'll do anything to be a dame in a panto!



She'll dance with any strange men for money (mostly for NRAS!)



She can be very bossy!



She makes me laugh a lot

I have many more incriminating photos I could share but I do want Clare to stay at NRAS so I best stop there!

Congratulations Clare, we couldn't have got here without you!

Ailsa Bosworth, CEO

(Dear Members – continued from page 2)

We welcome a number of new staff to NRAS, Matt Bezzant as Policy and Public Affairs Manager, Caroline Pryer and Katie Kent who join us in Information & Support, Alison Derrick... and in our Fundraising Team, Dawn Waterman who joins us in a new role as Trust and Foundations Manager and Laura Dominguezpastor, who will be our new Trust and Foundations Officer.

We're headed for a mega busy autumn period and will be publishing the results of our work

survey at a parliamentary event during the week of World Arthritis Day. Meantime, I wish you all a happy, safe and healthy summer with hopefully some lovely sunshine to warm our achy joints!

With best wishes to all of you

A warm welcome

The newest staff members of the NRAS team introduce themselves to you

Matt Bezzant

I joined NRAS in May as Policy and Public Affairs Manager, having previously worked in both public affairs and policy roles.

I'm delighted to have joined NRAS at an incredibly busy time in the political calendar, which means that I have been kept busy from day 1! I am really surprised at how a small charity can achieve so much on a large scale, and I'm looking forward to successfully planning and implementing all of our upcoming political campaigns work in order to make a positive difference to the lives of people with RA and JIA.

Alison Derrick

My career has mainly been spent working for local councils across Buckinghamshire and Berkshire, predominantly enabling multi agency partnerships; working on projects with third sector organisations and helping communities take more control of their local environment. Since 2011, I have worked for a wider variety of organisations including managing a charity providing demand responsive transport (and driving the aged 16-seater minibuses), and working for Living Streets (the UK charity for Everyday Walking).

My father lives with RA, so I look forward to providing him with excellent and well-informed advice about how he can manage his condition most effectively - which he will of course ignore!

Caroline Pryer

My background is in high pressure management roles in Customer Service, Projects and Operations, working very long hours. Following the birth of my beautiful granddaughter Emilia, I

decided on a major work/life balance adjustment and after a short break, feel honoured to now be part of the NRAS team. I can say already, with certainty, that working on the Helpline, providing support to those with RA, JIA and family members is far more satisfying and rewarding than anything I've done before. My spare time is spent with Emilia, of course, gardening, walking, reading and socialising with friends and family.

Katie Kent

My experience has been mainly within the medical industry, including working at an NHS diagnostic centre and a pharmaceutical company. I also spent time dressing up in a dragon costume as a kids' entertainer, but we won't say any more about that. I took the role at NRAS because I wanted to be able to help people in a more direct way. I have been working on the Helpline for a few months now and can honestly say I have found it to be incredibly rewarding and I am privileged to be working for such a supportive charity.

Laura Dominguez

Laura Dominguez joins NRAS as Trusts and Grants Officer. With experience working and volunteering in the charity sector in different countries and different roles, Laura arrives at NRAS full of energy and a passion for helping others. Previously she has worked as an alliance manager in an IT firm and is looking forward to putting all her knowledge into bringing success and support to people living with RA and JIA.

"It is a privilege to work in a patient focused charity and with such great and dedicated team of people. I look forward to this new adventure!"



Matt Bezzant



Alison Derrick



Caroline Pryer



Katie Kent



Laura Dominguez

Pen Pals wanted!

A few of our Members have mentioned the possibility of wanting to write to other NRAS Members, similar to our peer-to-peer telephone service but with good old pen and paper! If you would like an NRAS pen pal to write to, send us your advert including your age-range, hobbies and what type of person you'd like to respond to you and we'll feature as many as we can in our next edition! Send adverts to Emma at the NRAS postal address on the back page, call her on **01628 823524** or email it to **membership@nras.org.uk** We look forward to hearing from you!





Mark Arnold

...and fond farewells.

Goodbye Mark, May the Force Be With You!

In May we said goodbye to Mark Arnold, our Trusts and Foundations Officer. Mark had been with NRAS for nearly 3 years working in the Fundraising team. Mark has JIA himself and so was able to contribute to NRAS from the perspective of a patient which was invaluable.

Mark was known for his jokes and one liners, and his love of Star Wars. Of course, his favourite leaving present was his lightsabre.

We wish Mark all the very best in his new fundraising role with Reading University.



Tammy Mallowan

Goodbye, Tammy

After 5 years, it is with sadness that we say goodbye to Tammy this month. She has taken some time out to recover from an illness and has some further procedures to prepare for in the autumn, When she is fully recovered she is hoping to find an opportunity closer to home.

Being our receptionist and office administrator, many people would have spoken to Tammy when calling in to the office over the years. Tammy was often that first welcoming cheery voice on the phone and that smiling first contact for visitors to the office.

We all will miss Tammy and we wish her the very best of luck in whatever the future holds for her but especially a very speedy recovery.



Rheum for You 2017

Upcoming Membership conferences



Rheum for You conference 2016

We're delighted that our series of 'Rheum for You' Membership conferences are coming together nicely! If you are interested in attending any of the events please do let us know so that we can keep you informed as more details are confirmed nearer the time.

NRAS Members' Conferences will be in the following areas:

- **Swindon – Thursday 12th October**
Wrag Barn Golf Club, Swindon, SN6 7QQ (postponed from 21st June)
- **Wrexham – Wednesday 8th November**
Catrin Finch Building, Wrexham Glyndŵr University, Wrexham LL11 2AW
- **Durham – Spring 2018** (details to be announced in our winter magazine)

As with previous years it will be free to attend for all NRAS Members accompanied by one guest. Additional guests and non-Members are welcome to attend for small fee of £5.00 on the day to go towards the cost of lunch/refreshments, however priority will be given to current NRAS Members.

Interesting speakers and interactive sessions are being planned for each event but spaces will be limited so please do contact us to register your interest in attending. Please email membership@nras.org.uk with your full name, postcode, the Members' event you are interested in attending and also tell us if you will be accompanied by a guest(s). Alternatively you can also call the membership team on **0845 458 3969**.

We look forward to seeing you all very soon!

“Interesting speakers and interactive sessions are being planned for each event but spaces will be limited so please do contact us to register your interest in attending”



Wrag Barn Golf Club, Swindon



Hamper winner (take 2!)

As you may have seen in our spring magazine, Kate was selected as our hamper winner from our #BlueMonday prize draw. However, due to dietary restrictions Kate was unable to take advantage of the lovely treats inside, so not wanting to waste it she set to thinking about what she could do with it instead.

Kate kindly asked a friend if she could raffle it at the small sewing group she goes to. Although she

couldn't make it to the event itself (due to recent shoulder surgery), her friend told the group about NRAS and ran it for her, raising a lovely £30 in the process. The (second!) lucky winner of the hamper, was Hilary, and she was thrilled with her prize.

We hope you enjoyed the hamper Hilary and a big thank-you to Kate for her very kind donation!

“What a pleasant surprise – I don't win things often so that is lovely news!”

Free prize draw winners in RA Awareness Week!

NRAS ran a Membership free prize draw in the run up to, and during, RA Awareness Week. We are delighted to say that our two lucky winners were:

Ms Ross-Eskell from London and
Mr Konig from Hove

Both have now received their prizes of a Blu-Ray box set each and Ms Ross-Eskell said, "What a pleasant surprise - I don't win things often so that is lovely news!"

We look forward to more prize draws for Members in future editions of the magazine!



NRAS Membership Survey 2017

Thank you for being a Member of NRAS.

We are very interested to find out what you think of the current NRAS Membership and how we can improve it. Your feedback is incredibly important to us and we will use the responses to improve how well membership works for you and future NRAS Members. We will be running this survey on an annual basis and we hope it will become a valuable tool in finding out what's important to you, our Members.

This survey should take no more than 10 minutes to complete. The survey closes on 31st August 2017 and the link can be found here: www.surveymonkey.co.uk/r/NRASMembSurvey2017

If you have any questions about the survey please email membership@nras.org.uk or call Emma on 01628 823524.

Thank-you so much for your time!

NICE National Institute for
Health and Care Excellence

Managing osteoporosis in adults

The new osteoporosis quality standard (QS149)

A new quality standard for osteoporosis has been published on the NICE website. This quality standard covers managing osteoporosis in adults (aged 18 and over), including assessing risk and preventing fragility fractures (a fragility fracture is one that results from a force that would not normally result in a fracture). It describes high-quality care in priority areas for improvement.

Quality standards help improve the quality of care provided to patients and can be used by healthcare providers to:

- identify gaps and areas for improvement
- measure the quality of care
- understand how to improve care
- demonstrate quality care is provided
- commission high-quality services

The standard has four quality statements:

1. Adults who have had a fragility fracture or use systemic glucocorticoids or have a history of falls have an assessment of their fracture risk.
2. Adults at high risk of fragility fracture are offered drug treatment to reduce fracture risk.

3. Adults prescribed drug treatment to reduce fracture risk are asked about adverse effects and adherence to treatment at each medication review.
4. Adults having long-term bisphosphonate therapy have a review of the need for continuing treatment.

This quality standard is expected to contribute to improvements in the following outcomes:

- Health-related quality of life for people with osteoporosis
- Fragility fracture incidence
- Mortality rates associated with fragility fractures.

You can read more about this quality standard on the NICE website:

www.nice.org.uk/guidance/qs149

Take a look at the new information video on the website about osteoporosis and what to expect when going for a DXA scan.



Time is joint – joints over time

EULAR Edgar Stene Prize – Essay Entry by Fleur Farrell

Early Diagnosis and Access to Care in Rheumatic and Musculoskeletal Diseases (RMDs) – The Ideal World and the Reality – A personal story



Fleur Farrell from Herefordshire

I press my body even closer to the unforgiving rock and try not to look down. "Grab the rope, grab it now!" yells my climbing partner. "I can't, I can't move my hand!" I yell back. I lose my grip and start to slide down the mountain side. The rush of cold air takes my breath away as I tumble faster and faster until with a crashing jolt I hit the valley floor....and wake up.

For a moment, I am disorientated but the sense of relief at this being a dream is soon replaced

with a rising sense of panic. I cannot move the fingers of my right hand. I switch on the light. After 20 minutes of furious waggling I can just about get my thumb to bend, but with a nauseating crunch. I drift back to sleep not realising this is my first encounter with a disease that will take over my life for the next year.

I decide to visit my doctor. Like me, he thinks I have strained my hand but decides to send me for blood tests anyway. 2 weeks later I get a call. The doctor pauses for a few seconds then says, "Tell me, have you a family history of rheumatoid arthritis?" my heart sinks. Yes, yes, I do. I know all about rheumatoid arthritis, my grandmother had it. Diagnosed at 46, the same age as I am now, her deformed and swollen hands are an early childhood memory. "I think we will get you a rheumatology referral then," he says quietly.

So far this seems like an ideal scenario in the care of rheumatic disease. I visited my doctor as soon as I noticed my symptoms and I am lucky he considered all the possibilities and acted accordingly. The honeymoon period soon ends however when I receive my appointment date for the rheumatologist. It is for the 10th December, 5 months away. Now even I know this is a disease where early diagnosis and treatment are vital. I call the hospital and find this is normal in my area where waiting times for an initial consultation are anything between 4 and 6 months. I ask if there are any cancellations but I am told these are reserved for existing patients. Problematic when early treatment is crucial to limiting the damage this disease can do. I persevere and get an earlier appointment for September. When I arrive, my consultant is sympathetic. Yes, I do have rheumatoid arthritis. How could I have not noticed my swollen joints, she asks. Numerous leaflets are thrust at me. I am told to ignore the frightening bits in them. These leaflets though are no substitute for the meaningful face to face discussion, the short 40-minute appointment does not allow. I am told to call the hospital rheumatology helpline if I need more information.

I soon discover this helpline is an added source of stress. I call it on an almost daily basis as I prove unable to tolerate any of the drugs initially prescribed. It is open for just one hour a day and is the only way to contact the hospital. It is permanently engaged.

It is decided to offer me injections rather than tablets. The delivery of the pre-filled syringes however has been outsourced by the hospital to a private company. There is a 6-week delay whilst the paperwork is passed back and forth. Without the injections, I am receiving no treatment at all and the disease rages on. Eventually 4 months after being diagnosed and 6 months after first seeing my doctor my treatment is resumed. By this time however it is too late. I am off work, unable to drive or do even the basics.

In the intervening time, I have received appointments with physiotherapists and occupational therapists and have been asked to join a patient education programme called, 'Taking Control of Inflammatory Arthritis'. This programme will teach me how to live with my condition, understand the drugs I am on and manage my pain. It sounds like just what I need. It seems my area has a good, well thought out patient pathway for inflammatory arthritis. Very different from when my grandmother was diagnosed in 1956 and sent away with just a packet of aspirin. It is also painfully obvious, however, that what looks good on paper does not always work well in practice in a health system stretched to breaking point. I must wait months for each appointment. I am offered a place on the programme 7 months after my diagnosis. That is 7 months of trying to cope with the dismissive reactions of friends and family who do not understand the disease. 7 months in which I am free to 'google' my medications and their side effects. I find the internet awash with 'my life of methotrexate hell' horror stories and articles urging me to change my diet and cure my condition by tomorrow. What I desperately need in these first few months is someone to help me separate fact from fiction. I need perspective. My rheumatology nurse recommends I join the National Rheumatoid Arthritis Society. I'm glad I do. They balance those internet stories for me with the real facts. They also offer me booklets to give to my family and my employer so that everyone gets a better understanding of the challenges I might face, especially in this first year.

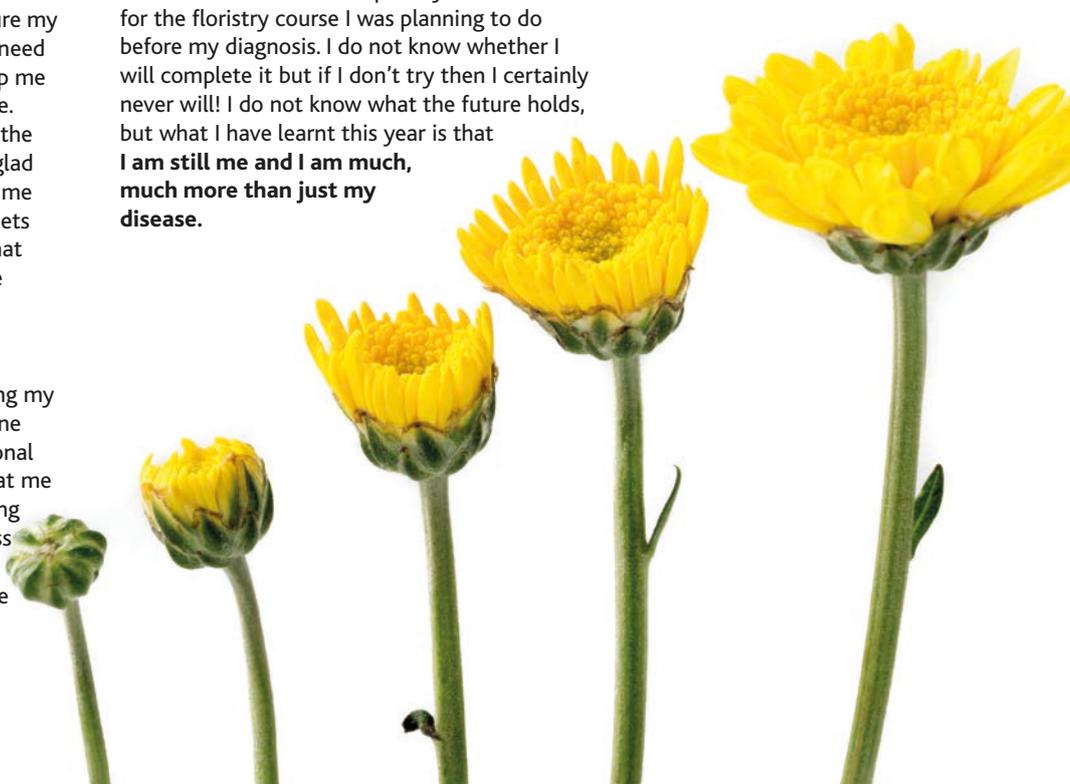
Before my diagnosis, I had planned on leaving my desk job for a more physically demanding one as a florist. I remember asking my occupational therapist about this. She looked doubtfully at me and suggested perhaps I shouldn't be thinking about making any changes...just yet. The loss of hope that I sense in many professionals when they hear my diagnosis is hard to cope

with. It reminds me of the complaint I hear most from the parents of children with disabilities I work with. Why does everyone concentrate on what their child cannot do instead of focusing on what they can. Everything about my treatment seems to revolve around the physical problems my condition might bring. It ignores the emotional issues of having this diagnosis, especially the impression of being written off when you feel you are only half way through your working life.

Over the last year, I have learnt a lot. I have learnt that an early diagnosis in a hard-pressed health system is no guarantee of a better outcome. I have learnt that when commissioners

.....
 "I have learnt I cannot let my condition, or the assumptions of others, dictate what I can achieve."

are designing new care pathways they need to consider all the factors that may affect its success rather than just concentrating on clinical need. Above all I have learnt I cannot let my condition, or the assumptions of others, dictate what I can achieve. I have put my name down for the floristry course I was planning to do before my diagnosis. I do not know whether I will complete it but if I don't try then I certainly never will! I do not know what the future holds, but what I have learnt this year is that **I am still me and I am much, much more than just my disease.**





Love Your Heart

An interactive, on-line education programme



“Before I did this programme I thought that I was doing pretty well in terms of diet and exercise but it showed me that I needed to do more to help myself”



Love Your Heart is a programme which has been developed by the National Rheumatoid Arthritis Society, NRAS, in collaboration with Dr Holly John, a consultant rheumatologist from Dudley NHS Foundation Trust. We have been working on the development of this innovative new resource for over two years, including the year it took us to raise the funds to do it!

Dr John originally developed this programme as a face to face group for people living with rheumatoid arthritis which was excellent, but this limited the number of people who could access the programme and NRAS was so impressed by the potential of the programme, we wanted to make it as widely available as possible.

In partnership with Streaming Well, a video production company, we have created an engaging and interactive online programme to educate people with RA about heart disease and atherosclerosis, explaining in simple terms why they are at increased risk. The programme gives

people the ability to calculate their own personal risk factors for developing heart disease and then provides them with the tools to reduce that risk and adopt a healthier lifestyle, thereby reducing risk of premature death from heart disease.

The programme will help people living with RA to reduce the risk factors which are within *their* control, risk factors that can make people more likely to suffer from heart disease at some time in their life.

Currently, cardiovascular disease accounts for just over a quarter of deaths in Britain and costs the economy billions in healthcare and other costs. Each year, tens of thousands of people die prematurely from cardiovascular disease. We know how to prevent half, and possibly three-quarters, of these deaths, but at the moment we are failing to do so.

People with rheumatoid arthritis are at greater risk of heart disease than the general population, so it's really important for people living with RA to be aware of this programme so they can take action to reduce those risks that they are able to do something about.

“Before I did this programme I thought that I was doing pretty well in terms of diet and exercise but it showed me that there was a lot I wasn't aware of, that my knowledge of lifestyle factors wasn't adequate and I needed to do more to help myself. I found it a valuable and life-changing experience to do this programme.”
– past programme participant.



“I found it a valuable and life-changing experience to do this programme”

The programme encourages participants to go to their GP and ask for a QRISK2 assessment to be done. The QRISK2 questionnaire is a prediction algorithm for cardiovascular disease (CVD) that uses traditional risk factors (age, systolic blood pressure, smoking status and ratio of total serum cholesterol to high-density lipoprotein cholesterol) together with body mass index, ethnicity, measures of deprivation, family history, chronic kidney disease, rheumatoid arthritis, atrial fibrillation, diabetes mellitus, and antihypertensive treatment.

A QRISK2 over 10 (10% risk of CVD event over the next ten years) indicates that primary prevention with lipid lowering therapy (such as statins) should be considered. This may all sound a bit scary but actually flagging up that there may be an issue which can then be addressed and

improved upon is better than ignoring something which could subsequently lead to preventable heart disease.

There is a built-in evaluation form at the end of the programme and at 6 months following completion of the programme, and we would encourage everyone who participates to complete these as they will enable us to measure the impact of the programme and make improvements for future versions.

We are all excited by its potential and piloting will take place in early autumn. For more information, please email Lorrainep@nras.org.uk



Shop with NRAS...

From running vests to wrist bands we are sure to have something that takes your fancy in the NRAS shop

- Apparel
- Car Stickers
- Stress Ball
- Pin Badge
- Water Bottle
- Wrist Bands

www.nras.org.uk/shop

Or call us - 01628 823 524 and ask to speak to a member of our Fundraising Team

Thank you for supporting NRAS!

Charity of the Year

A partnership to raise funds and awareness of rheumatoid arthritis & juvenile idiopathic arthritis



raise awareness of rheumatoid arthritis and juvenile idiopathic arthritis.

They can also help energise staff, rally support for your community group, business social club or sports club and give you and NRAS excellent press coverage. If you are a forthcoming golf club captain, Rotary or Lions president, or staff

Charity of the Year partnerships are a fantastic way to support NRAS, not only do they raise much needed funds for your society, they also help NRAS to reach many more people and

member whose company runs a charity of the year initiative, you can choose to support NRAS.

Whether you have one or one hundred offices, sites, or stores, we can provide a tailor-made package for you:

- Press and PR Support
- A calendar of events
- Volunteering opportunities
- Support resources
- Places for national sporting events, charity treks and other fun activities.

Contact the fundraising team on 01628 823524 or email us at fundraising@nras.org.uk.

Conference Contacts chose NRAS as their charity of the year for 2017 and so far, have raised almost £8000! Conference Contacts Limited is one of the most experienced global event management companies in the UK, delivering creative event solutions for clients all over the world. In May 2017, they celebrated their 30th Anniversary by hosting an event which included a silent raffle and all the funds raised were donated to NRAS!

We could be great together!

A partnership with us is a great way to motivate and unite your employees while helping us raise vital funds and awareness for Rheumatoid Arthritis and Juvenile Idiopathic Arthritis (RA and JIA).

We provide:

- Press and PR support
- A calendar of events
- Support resources
- Places for national sporting events, charity treks and other fun activities
- Volunteering opportunities

www.nras.org.uk/charity-of-the-year



Abseil challenge!

Val takes the plunge for NRAS

Back in March NRAS was given the opportunity to take part in an abseil at the Queen Elizabeth Olympic ArcelorMittal Orbit and in a moment of madness Val, our Events Fundraiser, said she would do it!

Val and Brianna (our Fundraising Coordinator), along with Val's husband, David, set off on a beautiful sunny day and made their way to the park. Finally, the moment arrived for Val to do her abseil, this is the longest freefall abseil in the UK at 262 feet! Val said, *"Taking part in the abseil was the scariest thing I have ever done, stepping off the platform was terrifying, it's not for the faint hearted! I am so proud of myself for doing it, this really was a huge achievement for me."*

Teresa Shakespeare Smith, our NRAS Hertfordshire Group Coordinator, heard about Val's abseil; she got talking to Sharon, a Rheumatology Nurse at the Lister Hospital in Stevenage, and persuaded her to sign up and take part in the very same abseil! Sharon, along with Louise Hawkins, Rheumatology Staff Nurse, Angela Cook, Rheumatology Research Nurse and Spencer Ellis, Consultant Rheumatologist will all be taking the plunge on 16th September, they will pass the baton on to 11 people either walking, running or cycling to symbolise passing on the message of the importance of early diagnosis: they will complete a distance of 10K within the Olympic Park. You're all amazing, thank you!



.....
 "Taking part in the abseil was the scariest thing I have ever done, stepping off the platform was terrifying, it's not for the faint hearted! I am so proud of myself for doing it, this really was a huge achievement for me"

Abseil the ArcelorMittal Orbit for NRAS

A 80 metre freefall drop over the edge of the ArcelorMittal Orbit...the tallest sculpture in the UK.

The ArcelorMittal Orbit, designed by Turner-Prize winning artist Sir Anish Kapoor is a truly spectacular and unique venue set within Queen Elizabeth Olympic Park.

It is 22 metres taller than the Statue of Liberty and almost six times taller than the Angel of the North. From the top you will see the amazing panorama that includes iconic buildings such as The Shard, Big Ben, The Gherkin, St Paul's, Canary Wharf and Wembley Stadium and the world-famous sporting venues of Queen Elizabeth Olympic Park.

Before stepping over the edge professional abseil instructors will provide a comprehensive safety briefing and all the specialist equipment required for your challenge.

To find out more email us at fundraising@nras.org.uk or call us on 0845 458 3969



If you fancy taking part in an abseil for NRAS visit

www.nras.org.uk/adrenaline-rush-2017 for more information





**Wendy
Garwood**

July 1966 - April 2017

A TRIBUTE TO Wendy Garwood

July 1966 - April 2017



Wendy Garwood was a previous NRAS Board Member and passed away earlier this year following a short illness. Naturally all of us at NRAS who worked with Wendy over the years were devastated by the loss and our sympathies and thoughts continue to be with her husband Alan and her family.

I first met Wendy in 2002/3 when I was invited onto the Research Committee of the Early Rheumatoid Arthritis Network, chaired by Dr Patrick Keily and of which Wendy was the Project Manager. ERAN was an inception cohort of people with early RA, all recruited at the time of first physician's diagnosis of RA, with data collection from 2002 until 2014. As a consequence of working with Wendy, she soon became a good friend, not just a work colleague, and when we recruited our first full Board of Trustees, Wendy was one of the first people I approached. Wendy joined the Board at NRAS in May 2004 and was a wonderful supporter of the work of the Society. Originally a Registered General Nurse, Wendy worked in the pharmaceutical industry within clinical research since the early nineties.

Wendy was an amazing, caring and gentle person who showed great compassion and genuine interest in the lives of people with RA. I quote from an article she wrote for the magazine back in 2004 when she said, "On a personal note, I feel greatly honoured to be invited to become a Trustee of such a pro-active charity. NRAS is run by such dedicated people." But honestly it is we who were honoured to have her representing NRAS as a Trustee.

Not satisfied with supporting people with RA by being on the Board though, Wendy went above and beyond – she ran, sang and even danced for NRAS!

Wendy is one of those people who, the minute you met her, made you feel special. Her smile was always warm, her words gentle but most of all her friendship treasured. All those who knew her have had their lives enriched by knowing her and she has left this world a better place by her dedication to serving others.

"Wendy, it was truly an honour to know you and I thank you for touching our lives and helping hundreds of people throughout your, all but far too short, life. Rest in peace."

Ailsa Bosworth MBE
Founder & Chief Executive
National Rheumatoid Arthritis Society



Living with RA

Alan was diagnosed with RA 10 years ago, this is his story

I was a typical child, I came from a military family and grew up in the 70s; what could be better; parties, discos, girls and lots of beer of course.

Within 2 weeks of passing my driving test, I was working as a driver at Heathrow for Hertz rent-a-car. I got the bug and went on to get my (Public Service Vehicle) licence and moved on to driving coaches for a Weymouth based company all over Europe. I loved every minute of it. There I was, doing what I wanted to do, feeling like I was on a continual holiday and getting paid for it to boot. Little did I know what was ahead of me.

I started to feel tired a lot and I was in pain most of the time. I'd also fallen over a few times so I was referred to a doctor in Southport. After a series of tests, I was diagnosed with rheumatoid arthritis. Because of the nature of my work, I had to give up the job I loved. It felt like the bottom of my world had fallen out. What followed were treatments and procedures but nothing seemed to work.

You know, living with pain 24/7 is not easy – doing simple things I enjoy like taking my step

daughter to school is difficult because of the pain and fatigue. People who do not have RA do not understand what life is like, the pain just keeps coming, it never stops. But what do we do when someone asks, "How are you?", we simply say, 'I'm fine', when really, we're not.

I also suffer with depression and probably drink more than I should. I have not worked for some 10 years now and I am on crutches: it's getting harder and harder to find something to do each day.

I used to walk about 5 miles every day because I liked to get out. I can't do that now. Winter is the worst time, I just sit indoors. I love living by the sea but it's cold in the winter, but, summer's around the corner; time to dust myself off, charge the batteries on the OLD 6IT scooter and get out and about.

Well that's my story, but despite my rheumatoid arthritis and everything that comes with it, the one thing that no one can take from me, you, or us, is our smile and most of all our family.



Alan Wiles



Help us make Christmas shine...

Sign up to receive our free fundraising pack

- Christmas Carol Sheet
- Christmas Quiz
- Christmas Bunting
- Christmas Recipes
- Fundraising Stickers
- Appeal flyers

And much more....

Contact the Fundraising Team to book a pack

Email – Fundraising@nras.org.uk

Telephone - 01628 823 524 and ask to speak to a member of our Fundraising Team.





Using a computer

I need to use the computer a lot at work and am finding it difficult using the mouse and keyboard. My hands are really swollen and stiff at the end of the day. Is there anything that I can do to help with this?

These days many of us must use a computer at work and it can be a struggle for people who have long term conditions that affect their joints. Long periods of keyboard/mouse use can cause swelling and pain in the fingers, and wrists.

Thankfully, there are many things that can now be done to help alleviate the problems associated with long term computer use. Here are some examples of the things that you can do to help.

If you find that your wrists swell and get painful when using a keyboard and mouse try using a wrist support/rest. Keyboard gel pads can also help. A smaller, laptop wireless mouse is often useful as the smaller size allows the base of the hand to rest on the mouse mat.

If using the mouse is a problem, try using keyboard shortcuts. It may be slower at first but for many people it is much easier than using the mouse constantly.

If typing is a real problem then there is voice recognition software available. One commonly available is called Dragon. Using a "keyguard" can also help. Keyguards have two main functions: they provide a platform which the user can rest their hands on without pressing down on the keys and they make it difficult to hit more than one key accidentally.



When considering solutions to help with computing remember that one size does not fit all. You can read more on our website on the following link:

www.nras.org.uk/rheumatoid-arthritis-computing

AbilityNet is an organisation that provides advice and information for individuals, charities and employers on assistive technology and accessibility. They have an extensive range of factsheets giving practical advice about specific conditions and the hardware and software adaptations that can help people of any age use computers to the full.

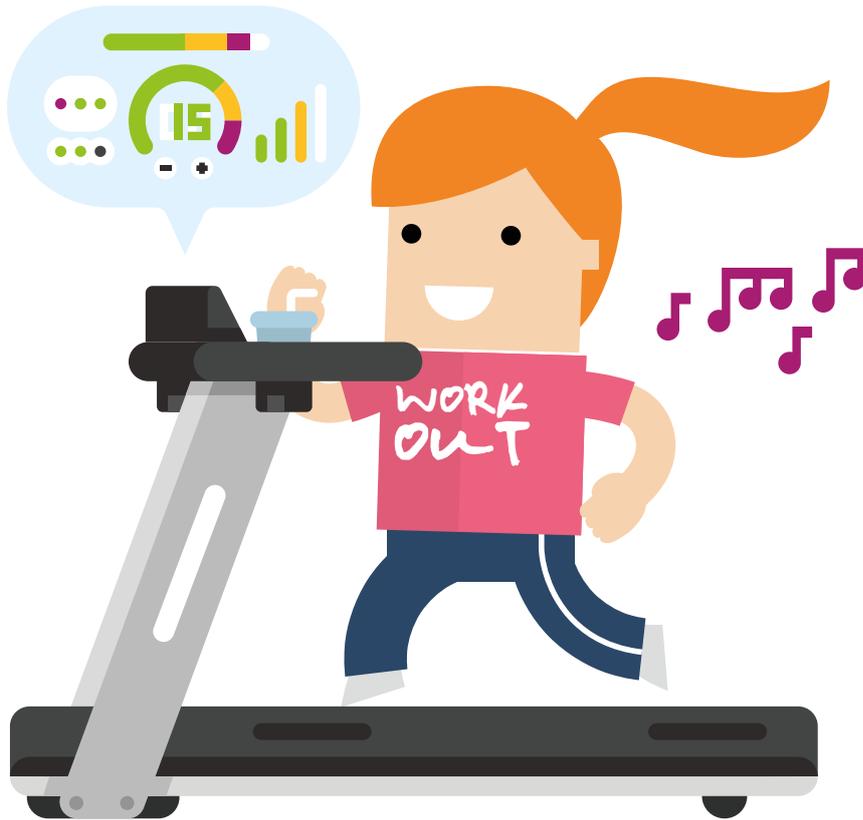
You can find out more about AbilityNet, the services that they offer and download their resources from the following link:

www.abilitynet.org.uk



Which exercises should I do?

I have recently been diagnosed with rheumatoid arthritis and I was wondering if I should be doing any exercise? If so, what sort of exercise should I be doing?



Find something that suits you and something that you enjoy

This is a question that we frequently get asked on the helpline. There is evidence now to suggest that exercise is beneficial for people with RA and can improve their symptoms.

The first thing to remember when choosing an activity is to find something that suits you and something that you enjoy. What is suitable for one person may not be right for another. If you haven't been used to exercising and are not sure about your level of fitness then seek the advice of your GP before engaging on an exercise programme. Many leisure centres have fitness instructors who are trained to help people with long term conditions such as RA and they can devise a workout routine that is suitable for your needs.

When starting exercise, the important thing is to warm up suitably first. Gentle jogging on the spot or walking if you are outside or if you are in the gym then you can use cardiovascular equipment such as the bike, treadmill or cross trainer but start gently and increase your effort gradually.

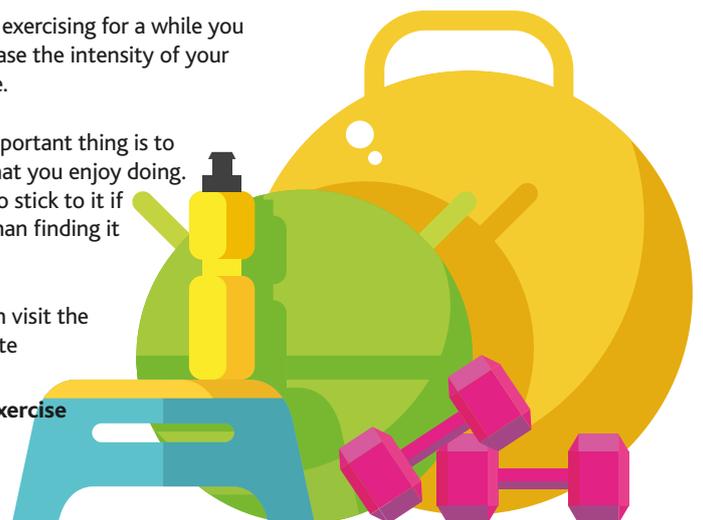
If you are not used to exercise then don't push yourself too hard to begin with. Choose low impact exercises. Swimming, cycling and Tai Chi are good examples of this. Check with the trainers in the gym as to the best machines to use for low impact there.

Once you have been exercising for a while you may be able to increase the intensity of your workout if you desire.

Possibly the most important thing is to choose something that you enjoy doing. You are more likely to stick to it if you enjoy it rather than finding it a chore.

For more information visit the section on our website about exercise:

www.nras.org.uk/exercise





Hope offered by stem cell treatment

for people with rheumatoid arthritis

The possibility of a stem cell based drug to treat rheumatoid arthritis (RA) has moved closer after a new medication has done well in a phase II trial.

Stem cell treatment has been talked about for a long time and now an Australian company, Mesoblast, has developed a potential treatment involving stem cells to give to people with RA. Patients who have not responded well to anti-TNF treatment would be given the stem cell therapy intravenously.

Therapeutic benefits of up to 9 months were felt by the people on the trial carried out on 48 patients. Further studies will need to be carried out in a phase III trial but this type of treatment, if successful, will be beneficial for many people, for example those who do not respond well on anti-TNFs. Initial results suggest that unlike other drugs used to treat RA, these have little toxicity or side effects.

The treatment uses cells derived from adult stem cells, known as mesenchymal precursor cells

(MCPs). They do not provoke a negative reaction in the body's immune system when introduced to the body. They change the way in which the immune system works in a person with RA.

A statement from Mesoblast said that:

"The way the cells work is, they have receptors on their surface that are activated by every major cytokine (substances secreted by certain cells of the immune system) that is important in progressive RA. Those cytokines drive the disease and also bind to receptors on our cells. When they bind to our cells they activate the cells to release other factors that switch off the very cells that made those cytokines."

Major research is being carried out in the area of stem cell therapy to treat immune, autoimmune and inflammatory diseases and hopefully new treatments based on this type of research will prove fruitful. However, stem cell therapy is still in its early days and its potential as a treatment for RA is a long way off.



Using a pedometer

increases activity levels whilst also decreasing fatigue in rheumatoid arthritis patients

A new Arthritis Care & Research study carried out has shown that providing patients with pedometers not only increased activity but also reduced fatigue in rheumatoid arthritis patients. These improvements were noticeable with or without step targets being set.

Average daily steps declined in control patients who were not supplied with pedometers, and fatigue levels did not change.

These results are important as fatigue seriously impacts quality of life for rheumatoid arthritis patients and effective treatments are limited.

"Because rheumatoid arthritis medications have only small effects on fatigue, it's important for patients to have other ways to manage their fatigue," said Dr Patricia Katz of the University of California, San Francisco, lead author of the study. "These results suggest that something as simple as increasing physical activity by walking can help."



Predicting disease course

New tool for predicting disease course and aiding choice of appropriate therapy in RA patients

In rheumatoid arthritis (RA) inflammation in the joints is affected by the forming of various antibodies. In a recent article, researchers at Uppsala University show that certain antibodies could result in a good prognosis.

"Analysing these antibodies, in combination with other relevant antibodies, could be used for predicting prognosis and choosing therapy for rheumatoid arthritis patients," says Professor Johann Rönnelid who has led the study.

An important protein in joint cartilage is targeted by anti-bodies present in some people with RA. Early in the disease and at time of diagnosis the highest levels of collagen antibodies have been detected, and drive inflammation, but the levels then reduce during the first year.

Over a period of five years, researchers at Uppsala University, in collaboration with colleagues at Karolinska Institutet, have followed a large group of RA patients to see if there is a connection between the development of the disease and collagen antibodies.

"We found that patients with collagen antibodies showed increased signs of inflammation during the first six months after diagnosis, after this there was no difference compared to patients without

any collagen antibodies. We also discovered that the presence of collagen antibodies at the time of diagnosis was associated with a better prognosis," says Vivek Anand Manivel, PhD student at the Department of Immunology, Genetics and Pathology and first author of this article.

It is usual to test for the presence of antibodies against proteins called citrullinated peptides in RA patients. The presence of such antibodies, in the studied patient group, showed an opposite link to inflammation in comparison to the collagen antibodies. Patients with antibodies against citrullinated peptides had increased inflammation at a later stage and therefore a more severe disease course.

"In all, our findings suggest that a combined analysis of antibodies against collagen and antibodies against citrullinated peptides could be a new tool for predicting the disease course and perhaps also for choosing therapy in newly diagnosed RA patients," says professor Johan Rönnelid.

Potential prognostic biomarkers could be useful in the future to predict patients who will go on to develop aggressive disease and perhaps allow doctors to target these patients with second line therapies earlier on.



New video resources

on the NRAS Website

Short informative videos on a variety of topics are now available on the NRAS website including:

- Important things to know about methotrexate, leflunomide, sulfasalazine, biologics
- Having a DXA scan
- The treatment for osteoporosis and osteopenia
- Why you need to have blood tests when taking RA medications

The 16 Health and Care Videos were produced by the Horizon Centre at Torbay & South Devon NHS Foundation Trust in Torquay. Each video lasts under 2 minutes and is delivered in a friendly informative way. Take a look around the NRAS website in the relevant areas to view them.

www.nras.org.uk/dmards

www.nras.org.uk/ra-medication





The link between RA and obesity

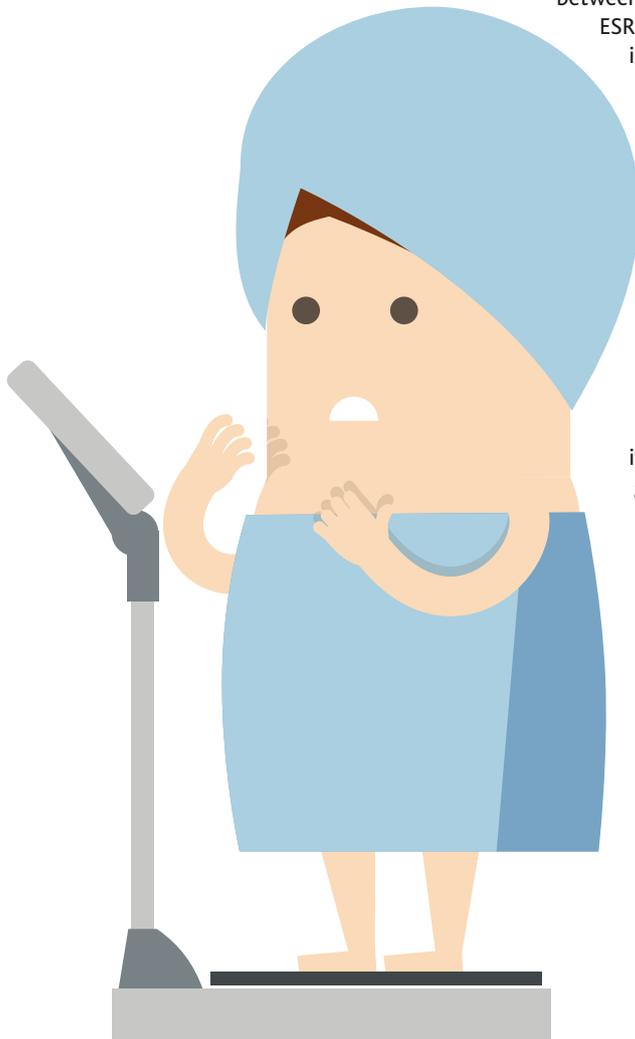
Obesity may have an impact on rheumatoid arthritis blood test results

Researchers have discovered that obesity in women may have an impact on blood test results used to detect rheumatoid arthritis. The results shown in Arthritis Care & Research, indicate that doctors may need to consider obesity as a factor when taking the tests.

The two blood tests: C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR) are both used by doctors to assess levels of inflammation in the body.



There has been some evidence of links between higher levels of CRP and ESR with a higher body mass index. Michael George MD MSCE, based at the University of Pennsylvania Health System, and his colleagues worked to determine the extent obesity has on these markers. The team studied the information on over 2000 people with rheumatoid arthritis and compared it with statistics from the general population.



Evidence has shown that in women with rheumatoid arthritis and in the general population, a higher BMI was associated with a higher CRP. This was especially the case among women with severe obesity.

There was also a connection between obesity and ESR in women. The connection between the two was also seen in men in the general population, but the connection between obesity and inflammation did differ in men with rheumatoid arthritis. In said individuals, lower BMI was linked with higher CRP and ESR. This result may be significant for understanding the connection between weight and inflammation, and how it may be different between male and female.

"Our results suggest that obesity may lead to increased levels of CRP and ESR in women with rheumatoid arthritis," said Dr George. "The increase in these levels of inflammation was not because rheumatoid arthritis was worse in these women. In fact, we found that obesity leads to very similar increases in these lab tests even in women without rheumatoid arthritis."

Dr George did state that doctors need to be cautious when understanding the tests as both rheumatoid arthritis and obesity can contribute to levels of inflammation. "Doctors may assume that high levels of inflammation mean that a patient has rheumatoid arthritis or that their rheumatoid arthritis requires more treatment when in fact a mild increase in levels of inflammation could be due to obesity," he explained.

Moderate alcohol intake

OK for RA patients on methotrexate



Risk of liver damage for people who are on methotrexate is a concern that may increase when the decision about whether alcohol can be consumed is discussed.

The American College of Rheumatology 1994 treatment guidelines stated that patients on methotrexate should not drink any alcohol. Then in 2008, the British Society for Rheumatology recommended limiting the amount of alcohol drunk by patients on methotrexate. However, there is still some confusion about the amount of alcohol that can safely be drunk and some people feel nervous about drinking at all. But for some, it can be hard to abstain from drinking completely.

Researchers at the University of Manchester undertook a study to see if there is a safe amount of alcohol to consume whilst on methotrexate and if there is, how much is safe?

"In this study, we have demonstrated that the risk of transaminitis (liver damage) in patients with RA taking methotrexate does increase with increasing levels of alcohol consumption. However, the risk in those patients who consume 14 units or less of alcohol per week is no greater than those who do

not drink alcohol", wrote William G Dixon, PhD and colleagues.

This study, the first large scale one looking at the risks associated with different levels of alcohol, was a retrospective one based on data collected in the UK.

The authors of the report suggest then that patients on methotrexate may be able to drink up to 14 units of alcohol a week but over this limit there is a higher risk of liver damage in a dose dependent fashion. However, caution must be used by doctors in talking to patients about alcohol on high doses of methotrexate as the size of dose of methotrexate was not included in this study.

"Inclusion of acceptable alcohol levels into clinical guidelines and patient information may well improve informed decision making, clinical outcomes, reduce conflict and improve overall quality of life," conclude the authors.

It is always best to discuss alcohol intake with your rheumatology consultant on an individual basis.

Researchers at the University of Manchester undertook a study to see if there is a safe amount of alcohol to consume whilst on methotrexate and if there is, how much is safe?

What does 1 unit of alcohol look like?

Standard 4.5% cider	Standard 13% wine	Standard 40% whiskey	Standard 4% beer	Standard 4% alcopop (275ml)

You shouldn't regularly exceed 14 UNITS per week

drinkaware



Success in the 3D-Bioprinting of Cartilage Cells



.....
 “Research has taken a step forward towards someday being able to bio-print cells that become body parts for patients”

A team of researchers has looked at the potential of growing new cartilage by studying 3D-bioprinted human cartilage cells in an animal model.

To achieve this breakthrough, a team of researchers from Chalmers University of Technology in Sweden used biomaterial based on nanocellulose. This discovery is a stage closer to making it possible to repair damage to cartilage seen in osteoarthritis.

The study, published in the journal 'Plastic and Reconstructive Surgery Global Open' consisted of a hydrogel construct of nanocellulose and alginate mixed with human-derived cells and stem cells. This was printed using a 3D bioprinter and implanted into test mice.

The outcome was that the cartilage tissue was able to carry on growing, not only that, the implants grew more cartilage in the presence of stem cells than when the cartilage cells were grown alone. The reason for this may be because the cartilage cells grow more efficiently due to the special chemicals that the stem cells produce. They also noted the formation of new blood vessels.

60 days later and white tissue resembling normal human cartilage was formed and worked the way it was anticipated to work. This is the first time human-derived cartilage cells have been printed, implanted in an animal model and grown.

Research liaison manager at Arthritis Research UK, Dr Devi Rani Sagar said, *“This study expands our understanding in using stem cells for the treatment of osteoarthritis. We welcome any research that brings us closer to finding a treatment for osteoarthritis, and that will help people to break free from the limits of their condition.”*

This process could lead to the creation of cartilage implants for the treatment such as arthritis as well as a wide variety of replacement body parts and organs.

Professor of biopolymer technology at Chalmers University of Technology, Paul Gatenholm, said *“With what we have done, the research has taken a step forward towards someday, we hope, being able to bio-print cells that become body parts for patients.”*

This could be useful for people with RA where joint damage has occurred.

The introduction to the UK market of The first JAK inhibitors

We have been waiting for the arrival of a new class of drug which has been in development for a number of years, called JAK inhibitors.

Advances in chemical engineering have allowed the production of so called 'small molecule' drugs, chemicals which are highly specific for blocking molecules that have been identified within cells that cause chronic inflammation. The advantage of these 'small-molecular targeted synthetic disease modifying drugs' is that they can be taken by mouth as tablets, unlike biologic disease modifying drugs. NICE have passed the first of the JAK inhibitors 'baricitinib' for use in the NHS with the following stipulations:

Baricitinib, with methotrexate, is recommended as an option for treating active rheumatoid arthritis in adults whose disease has responded inadequately to or who cannot have other DMARDs, including at least 1 biological DMARD, only if:

- disease is severe (a DAS28 of more than 5.1) and
- they cannot have rituximab and
- the company provides baricitinib with the discount agreed in the patient access scheme

Baricitinib can be used as monotherapy for people who cannot take methotrexate because it is contraindicated or because of intolerance, when the above criteria are met.

Here NRAS Chief Medical Advisor, Professor Peter Taylor explains about this new class of drug:

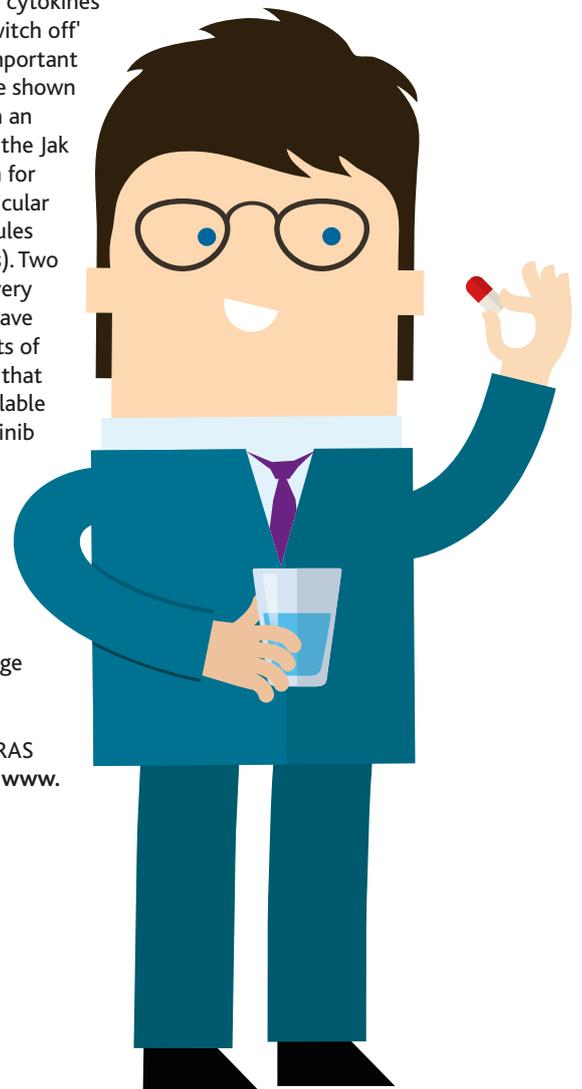
The biological (anti-TNF) therapies that came to market at the end of the nineties and those targeting other parts of the immune system, such as IL6, B Cell and T Cell blockers, introduced in the early 2000s, are all 'large-molecule' biologic therapies which work by blocking action on the outside of cells. Because they are very large molecules they cannot be taken orally and are injected subcutaneously (under the skin) or given by intravenous infusion (or 'drip'). The JAK inhibitors are new small-molecule therapies that work on the inside of cells to affect cell signalling. Two of these new drugs are coming to the UK market in 2017. Because they are small molecules, they can be taken by mouth and herald a new class of so-called 'targeted synthetic' disease modifying drugs or 'small

molecules' because unlike biologic drugs that are made in living cells and comprise large numbers of atoms, the 'small molecules' are chemicals comprising just a relatively few atoms.

What does cell signalling mean? Cell signalling has to do with the way that cells communicate with one another. The tissues and organs of our bodies are comprised of different sorts of cells and the material they secrete around themselves. In order for the organs and the whole body to function as a coordinated and integrated whole, the cells need to communicate with each other. One family of molecules that communicate between cells in this way are known as 'cytokines'. Cytokines are small proteins that take part in all biological processes involved in health such as growth and repair, movement of cells, manufacture of blood and the regulation of immune function that in health protects us. But cytokines are also involved in the regulation of inflammation. In diseases, such as rheumatoid arthritis, these inflammatory cytokines are over active and fail to 'switch off' immune responses. A very important group of new drugs that have shown very impressive efficacy with an acceptable safety profile are the Jak inhibitors. 'Jak' is an acronym for the scientific term for a particular category of signalling molecules within the cell (Janus kinases). Two such drugs have undergone very extensive clinical trials and have approval for use in some parts of the world. Two Jak inhibitors that are expected to become available in the UK in 2017 are tofacitinib (trade name Xeljanz) and baricitinib (trade name Olumiant). These are oral drugs. They have a similar magnitude of benefit to biologic anti-TNFs. There are other Jak inhibitors in clinical trials at an earlier stage of development.

For more information, see NRAS publication: 'Medicines in RA' www.nras.org.uk/publications

“A very important group of new drugs that have shown very impressive efficacy with an acceptable safety profile”

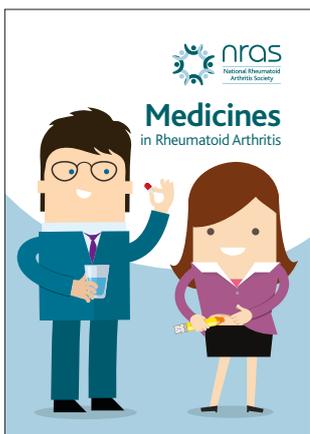




By Clare Jacklin
Director of External Affairs

Spring Conference Season – a busy time for NRAS

As Ailsa alluded to in her 'Dear Members' section, the NRAS presence at both the British Society of Rheumatology (BSR) conference in Birmingham in April and the European League Against Rheumatism (EULAR) congress in Madrid in June was very evident.



Medicines in RA booklet

The BSR conference brings together clinicians, health professionals, patient organisations and industry from across the UK to share best practice, latest research, launching of new products as well as the all-important networking which leads to so many great opportunities.

The big draw to the NRAS stand at the BSR conference was the launch of the brand new hot-off-the-shelves, *Medicines in RA* booklet.

This unique booklet covers all medications used in the treatment of RA and symptom management ie pain relief, NSAIDs, steroids, DMARDs, biologics, biosimilars and what's coming in the future, like JAK inhibitors. All sounds like medical jargon, well, that's exactly what we hope the booklet will decipher and demystify for those living with RA. Also in the booklet are sections covering adherence, how to report side effects and the role the Disease Activity Score plays in decisions about the medicine pathway. All that in one A5, user friendly booklet. I'd like to say a huge thank-you to all our contributors to the booklet: Professor Peter Taylor, Professor John Isaacs; the author of the booklet, Nicky Kennedy, as well as our editor, Colin Richardson,

not forgetting sub editors, Victoria and Ailsa. Like all our booklets they are first brought into embryonic stage at a focus group of our Members and then nurtured and developed over many months before being released into the wild having been proof read, peer reviewed and reader reviewed. It really is a massive team effort and NRAS can't do it without your input so thank you to all those who helped from idea conception to the launch date.

Every rheumatology department in the UK has been sent a minimum of 12 copies FREE of charge already, however if you are a rheumatology health professional and you haven't seen them in use, then call today to order a supply for you and your colleagues. If you are someone living with RA and would like a copy, call today or order online, also, take it with you at your next visit and show it to your consultant, nurse, physio etc to ensure they know about them. Help NRAS spread the good news; no more flimsy leaflets for each medicine that get lost down the back of the medicine cabinet! We hope this booklet will reduce anxiety for patients who may worry about being on a treatment that doesn't seem to be making a difference. In this

resource booklet it is easy to see what may be next to try and that there is even more being developed for the future.

Get your copy today at www.nras.org.uk/publications or call 0845 458 3969

Also at the BSR we launched version 2 of the DAS app.



This version has had medicine reminders and usage sections added as well as improved functionality. Download the Know Your DAS app at www.nras.org.uk/know-your-das-mobile-app

The joint project that NRAS has carried out with the University of Chester was also shared at the conference via a poster presentation as well as an oral presentation on the project by Ailsa at the EULAR congress.

The 'BRASS' project – Burden of Rheumatoid Arthritis across Europe – A Socio-economic Survey of 476 consultants across 10 countries with information on 4,200 patients. This data will be incredibly valuable to many stakeholders and it has been a real pleasure to work with the team from the University – Jamie O'Hara, Tom Burke and Alison Rose.

An Introduction to "The Burden of Rheumatoid Arthritis across Europe: a Socioeconomic Survey" (BRASS)

INTRODUCTION

- Rheumatoid arthritis (RA) is a progressive autoimmune disease that often starts at a young age, causes increasing levels of disability and pain to patients [1].
- The annual incidence of RA is estimated to be anywhere between 20 and 50 cases per 100,000 population in European countries [2].
- Recent data on the impact, burden and true costs of rheumatoid arthritis is needed to quantify the wider impact of the condition and enable a full understanding of the potential impact of both treatment and best target strategies.

OBJECTIVES

- To quantify annual direct and indirect costs of three treatment groups, biologic therapy, conventional synthetic (csDMARDs) and biologic, biologic or targeted synthetic drug, referred to as csDMARDs, biologics, biologic or targeted synthetic drug, referred to as csDMARDs/biologics, biologics or targeted synthetic drug, referred to as csDMARDs/biologics/biologics.
- To capture a broad spectrum of information on the clinical, economic and humanistic burden of rheumatoid arthritis.
- To present a bottom-up comparative approach to quantify the burden of disease for persons living with rheumatoid arthritis (RA) across the following European countries: Denmark, France, Germany, Hungary, Italy, Poland, Romania, Spain, Sweden and UK.

METHODS

- Our retrospective survey captured resource use for a 12 month period including patient-reported information and measures such as work loss and health-related quality of life.
- Rheumatologists, RA specialising interests and general practitioners were recruited and surveyed during the period April/June 2016. French data was collected in March 2017.
- These practitioners were then tasked with providing a non-random cohort of RA patients meeting the study inclusion/exclusion criteria. Our total target sample size was 4,000 patients.
- Physicians completed a patient record form (PRF) for the next 4-10 eligible patients and mailed each patient to complete a corresponding patient self-completion (PSC) questionnaire.
- Patients provided direct and indirect non-medical cost information, including work loss and non-work-related expenses, as well as information on quality of life and adherence.
- A corresponding cost database was developed for each participating country, with a comprehensive cost profile for each patient.

RESULTS

- A total of 476 physicians participated in the study from across 10 countries, capturing information on 4,200 patients.
- Within the sample the defined treatment groups comprised 502 csDMARDs therapy, 1,286 csDMARDs/biologics and 1,402 biologics/biologics.
- A total of 2,087 patients completed corresponding PSC questionnaires, with over 70 variables captured on each patient. Study demographics were largely balanced across the sample and verified by the EULAR.
- The mean age and standard deviation for each treatment group was estimated at 54 (15.4), 55.9 (13.4) and 54.4 (14) years respectively.
- Patients completed the PSC with each group ranging from 88-176%.
- Overall mean disease duration ranged between 10.7 (2.2) - 12.3 (2.3) years.
- Mean annual total indirect cost for the csDMARDs therapy group was €2,142, for the csDMARDs group €1,111, and the biologics/biologics group €1,842.

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ACKNOWLEDGMENTS

This work was supported by the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant number 101019188). The work was also supported by the University of Chester. The survey was conducted in collaboration with the National Rheumatoid Arthritis Society (NRAS) and the National Rheumatoid Arthritis Society (NRAS) in the UK. The work was also supported by the University of Chester. The survey was conducted in collaboration with the National Rheumatoid Arthritis Society (NRAS) and the National Rheumatoid Arthritis Society (NRAS) in the UK.

The BRASS project

Another abstract poster accepted for BSR conference was on the work NRAS has done with the University of Aberdeen and Dr Kathryn Martyn was asked to present on the topic at the Sanofi-Genzyme symposium.

Who Cares? An investigation of the health and perceived social care needs of people with Rheumatoid Arthritis living in Scotland.

Kathryn R Martyn, Conon O'Neill and Ailsa Bosworth MBSP
 Epidemiology Group, University of Aberdeen, Aberdeen, UNITED KINGDOM, National Rheumatoid Arthritis Society, Manchester, UNITED KINGDOM

BACKGROUND

- Effective and sufficient levels of care and support for individuals newly diagnosed and those with established Rheumatoid Arthritis (RA) are needed to ensure optimal physical and mental health, as well as health-related quality of life.

AIM

- To explore the extent of care needs among individuals with RA living in Scotland and the factors that contribute to these, such as socio-economic, personal caregiver burden and complex care needs.

METHODS

- A cross-sectional study of individuals with RA who responded to an online survey (available 15 Nov 2015 to 22 Feb 2016) who were aged 18 years, lived in Scotland and reported they had received a clinical diagnosis of RA.
- Respondents were allowed to skip questions they wished not to answer. Identifiable comments were used (e.g. the Self-Perceived Burden Scale, Descriptive analysis of quantitative data and thematic analysis of free text responses were conducted.

RESULTS

- 187 self-reported participants; the majority were female, of White Scottish or White British background, 45-64 years, and lived in a household with 2 people.
- The majority (83%) reported well established RA (diagnosis >2 years ago) and at least one other comorbidity (78% - most commonly depression (35%).
- The average number of medications taken for RA was 3.2 (range 0-7) and 59% reported taking 1 medication in total.

CONCLUSIONS

- Survey responses suggest individuals with RA lack fundamental information about qualifying for and accessing formal resources and services provided by their local council.
- Only 10% reported receiving information about care and support from their local council. Of those, information about disability living allowance, assessment for help from the local authority with care and support, types of available care and support services, and eligibility criteria for local authority help were most commonly reported.
- Very few (3%) had an assessment which had been deemed eligible for support from their local council.
- 83% reported that they did not know what types of circumstances might make them eligible for care and support from their local council.
- Only 10% reported receiving information about care and support from their local council. Of those, information about disability living allowance, assessment for help from the local authority with care and support, types of available care and support services, and eligibility criteria for local authority help were most commonly reported.
- Very few (3%) had an assessment which had been deemed eligible for support from their local council.

ACKNOWLEDGMENTS

- Many thanks to the individuals who participated in the online survey. A copy of the report can be found at: www.nras.org.uk/publications/who-cares
- The National Rheumatoid Arthritis Society received an educational grant from Abbvie to fund this project. NRAS made a donation to the University of Aberdeen to thank Dr Martyn for her time and effort.

FIGURE 1 - What does social care mean to you?

Of those receiving care, the majority (97/202) named family or carers/family/friends as caregivers and 70% (80/207) had an elevated level of self-perceived burden on their caregiver.

FIGURE 2 - Barriers to asking for care and support

63% of respondents reported anxiety or depression had significantly hindered their ability to ask for care and support compared to those without, 31.6 versus 27.3.

University of Aberdeen 'Who Cares' poster

If we thought we were kept busy in Birmingham the trip to Madrid to EULAR congress was really going to test our staying power! Ailsa and I would pass each other among the 14,000 other delegates as we zipped from one presentation or meeting to another. The scale of the EULAR congress never ceases to amaze me, it really could be called GloLAR (global league against rheumatism) but that doesn't sound quite right! Scientists, physicians, patient groups from all corners of the world are there. Meeting representatives from other patient organisations helps to develop a much stronger global patient

voice and you won't be surprised to learn that someone living with RA in Canada or Romania or Holland face many of the same struggles and issues that we do here in the UK. Working together we can only get stronger and build more momentum to get rheumatic conditions pushed further up the agenda as well as recognised and understood better by the public, politicians, and decision makers the world over. The EULAR campaign of 'Don't delay connect today' is just one great initiative to come out of this year's congress and I urge you to get involved when the call comes later this year to get connected!



Presenting on the Behind the Smile campaign, the DAS app, our work on helping people understand their cardiovascular disease, volunteer engagement, as well as meetings with various partners on other global projects were just some of the other activities we were involved with in hot and humid Madrid.

As we always do after EULAR, we returned home exhausted but exhilarated; with sore feet but big smiles and lots of really challenging ideas to take forward, helping NRAS in our mission of Changing Minds, Changing Services, and Changing Lives.



Clare Jacklin, Ailsa Bosworth and Matt Bezzant at EULAR

NRAS Groups' update



The team at NHS Tayside

As promised in the spring magazine we bring you more details of the Tayside Group launch at Ninewells Hospital in Dundee, which took place in March.

Gill and Kim flew to Scotland to host the evening with full support of the rheumatology team – special thanks to Diane Crake, Lead Rheumatology Specialist Nurse, for all her organisation leading up to, and including,

meetings. More details can be found here: www.nras.org.uk/groups/tayside-nras-group

In May, Gill and Kim travelled to Kent to host an information evening in Ramsgate. The Thanet Group has been meeting since 2013 and has now decided to change their venue and meet four times a year, so they decided to relaunch the Group. Despite a really hot evening there was an excellent turn out for this event. Leanne Hawker, Group Coordinator, spoke about the group and what she is planning for future meetings. There were many people in the room who were not aware that there was a local group and all seemed keen to attend in the future. Dr DeLord, Lead Consultant, and Kathryn Walton, Specialist Nurse, both gave excellent presentations giving an overview about RA treatments and day-to-day management. Leanne and the coordinating team are busy planning future group meetings and more details can be found here: www.nras.org.uk/groups/thanet-nras-group

Groups launched last autumn, **Stoke-on-Trent, North Lincolnshire, Torbay** and **West Wales** are all now holding regular meetings: www.nras.org.uk/groups. Well done to all these Groups and we wish them continued success.



Large crowd at Thanet relaunch

the evening itself. Dr Tan, Consultant Rheumatologist, did a fantastic keynote speech - 'Rheumatoid, psoriatic and osteoarthritis – what's the difference?'. This was followed by a Q&A with a cross section of the team – Dr Tan, Dr Vinod (Clinical Lead for Rheumatology), Diane Crake, John Ellis (Rheumatology OT), Alison Knight (Specialist Rheumatology Physio) and Nicola Bywater (Specialist Rheumatology Podiatrist).

The appeal for volunteers brought forward six people who are currently planning future

Coming up in your next NRAS Magazine...

Kim & Gill will be in Dumfries & Galloway on Thursday 24th August 2017 to host the launch of a new Scottish Group for full details and to register to attend email groups@nras.org.uk or visit www.nras.org.uk/groups/nras-nhs-dumfries-galloway

 New NRAS group

 New NRAS group coming soon

Wedding Favours

By the new
Mrs Jo Marriott
in County Durham

We had decided that we wanted to keep our wedding relaxed and low key, with no official photographer, no bridesmaids, just our close family and friends.

However, one of the traditional things that we really wanted to keep as part of the day was the idea of wedding favours for all of our guests. My husband Lee's Mam was diagnosed with rheumatoid arthritis over 20 years ago and although she is a feisty fighter, we know she has struggled with it, to the point where she eventually had to give up work which obviously had an impact on the family.

We had been to other weddings where charity pins were given away often for more mainstream charities, but we wanted to choose a charity that was close to our hearts and that we know provides support for people living with the impact of RA. We asked our guests to help

themselves to the pins as they entered, as we wanted to ensure that all our guests, both daytime and evening, received a pin. Everyone thought it was a brilliant idea, we had kept it as a surprise so Lee's family were really touched by the gesture.

Traditionally a wedding favour (usually sugared almonds) is a way of saying thank you to your guests; a small token of your appreciation for their sharing in your special day. For Lee and me giving an NRAS pin, did that and so much more, it honoured Lee's Mam and is something all our guests will never forget.



We Did It!

Brother and sister team up to run the London Marathon to fundraise for NRAS

Back in 2015 Mark Rind and his sister Rachel were watching the London Marathon on TV; Mark had always admired people who took part and it was on his list of things to do one day, although he wasn't a runner, in fact he wasn't sporty at all!

That same year Rachel (then 32) was diagnosed with RA. She was very sporty, always active and thrived on adrenaline, however her RA now determines how she can exercise; if she does too much her joints can cause her horrendous pain. Rachel is now managing her disease with a cocktail of drugs, regular check-ups and eating an incredibly healthy diet. Out of the blue Rachel found NRAS and discovered how widespread the disease is, particularly in younger people.

Fast forward to 2016, a conversation was had with Val, our Events Fundraiser, and 2 London Marathon places were secured for Mark and

Rachel! Months of training and fundraising followed with them both struggling to find the time to train, added to this was Rachel's RA and when it would allow her to train.

We are delighted to say they completed the marathon, it was a massive challenge for them both, they ran to the half way point, achieving a mini goal of running over Tower Bridge, a very emotional moment for them.

They raised an amazing **£5,503** for NRAS! Thank you both so much for all your hard work beforehand and on the day. To read their full story visit our website at www.nras.org.uk/mark-and-rachel-run-london





By Viv Moore

PhD PGDip MBIs
MTUK Listed
Mindfulness Teacher

Mindfulness

Reclaim your life and body by learning to live with pain

Living with chronic pain, whatever and wherever that pain may be, can be the daily focus of our lives. Other people just stand, sit, walk, make tea, anything! For us, everything takes enormous amounts of conscious effort, which adds to our fatigue.

Mindfulness means paying attention in a particular way, and without judgement. There's plenty about mindfulness and meditation in the media, usually accompanied by a sylph-like girl, cross-legged in an impossible position. Mindfulness is incredibly simple, but that doesn't mean it's easy. Paying attention to each moment can be extremely difficult when you're in pain; who wants to stay with that?

I was lucky enough to have my first big flare the very day my Mindfulness Based Stress Reduction (MBSR) teacher training began. Lucky? The fatigue, spasms and intractable pain meant I could do nothing but practise. I got to know pain in a different way by learning to live with pain, instead of shrinking from it. We can take the suffering out of the equation by working through the course, and opening to a radical shift in perceptions. The incapacities of using my hands became challenges. But, yes there was a lot of swearing too, because I'm only human.

MBSR was specifically designed for people with chronic conditions. Typically beginning with an orientation (about 1 hour) to check this is the right time for you and to establish your support. The course consists of an 8-week programme (roughly 2 hours each week). Participants are required to use the workbook and meditation recordings for home practice, as a vital component of the programme. The first 4 weeks concentrate on building confidence in specific practices together with an understanding of how our bodies and brains deal with pain. In the second half of the course these tools are polished into skills and utilised to face all of life's difficulties. The teacher will bring their personal experience into their teaching; for example, I draw upon cognitive psychology and neuropsychology, because that's my background.



Mind Full, or Mindful?

If mindfulness means paying attention in a particular way, and without judgement, how does this help with pain? MBSR is different from other forms of mindfulness and meditation, because they are not targeted at pain and difficulty. The Mindfulness Based Stress Reduction (MBSR) and Mindfulness Based Cognitive Therapy (MBCT) programmes are supported by substantial scientific literature with thousands of studies demonstrating significant benefits to many conditions. These include: fibromyalgia, ME, osteo- and rheumatoid arthritis, cancers, psoriasis, leukaemia, heart disease, hypotension, anxieties and phobias. This does not suggest that MBSR will 'cure' anything: instead through regular and determined practice we effectively change our bodies and brains to make different responses when pain and difficulties arise.

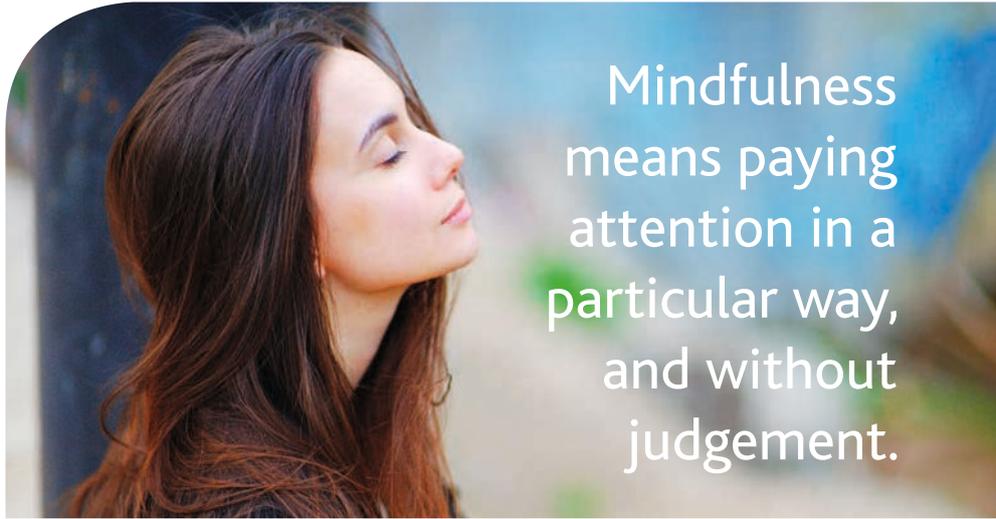
Mindfulness is deceptively simple, and people think they know it, and can teach it. However, presented simplistically, or with misinterpretations, that vital radical perspective-shifting potential becomes diluted or even lost. Although counselling, clinical and IAPT psychology, medical/psychiatric training are vital health professions, unless teachers have individually taken the experiential training, they are not qualified to teach MBSR or MBCT (for depression and anxiety). It is vital to be trained by one of the accredited institutions (eg Bangor, Exeter and Oxford Universities or Breathworks). Teachers should be signed up to 'UK Network for Mindfulness-Based Teachers' Good Practice Guidelines for Teaching Mindfulness-Based Courses'. This is very important because the teacher must have at least a personal

“Mindfulness Based Stress Reduction (MBSR) was specifically designed for people with chronic conditions”

mindfulness practice, be trained and examined on the integrity of their teaching which can take 5 years. In signing up, they agree to have professional supervision and attend annual teacher training retreats. There is justified concern about the quality of mindfulness teachers, so do check credentials. No qualified teacher will object.

Viv Moore PhD PGDip MBIs
 MTUK Listed Mindfulness Teacher
www.vivmoore-mindfulbreath.org

To find qualified teachers:
www.mindfulnessteachersuk.org.uk/index.html#organisations



Mindfulness means paying attention in a particular way, and without judgement.

Sample a Moment of Mindfulness

By Viv Moore

I'd like to invite you to try something. When you've read these instructions, take a moment to try a little practice.

The * indicates an invitation to take 3 breaths (but it's ok to take one).



Put down the magazine.

Come to a comfortably supported position. *

Become aware of the simple fact that you are breathing. *

Follow the breath (as best you can) into the body and out of the body. *

Don't change anything, simply observe it. *

Perhaps feel the breath moving the chest muscles or the abdomen? *

Take a few moments to investigate this. *

Bring awareness to how you're sitting/lying. *

Notice which parts of your body are supported, and which parts aren't. *

Perhaps close the eyes and really hone attention into the points of physical contact. *

Become curious about how that feels. *

Is there any change of temperature? *

Allow yourself to be interested in the sensations of clothing/covers touching your body? *

Let any uncovered areas be sensitive to the air in the room. *

Now, come back to the physical contact of your body with the support. *

Breathe out and open your eyes. *

Take a moment before resuming any activities.



#WearPurpleforJIA 2017

Well done to every single person who took part in this year's amazing #WearPurpleforJIA 2017

NRAS were lucky enough to be chosen for a second consecutive year by Lynette Haselip (Mum of Farah who has JIA). Lynette came up with the idea of wearing purple to raise awareness about children with JIA, after Farah was diagnosed with the disease at just aged 2, and struggled to find the relevant information and support about the condition that affects around 12,000 children in the UK under the age of 16.

Team Purple which consists of Lynette and good friend Rachael, set to work on this year's campaign. The NRAS JIA and Fundraising Team worked in conjunction with Lynette to create a bigger and better #WearPurpleforJIA in 2017.

Alongside Team Purple, who were hotly selling and sending out their Purple merchandise from their base in Northampton, the Fundraising Team at NRAS in Berkshire got creative and produced a fun Fundraising pack with freebies and packed full of ideas and information to help make each Wear Purple day a success.

Friday 9th June was a great day with 176 groups and individuals signed up to take part one way or another. Staff from NRAS donned their purple wigs and visited our nearest children's clinic in Oxford and also a school in Guildford. There was a real buzz with lots of social media pictures and

tweets going on all day. The success has surpassed expectations and as we go to press with this article we have received £19,361 (gross) in funds raised from waxings to song warbling, from cake baking to sponsored runs and toddlers!

This is a huge increase on the 2016 total when we had 13 people signed up and raised £6107.77. A huge Purple thank-you to everyone who took the time and effort to get involved and to Team Purple for once again choosing to support our JIA services at the National Rheumatoid Arthritis Society.



The Markides family from Southport held a 24 hours Music-a-thon and raised **£2,252**



Burpham School, Surrey, where Isaac and his friends raised **£180**



Renaye aged 9 and her Mum, Paula, raised **£349**



Paula Edwards organised a dress-down day event at Birmingham City Council



The Mullins family bared to wax in Woodley, Reading and collected sponsorship of **£1,455**



Centre for Muscular Skeletal Research Team in Manchester held a bake sale and raised **£136**



Purple hands at Jessica Norton's school worked together and raised **£380**



Helen Gosney's cake sale raised **£70**



Lynette Cook and family whose school, Oakmere School, raised **£366**

"This year we really did a fantastic job of reaching out to families, schools and other organisations to support our #wearpurpleforjia day on June 9th. We exceeded last year's total by several hundred percent on every level. The schools, families and individuals who raised awareness and fundraised for us were incredibly creative and dedicated and after costs have been deducted, they have raised in excess of £21k to support our JIA-at-NRAS activity on behalf of all those affected by JIA. We thank everyone for their support."

Ailsa Bosworth CEO



Team Purple - Rachael Rennie and Family, Lynette Haselip and daughter Farah, age 6



Sophie, aged 6, and her friends at Cheritone Fitzpaine School in Devon donated **£228**



Elaine Parsons, Rheumatology Nurse and staff at the Nuffield Unit at Oxford got the children and staff at the clinic involved raising **£255**



Isaac enjoying activities at the Nuffield clinic



Anna Maria Walker and daughter, 3½ year old Dakota, raised **£235** in Worcestershire



£262 was raised by Lauren Edmonds and school friends with a Mufti Day



Friends Jessica and Megan showing off their Purple Hoodies



Sarah Evans' daughter's nursery gets crafty!



Lois Foreman and classmates at Edwards Hall Primary school raised over **£400**



Louise and her daughter Heidi held a fundraiser at home raising **£327**



NRAS Swansea Group

Swansea Group auction Welsh Euros football shirt to raise funds



L -R: Janet Evans, Commercial Marquee Hire, Cynthia Rees, Swansea Group Coordinator, Matt Jones, ex Wales International Footballer, Paula Lewis, Volunteer, Josh Ford, Commercial Marquee Hire

.....
 Matt Jones,
 former
 Welsh
 International
 and Leeds
 United
 player, was
 very happy
 to give his
 support

Over the last two years the NRAS Swansea Group have been very busy raising funds for their own group as well as for the society as a whole.

Last year they were given a signed Welsh Euro football shirt, courtesy of Matt Jones, former Welsh International and Leeds United player, who is also currently an Ambassador for Swansea City FC. Matt was aware of the work of the Group and the support they give to NRAS and people living with RA so was very happy to give his support.

The initial bidding was elevated by David Evans of Commercial Marquee Hire who very kindly had the shirt framed. A final, anonymous bid of £1,000 from a football supporter brought the auction to an end. Kevin, who also made a bid for the shirt but was unsuccessful kindly donated £100 towards the auction.

The Swansea group have set themselves a challenge to raise £3000 for a specialist infusion chair for Singleton Hospital and so are delighted that a share of the funds raised is going towards that too.

Other fundraising ideas the group have for this year are:

- **Swim a Mile** – collectively with around 5 people taking part
- **NRAS Tea Party** – great excuse to eat cake and drink tea!
- **Quiz Evening**
- **Carol Concert**
- **Walk up Pen y Fan**
- **Bag packing** in a local supermarket

We always appreciate it when NRAS groups support their society for the benefit of everyone. If your patient group, NRAS or otherwise, would like to do some fundraising activities for the charity email the fundraising team at fundraising@nras.org.uk as they would love to hear from you. Thank you Swansea Group, keep up the good work!

New Ambassadors

NRAS Ambassadors trained in Maidenhead



On 5th and 6th June, a number of Ambassadors came to our Maidenhead office for Ambassador training. One of the key roles of an Ambassador is to help NRAS to liaise with and lobby policy-makers in devolved areas in order to improve the lives of people with rheumatoid arthritis.

The training included time with each of the departments at NRAS, giving our Ambassadors an in-depth understanding of how the charity works and the importance of each department in contributing to our campaigns. We then had interactive sessions on campaigning and influencing skills to enhance the range and depth of skills that our Ambassadors bring to the NRAS team.

Our campaigns' work over the coming months and years in the devolved areas, Scotland, Wales, Manchester and Northern Ireland, will vary greatly depending on policy positions in each area. In Scotland, we hope to continue discussions on the recommendations in *'Who Cares? A report on the health and social care needs of people with RA across Scotland'*, with Members of the Scottish Parliament. We will also involve Ambassadors more closely with the work that we undertake in Maidenhead, including work with NRAS Groups in Scotland. The Chair of our Ambassador network in Scotland, Sheila Macleod, is also taking forward a major piece of work in regard to an audit of people with existing disease in collaboration with the Scottish Society for Rheumatology.

In Wales, we will continue campaigning for improved paediatric rheumatology services across South Wales, with Ambassadors playing a crucial role in meeting with Assembly Members and liaising with rheumatology units. This strategy was implemented successfully in Scotland and we will therefore seek to work closely with rheumatology units across Wales to make them more aware of the resources and value of NRAS and how we can better support their patients and their services.

The new devolution powers in Manchester present a promising opportunity, and our newly established Ambassador network will be working closely with the various NHS Trusts in the city to hopefully establish a common pathway, improving services for everyone with RA in and around Manchester.

We are currently running a major new survey on the impact of RA on work, 10 years on from our last survey on work, and we hope to be able to break the data down by devolved areas once the survey closes.

As stated in our Strategic Plan, we hope to establish an Ambassador network in Northern Ireland over the coming years. We continue to monitor the political situation in Northern Ireland, where, at the time of writing, there is still no government. Once a new Government is in power, we will seek to establish relationships within that government and work with people with RA to launch a network.

The training included time with each of the departments at NRAS, giving our Ambassadors an in-depth understanding of how the charity works

If you are interested in becoming an Ambassador or getting involved in any of our campaigns in other ways, contact Matt at matthew@nras.org.uk



By Matt Bezzant

Policy and Public Affairs
Manager



Updates from our Coalition work

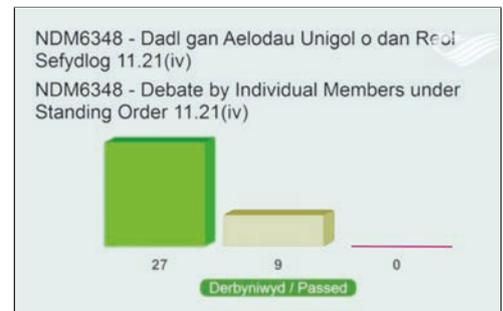
NRAS is proud of the success of its campaigning and advocacy work, achieved despite the limited resources and small team in Maidenhead. In addition to the campaigns work that NRAS undertakes solely, we also work in close collaboration with a number of other charities and professional bodies in order to deliver consistent messages to the Government and other decision-makers where we have common aims. Below is an update about some of our recent collaborative working.

Prescription Charges Coalition (PCC)

NRAS is Co-Chair of the Prescription Charges Coalition along with Parkinson's UK and Crohn's & Colitis UK. Together, we have co-ordinated efforts to campaign alongside 40 other organisations for a review of the exemption criteria for prescription charges. The current exemption list was written in 1968 and has barely been updated since. The PCC published a report in June called Still Paying the Price highlighting the ongoing detrimental impact that prescription charges are having on the health and wellbeing of people with long-term conditions, including rheumatoid arthritis. RA specific data from this survey has been extrapolated and we have press-released this data which is starting to be picked up by the health press. For more information see our website.

Welsh paediatric rheumatology services

NRAS is working with the British Society for Rheumatology and Arthritis Care Wales to campaign for a full paediatric rheumatology service in Wales. Families in Mid and South Wales are currently having to travel for hours to Bristol and beyond to get access to a full rheumatology team. Two of our fantastic Welsh Ambassadors, Rich and Gaynor, met with Assembly Members in Cardiff in June to discuss the campaign and to push for improved services in Wales. On 12th July, we managed to secure a debate in the Plenary Session of the Welsh Assembly to ask the Welsh Government to support our calls for the creation of a full rheumatology service; the motion was passed, and this will put added pressure on the Welsh Government to implement the service for children in South Wales with JIA. A review will now take place by the Welsh Health Specialist Service Committee (WHSSC) to assess current provision in South Wales and to make recommendations to the Government. The added political pressure as a result of the debate will help us as we work with WHSSC on the review.



DBC Disability Benefits Consortium

Disability Benefits Consortium (DBC)

As a group of over 50 disability charities, we consistently stand up for the rights of for the rights of people living with disabilities, including people with RA. Prior to the General Election, the DBC issued an open letter to the leaders of all the main political parties urging them to protect disability benefits from further cuts. Over 16,000 people, including NRAS Members and supporters, signed the petition.

#TooYoungForArthritis

The Pierhead Building, The National Assembly for Wales,
Cardiff Bay. 28th June 2017.

@ac_wales @NRAS_UK @RheumatologyUK

You can keep up to date with all ongoing NRAS campaigns at www.nras.org.uk/campaign

General Election

By Matt Bezzant

Policy and Public Affairs
Manager



When the last edition of the magazine was published, who would have thought that this edition would have followed a General Election? The election, somewhat unsurprisingly, focussed on 'Brexit' with other crucially important issues such as health, work and social care largely overlooked until later on in the campaign.

The Conservative Party has now formed a minority Government, however, there are certainly positives to take from the result. The Government will now find it difficult to pass controversial legislation and will be under additional pressure from opposition parties and backbenchers over other matters, as we have seen recently with the pressure to scrap the 1% pay cap for public sector workers. This presents unique opportunities for NRAS to work with Members of Parliament from across the political spectrum to campaign on important issues for people with RA.

The Queen's Speech, which announces the Government's proposals for the forthcoming Parliamentary year, took place on 21st June. Many of the Conservative Party's manifesto commitments notably did not appear in the Queen's Speech due to the result of the election. NRAS was disappointed to see that, of the 27 bills in total, there were no bills relating to health, social care or disability and employment.

Our CEO, Ailsa, was on the Department for Work and Pensions Expert Advisory Group (EAG) on Work and Health prior to the election. We will seek to work with the new Secretary of State, David Gauke, to continue NRAS' involvement on the EAG, meaning that employment aspects for people with RA will continue to be heard at the highest levels of Government. We will also seek to ensure that the 'Work, Health and Disability Green Paper' continues its course into the new Parliament and the consultation responses are brought forward where necessary. NRAS will continue to work with the Government and campaign for policies to improve rheumatology services across the UK.

We will seek to continue NRAS' involvement on the EAG, meaning that employment aspects for people with RA will continue to be heard at the highest levels of Government





By Sally Wright

Head of Marketing and Communications



and Michelle Vickers

Head of Fundraising

“I’m now doing yoga and pilates – it keeps me moving but I also love walking my dog, Cooper”

Love the Life You Live, Live the Life You Love!

An interview with American fashion designer Michael Kuluva

Michael Kuluva is an American fashion designer and founder of the New York Fashion Week label, "Tumbler and Tipsy". Born in 1983, he started out as a professional figure skater but now has a colourful career as a fashion designer. A lover of Birkin bags and chocolate, Michael was diagnosed with rheumatoid arthritis in 2011. He was so happy we made contact with him and agreed to an interview with myself and Michelle Vickers, Head of Fundraising, without hesitation!

In talking about his diagnosis, Michael explains, "I was sent to a Rheumatologist and my whole body lit up like a Christmas Tree. I couldn't believe that someone at 28 could have RA, something that's potentially so debilitating. And then things started making sense to me; why I wasn't cutting my fabric straight or why my sketching was a bit off. I was getting frustrated, my teachers were getting frustrated, and I thought, 'wow this is what's happening'."



SW Had you heard of RA before?

MK I heard it mentioned once. I was on a cruise with my Grandmother and they were having a talk about arthritis. They talked about osteoarthritis and rheumatoid arthritis, but I hadn't heard of it before and people always think it's about getting older or doing too much sport when you're younger. When I got my diagnosis, of course I Googled it – which I wouldn't recommend!!

SW When you were diagnosed, did you have a sense of relief?

MK Well it wasn't until I started treatment that I felt relief really. The first treatment I started on, I had a reaction; it was horrible for 3 or 4 weeks, so finding the right medication was a priority, as anyone living with this disease will tell you. I wanted to try and understand what this was and understand why my body was attacking itself.

SW What are your symptoms?

MK Fatigue mostly. I try and keep as active as I can. I travel so much that previously my body couldn't keep up. The regime I was on before wasn't suiting the frequent travelling so I've just started another regime, which is much better. I'm now doing yoga and pilates – it keeps me moving but I also love walking my dog, Cooper.

MV What made you go public?

MK You know, I kept it a secret until last year. I felt a stigma as well; I didn't want to feel that an editor wasn't picking up my designs because of my diagnosis, and my management and agents didn't want it to affect my endorsements. I always wanted to 'come out' about it, but I wanted to be established in my career, to get a voice and a following and know I could talk about it so I could draw more attention. Take something negative and persevere with it to where I am now.



SW Is there a relief about being 'out' now?

MK Oh yes. When Creaky Joints and I got together, we brainstormed about how we could raise awareness. I thought of the collection... showing pain visually. People can't see the disease so this collection brings attention to it so much more. We've had such positive feedback about the designs. I can't choose this disease, it

can't be 'fixed' or cured, but we can expand on what we can do for it.

MV What kind of advice would you give to other people especially people who are newly diagnosed?

MK Don't Google it! Find someone else who has the disease and talk to them, find a group (like yourselves) and talk to them, get information, and understand it. Get the real information. A lot of these things on the internet scare you, so get the real truth. It's not scary if you fully understand it and know your limitations. You have to figure out 'who can I talk to?' I have no problem explaining what I went through. The other advice I would give is to be patient, it's not a sprint but a marathon unfortunately.

SW We struggle to get men in particular to come forward and have conversations like we're having now. How was it for you 'coming out' with work?

MK I understand that people might feel that it makes them look weak, I've heard that a lot. It's quite easy to hide this disease, it's invisible to most people. I'm lucky now as I work for myself so I can control that situation. But people should be able to talk to their manager one-to-one, you have rights and need to be heard. Things can be adjusted at work to make things easier. There are laws to protect you.

SW What motivates you?

MK I was a professional figure skater in the US and to do something like that at that level requires a whole load of determination. With my collections, I push through deadlines. Fashion week is when I get my biggest flare-up because there's usually lots of stress. So, I make sure I get enough sleep, that I eat well and look after myself properly. My weight tends to go back and forth so I have to keep an eye on it, especially during stressful times.



SW If you had a superpower what would it be?

MK When I was doing Holiday on Ice, I was 'Dash' from the Incredibles. Speed would be awesome; it would help me get places quickly. I often think, 'I wish there were two of me'.

SW Do you have any guilty pleasures?

MK Oh, tons and unfortunately, they're very expensive! I collect Birkin bags. (At this point, I needed to have this explained to me by Michelle – apparently, they are a 'thing of beauty, to be looked at rather than used practically!'). They're the Rolls Royce of bags. I also love chocolate



(which I'm not supposed to have). And playing with my dog, he gets me out and he's a great companion.

SW If you could invite 3 people to a dinner party, who would it be?

MK Ooh, good question. Probably the Dalai Lama so I could get more insight to life. Maybe someone from the Royal Family like Queen Elizabeth – it would be just so over the top and cool. She would have the best stories! And then my partner – I want him to enjoy it with me.

SW What 5 items would you take with you on a desert island?

MK My bags, obviously!! Water, my dog, a computer to stay in touch with people and a tent - I like to be in the shade.

We are truly thankful to Michael for giving up time in his busy schedule to talk to us all the way from California. He's currently enjoying working towards his next collection for New York Fashion Week in September, we wish him all the best!

You can follow Michael on Twitter here www.twitter.com/MichaelKuluva





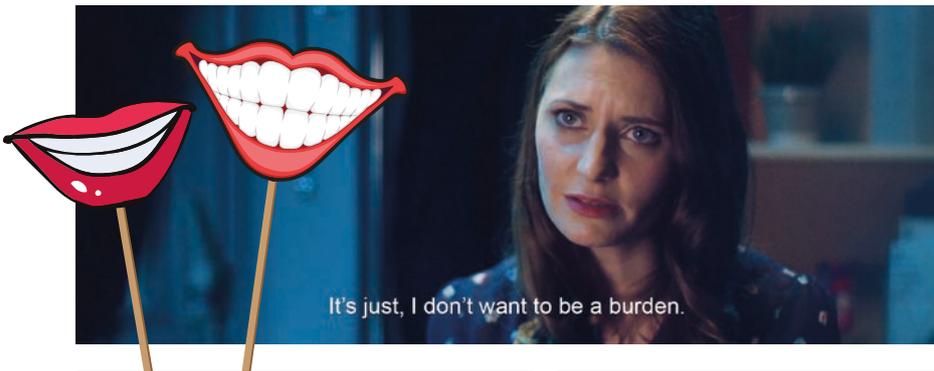
Rheumatoid Arthritis Awareness Week 2017

Behind The Smile

By Sally Wright

Head of Marketing and Communications

Thank you to everyone for making RA Awareness Week such a huge success. 2017 really has been the biggest RAAW so far. I am particularly proud of the team involved in promoting the week far and wide, which included Penny Prideaux, one of our NRAS Members, and our PR company Mash PR.



The theme, invisible illness, having been voted for by our Health Unlocked and Facebook Community, proved to be incredibly popular and something that resonated with so many people. The different themes we promoted each day focussed on a variety of perspectives; from surveying the general public in a street poll, to a social media quiz on the S Factor to the release of our Lilly collaboration film, *Behind the Smile 2*. We have been overwhelmed with comments and posts during the week.

National Rheumatoid Arthritis Society (NRAS)
21 June at 16:03

No googling! 😊

S Factor QUIZ

Do you know what The S Factor stands for?
The S-factor was introduced as part of an awareness campaign to inform public about the common early signs of Rheumatoid Arthritis (RA). Can you guess what they are?
SURVEYMONKEY.CO.UK

National Rheumatoid Arthritis Society (NRAS)
25 June at 13:27

One of the major misconceptions about Rheumatoid Arthritis (RA) is that it only affects older people! RA can strike at any age after 18.
Katy (34) was just 28 when she was diagnosed with RA. The condition taken a toll on her, but she is determined to not let it control her.
#behindthesmile

Katy Pleris
Living with Rheumatoid Arthritis

5.8k Views

Like Comment Share

173

Chronological

National Rheumatoid Arthritis Society (NRAS)
23 June at 16:57

Being a single parent for two young children can be tough. Being unemployed whilst being a single parent can be even tougher! Today's theme is Work and RA, here's a case study from Anon, who was made redundant from her job 3 years after diagnosis

Work and RA - Being a single parent (anonymous)
I am a single parent of two young children. Prior to my diagnosis of rheumatoid arthritis, I was working full-time as a Health and Safety Officer, which involved both desk work and visits to building sites.
NRAS.ORG.UK

National Rheumatoid Arthritis Society (NRAS)
20 June at 11:51

Donna (42) was diagnosed with RA at the age of 21. Watch this video to find out how Donna's family have supported her through her condition.

Donna, 42
Diagnosed with RA at age 21

Susan Lymer Brilliant xx Donna is a great coordinator for nras group in Worcester. But I would like to add she and her family have become great friends over the years I have known them. Thankyou for all your support and what do xx
Like - Reply 3 - 20 June at 12:28

Theresa Holton I've had Ra since I was 18 months old. I'm now 51
Like - Reply - 20 June at 14:53

Kate Mann What a fantastic video Donna, such a loving supportive family & it's great that you help spread the word about what advice and support is available for other sufferers. XxxX
Like - Reply 3 - 20 June at 20:07

Christina Denniss Great video, I have shared. Might even come to the next meeting 😊
Like - Reply 1 - 21 June at 14:29

National Rheumatoid Arthritis Society (NRAS)
19 June at 16:16

We asked people on the street if they had heard of Rheumatoid Arthritis (RA). Here's what they said:

What is the first thing that comes to your mind?

Diane Rice 'Oh yeah, my Nan's got that' 😊
Like - Reply 1 - 20 June at 18:00

Jan Patterson OH of course I know ... it's what my grandma had or I have it in my toe... I have had more people tell me they have it to... if only they knew...
Like - Reply 1 - 21 June at 08:24

Cheavourne Whittaker I am completely in shock to how closed minded people have been when I have tried to raise awareness about RA. I am not going to give up trying although living with this illness and lack of support/understanding would make it a lot easier. I need to find a better way to get my story out there but more so to raise awareness for this condition
Like - Reply 1 - 21 June at 15:56

Nikki Cox Shocking!! I have RA but I also have Palindromic rheumatism I wonder how many of the public has ever heard of that?
Like - Reply - 22 June at 13:53

National Rheumatoid Arthritis Society (NRAS)
24 June at 14:00

Today's theme is Intimacy and Relationships and we want to share with you an important resource that we launched last year. It tackles emotions, relationships and sexuality, and how these very personal and intimate issues are affected by being diagnosed with and living with rheumatoid arthritis.

Emotions, Relationships and Sexuality Booklet
Order or download your free copy from our website today.
NRAS.ORG.UK

Amanda Wiles This is really good. I am really struggling emotionally recently...
Like - Reply 1 - 24 June at 19:11

Kate Viner brilliant resource for everyone with Ra and their families .
Like - Reply 1 - 24 June at 15:18

Heather Senior This is excellent 🙌🙌🙌
Like - Reply 2 - 24 June at 16:13

We have reached more people this year and had more conversations than ever before.



Thank you

to those of you who requested our RAAW packs

Thank you

to those of you who bravely shared their own stories and experiences

Thank you

to those of you who simply retweeted or shared our posts and films

Thank you

to many volunteers, health professionals and staff who helped man information stands

The list goes on, but whilst NRAS can promote RA Awareness Week, it really would not be possible without you, so THANK YOU again.

Sally Wright, Head of Marketing and Communication

Thank you

to those of you who had a 'conversation' about RA at some point during the week

Thank you

to those of you who hosted RA awareness stands during the week

Thank you

for using the profile frames and smiley lips on social media

"I think this year was our best ever RA Awareness Week. The fact that we launched something new every day not only raised more awareness with different audiences, it held people's attention for the whole week. I have to congratulate our Marketing and Communications team and everyone who contributed for all their hard work, and for achieving a stunning result in reaching many more people than in any previous year, and raising a whole lot of awareness on this misunderstood and invisible disease."

Ailsa Bosworth, CEO

A Happy 'Tail'... BorrowMyDoggy!



How a 4-legged friend helps keep Heather on her toes

In April 2011, I was diagnosed with RA and had to retire from my job as a Physical Education Teacher. There were SO SO many losses, too many to mention, followed by grief work, and depression and anxiety. I was so ill; crawling to the toilet at one stage. I felt my active life had ended, and on some days, I didn't want to be here anymore.



6 years on and I am slowly getting there, mainly due to disease control and improved mobility. My feet have been on quite a journey, I've had numerous steroid injections, but if your feet hurt, you are going nowhere. I now have wonderful orthotics and no inflammation!

Once my feet were less painful, I was on my way, and what has really helped, in so many ways, has been to borrow a dog! I take out Zak, a beagle and I 'borrow' him from BorrowMyDoggy.com. For a small monthly fee, you get to take a dog out for a walk, and you also get 3rd party liability insurance and 24-hour calls to a vet.

The advantages are numerous! I have a new friend, whose greeting when I call for him is truly joyous. We both make each other's lives better, for the dog, they get to go out into the fresh air and get exercise, and so do I! I meet other dog walkers and have

a lovely chat; I see nature in all its beauty. I bird watch, and have a little book to help me identify them all. I have watched a kingfisher diving for fish, a woodpecker tapping at a bark, a nuthatch, dipper and tree creeper. The sunlight and exercise directly enhance my mood, and serotonin is produced in my body, all adding to my well being.

Zak is so much fun to be with, he makes me smile, and at times laugh out loud. He chases

a ball, and keeps coming back for a little treat. Both our mental health has improved from this friendship, and I have grown to love him and miss him when it's the weekend, and his owner takes him out. It is a win win combination, and I am so pleased I signed up for this opportunity.

We spoke to Casey at BorrowMyDoggy and she was delighted to read Heather's story. They believe that dogs are man's best friend for a reason and the benefits of spending time with them are endless. One of the benefits is that dogs are the ultimate workout partner. In fact, they bet you won't find a more eager cardio companion than dogs.

Even if you prefer walking, many dog owners admit they wouldn't walk as often if they didn't have a dog wanting a walk. So, whether you own or borrow a dog, you'll end up walking on average an extra hour a day compared to people without dogs. Their enthusiasm and happiness for exercise is contagious and just when you think you've hit your workout peak, a sudden squirrel sighting will push you through that last sprint.

BorrowMyDoggy connects dog owners with trusted local people who would love to look after their dog. Its new and exciting and they already have over 600,000 dog lovers in their community.

You may not have the time or personal circumstances to own a dog full time, so BorrowMyDoggy enables you to meet and spend time with dogs locally, get more exercise and have fun meeting new people. You can care for different breeds and find out if owning a dog is for you or your family.

If you want to learn more about the initiative and find out how you can get involved, visit www.borrowmydoggy.com

Living Better with RA

Another new self-management workshop ready for delivery!



'Living Better with RA', a 3-hour workshop for people with existing rheumatoid arthritis, has now joined the 2-hour 'New2RA' workshop and the 6-week RA Self-management programme as part of the comprehensive package of direct support NRAS can offer to people at every stage of their lives with RA.

The Living Better workshop has been designed and written to provide either a follow-on support for those who have attended 'New2RA', or a first opportunity to learn about better self-management for those with more long-standing disease. Like the other two, 'Living Better with RA' has been piloted and refined with the input of people living with RA and with specific expertise in adult training and education programmes.

The main elements for participants in the Living Better workshop are:

- Meeting and sharing with others living with RA
- Learning more about the disease and medications
- Finding out how practising better self-management will help
- Hearing and exchanging top tips on managing day to day

- Discovering how setting simple, realistic goals helps you improve

As a result of attending the workshop participants will be able to:

- Continue to improve their knowledge and skills for managing the impact of their RA
- Make the most of their visits to the rheumatology team and ensure they get quality care
- Pursue actions to take back more control and have a better overall quality of life

The first volunteer lay tutors have been trained, and delivery of 'Living Better with RA' will begin in Sussex in July. NRAS is pleased and excited to be able to provide this new workshop, and we look forward to seeing the results in the first groups of RA patients.

As much as we would like to be able to offer this new resource across the country, we are reliant on the workshop being commissioned or funded externally. At present, there are no plans to deliver the workshop outside of East and Central Sussex, but if you think your own rheumatology team would be interested in hearing more about it, we would be happy to provide further details for you or direct to the team.

Contact Alison Derrick alison@nras.org.uk



Discover how setting simple, realistic goals helps you improve

Family Fun Day!

JIA-at-NRAS Family Fun Day – Saturday 1st July



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 “I wanted to send a message to thank you all for the fantastic family day you organised at the weekend”

After what was said to have been the wettest June for 30 years the sun shone on the JIA-at-NRAS Family Fun Day on 1st July, which was again held at Nell Bank, Ilkley in West Yorkshire.

Nell Bank is a purpose-built activity centre, with inclusive and accessible activities for all abilities and ages. Children and teenagers with JIA, and their siblings, took part in supervised activities and at lunchtime everyone sat together mingling and chatting with each other.

Whilst the children enjoyed pond dipping for water monsters, hunting down cuddly brown bears, den building and general water play, their parents were able to listen to and talk with wonderful specialist health professionals.

This year we were joined by rheumatology experts Dr Gavin Cleary, Consultant Paediatric Rheumatologist at Alder Hey Children’s Hospital, and Dr Martin Lee, Consultant Rheumatologist at the Freeman Hospital, who spoke about mental health, transition (making the move from paediatric to adult care), research and JIA in general.

The audience made full use of the Q&A sessions at the end of the presentations, posing a huge number of questions, to which fantastic answers, full of clarity and compassion, were given.

Chloe Scarlett, now in her early 30s, who has had JIA since she was 2 years old, also spoke to parents. Chloe has recently qualified as a Drama Therapist, and enthralled the audience with an inspirational presentation about her journey with JIA. Audience members were inspired by her lust for life and her embodiment of the fact that a good life can be lived despite JIA.

Eventually the fun had to come to an end and all the families gradually made their way home, with exhausted but happy children.

“I wanted to say what a great day we all had on Saturday. My son didn't want to leave, he had such a fab time. It was so nice to do something for him that he didn't struggle with and he could be himself. His dad and I found the workshop very interesting and we loved Chloe – she was fab talking about her life and what it has been like for her growing up with JIA. I feel now that I am more confident to speak with his school and I can ask them to help more. We also found it helpful to meet other families experiencing the same as us. The last thing my son said was, 'when can I come back?'”

More quotes from the family day...

"My daughter was only diagnosed at the start of this year so this is all still quite new to us. I attended the parents' session in the morning which was really interesting and informative. My husband joined in with the water play and bear hunt activities with my daughter and they both thoroughly enjoyed their time. My daughter is just four so we explained that lots of the children there had the same 'children's arthritis' that she has."

"I also got a chance to speak with a couple of other parents and exchange our numbers. It was great to talk to people who understand. In the nicest possible way, a lot of my friends don't really know what to say, so they end up changing the subject or making a 'positive' sort of comment that doesn't always match the circumstances."



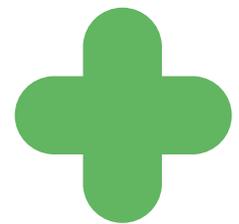
The Health Conditions in School Alliance

JIA-at-NRAS are working collaboratively with the HCSA to keep children with medical conditions safe in school

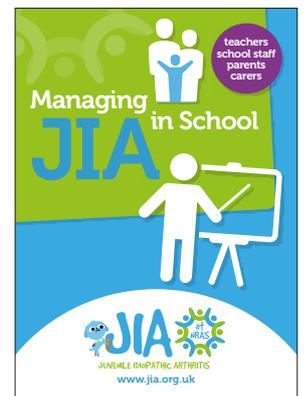
The Health Conditions in School Alliance is made up of over 30 organisations, including patient organisations, healthcare professionals and trade unions who work collaboratively to make sure children with health conditions get the care they need in school.

The aim is to raise awareness and alert schools about the need to have a medical conditions policy in line with the statutory guidance, issued by the Department for Education. JIA-at-NRAS is part of this alliance and is urging all parents to write to their schools to ensure that these measures are in place and that children and young people with JIA are supported in school to fulfil their academic potential and achieve what they want in their social life in the same manner as their peers. Our 'Managing JIA in Schools' booklet goes a long way to supporting this national campaign, however, in the coming weeks you will be seeing a lot more activity on our website and social media platforms, so please do keep an eye out. You can find all the information you need on the JIA-at-NRAS website, including useful links to templates to help you write to your school.

www.jia.org.uk/campaign
#safeinschool



**HEALTH CONDITIONS
IN SCHOOLS ALLIANCE**





By Anne Gilbert

BSPAR Parent Group

The British Society of Paediatric and Adolescent Rheumatology

BSPAR is a charity that connects the combined efforts of doctors, nurses, therapists and other professionals to support the advancement of paediatric rheumatology care in the UK and Ireland. BSPAR's goals include helping to raise the standards of clinical care, enhance the quality of training, promote research and raise awareness of all relevant conditions to all health professionals and the public.

The BSPAR parent group was set up in March 2013 to ensure the voice of patients and their families leads future developments in the provision of care for children and young people with rheumatological conditions.

All members of the parent group are experts in their field, in that they understand and manage the day to day living with, and caring for, a child or young person with a rheumatological condition. They also have experience of the NHS services. The group works closely with, and has a seat on, the BSPAR Council. It also has a good working relationship with two consultants, who regularly attend meetings in a liaison role.

The group currently comprises 11 parents (including 1 in Ireland) and 1 youth member from around the UK and Ireland. Ideally it would like a core group of around 15-20 so would like to hear from any parents, carers and patients with direct experience of paediatric rheumatological inflammatory conditions such as JIA, SLE or other MSK conditions who are interested in applying to join the group. Members meet approximately every 6-8 weeks by teleconference and try to have two face-to-face meetings in the year, one of which usually takes place at the BSPAR Conference in the Autumn.

The BSPAR board believed it must include the views of patients and their families in the development of services.

The group identified a number of ways that parent/carer representatives could help in terms of supporting the provision of care for all children and young people in the UK with juvenile idiopathic arthritis and other musculoskeletal and inflammatory conditions. The parent group aims to:

- Represent the parent voice – it seeks and represents the views and experiences of patients and their families from across the UK and Ireland. This includes working with other local and regional parent networks. In addition, it builds relationships with charities

and other organisations both nationally and internationally so it can establish a common purpose and combine efforts.

- Communicate with and support health professionals and work with all organisations with an interest in JIA and SLE (systemic lupus erythematosus) supporting all stakeholders under the rheumatology paediatric umbrella.
- Contribute to BSPAR meetings – it provides a voice for patients and their families at BSPAR meetings and committees to ensure their input into national strategy and guidelines. It helps to develop a structured feedback system to ensure there is clear and regular communication between BSPAR, patients and their families, local and regional services, charities and other organisations.
- Promote regional and national services – it advocates and lobbies for regional and national paediatric rheumatology services, so all patients receive the best possible care regardless of where people live in the UK.
- Support research – it collaborates with parents and professionals who support the research agenda for paediatric rheumatology (coordinated through a clinical specialty group) to endeavour to drive forward advances in care.

Whilst the parent group aims to promote the provision of care for children and young people with rheumatological conditions, it is important to understand that it is not a support group for parents, nor has it counselling expertise. It is a link between BSPAR, charities, patients, parents and, if necessary, can provide a parent voice to members of the government in order to achieve its goal.

If you are interested in becoming a member of the group, please get in touch using the following email parents@bspar.org.uk



BSPAR Parent Group

“Ideally BSPAR would like a core parent group of around 15-20”

Growing Pains

Lucien's story with JIA

When I look at a photograph of my boy just before his 3rd birthday, he's like a live wire, bursting with energy. That's the way we see young kids. Yet my kid has what's called Systemic Onset Juvenile Idiopathic Arthritis which is the rarest form of JIA and can have the greatest impact.



Multiple joints can become inflamed and also the blood, which in turn can affect organs and in certain circumstances be life threatening.

3 is a very young age for one's body to freeze up, to be in pain and to find oneself trapped in a hospital environment amongst strangers in isolation. It's a very young age to be pinned down in a chair while a needle or cannula is stuck in. From the nurse's point of view, 3 is a tiny person to take a blood sample from since little veins are not always yielding. And scared kids are difficult to reason with.

The first few months and years of living with JIA are testing. All the ordinary changes you expect as parents: going to preschool or school, growing, potty training, normal sleep, changing interest in food, growing independence or confidence: these are turned upside down.

I remember being chastised on more than one occasion for pushing my son around in a pram because he was 'too old for a buggy'. I wasn't going to tell a stranger he had inflamed joints. Instead, I swapped the buggy for a scooter with a little platform attached. This made a fun and novel way to get around, as we could slide down the streets

together at high speed. The consultant was happy, at least he was standing! It gave the right message.

Play dates were difficult, most obviously when it came to food. He either wanted to eat everything in sight because of the hunger induced by steroids, or leave well alone because of nausea triggered by a drug.

There's something so alarming about having JIA, that can attack young bodies so drastically. It can shrink their world making it difficult to go to school, to socialise, to grow in the largest sense. Any child with a serious illness is very aware of their own fragility and dare I say, mortality. But they're too young to deal with it emotionally. Hell, most adults can't.

In the early days of uncontrolled illness my son frequently asked if he was going to die. He wanted to know what happened after death. Would he still be him when he returned to the earth?

At first, I was alarmed and struggled with it. Then I realised this is one of the hidden riches of such an extreme situation. We turn in on ourselves to ask important questions.

Kids isolated by illness often become far more creative, empathetic and wise. They may become fascinated by the body as well as how medicine and science play a role in different ways in the mastery of the human form. In my son's case, he became interested in how power expresses itself in nature, by carnivorous plants and poisonous spiders, a symbol of power he could relish and which he personally felt he lacked. Alternatively, kids may turn to the spirit, expressing it through the arts, or through a sharpened sense of humour or heightened sense of fun.

So, there is real and impressive growth with childhood illness. Not the obvious milestones, not the growth we asked for, something more profound.

Anne Gilbert, JIA-at-NRAS Service Manager, spoke with Lucien's mum, Annabel, recently and she told Anne that Lucien's arthritis is well managed and he is doing fine, which is great news. Annabel and his consultant believe Lucien's treatment plan, which included a biologic early on in diagnosis, has really made a huge difference to his long-term outcomes and wellbeing; and even though he still suffers some side effects from the drugs, and has to visit hospital regularly, he is a happy little boy and slowly but surely catching up at school (with extra help from mum and dad) and has a really great friendship group.



Lucien Lagasse and family

.....

“Kids isolated by illness often become far more creative, empathetic, and wise”



JUVENILE IDIOPATHIC ARTHRITIS

Events Diary

8th August **Camp Wilderness.** Cornbury Park, Oxfordshire – A Bushcraft day for children with JIA aged 10+.

15th to 17th September **Family weekend in Wales, Morfa Bay Adventure West Park.** Pendine, Carmarthenshire - During the weekend we will host information sessions with health care professionals and NRAS staff. There will be multi-fun activities for parents and children as well as activities just for children and young people.

21st October **JIA and Me Art Competition.** Leigh Golf Club, Warrington – A collaborative event between Alder Hey Children’s Hospital and Manchester Children’s Hospital. This competition is as much about raising awareness of JIA as it is about supporting children and young people with JIA; providing an opportunity for them to share what living with JIA is really like and connect with others who have juvenile arthritis.

November date TBC **JIA Family event at the Evelina Children’s Hospital.** to support children under 12 years old and their families.

All events are free programmes – to register, please visit www.jia.org.uk/events

This magazine is based on currently available knowledge and information provided by third parties that has been accepted in good faith, but has not been verified independently. NRAS cannot be held responsible for any consequences arising from reliance on such information.

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