# Members' MAGAZINE

WINTER 2018

nras
National Rheumatoid Arthritis Society

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## RA AWARENESS WEEK

17th-23rd June
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# Dear Members

**By Ailsa Bosworth, MBE**

Chief Executive

On 1st November we launched our 2018 report: 'Emotional Health and Well-being Matters'. I'd like to thank everyone who took part in the survey back in the summer which provided the data for this important report, as well as those who participated in the focus group which informed the survey. I hope you will all agree, when you read it, that the information revealed is vital for all rheumatology teams, trusts, commissioners and policy makers to be aware of. Some of the data is new, particularly in regard to adult juvenile idiopathic arthritis where the research data is poor.

A big part of the reason for setting up NRAS in October 2001, was to provide the kind of help and support to people with which my family and I had been unable to get when I was first diagnosed nearly 40 years ago. A large element of the help and support that NRAS provides is about reducing anxiety, normalising the fears, particularly about impact of the disease on the future, and feelings of isolation (even when surrounded by family), and preventing anxiety and depression. In every major survey we have done in recent years, anxiety and depression have come out as one of the major comorbidities. There has also been a lot more research into anxiety and depression in the last 10 years and we know that many people diagnosed with RA will suffer with these debilitating symptoms, sometimes leading to severe consequences.

When you feel down or worry excessively, these feelings can sometimes be overwhelming and limit your ability to look after yourself and manage your RA or your emotional health. Pain, mental health and disability are strongly linked, so not recognizing or treating one can impact the others greatly.

For example, experiencing regular bouts of low mood, anxiety and/or depression may mean you don't have the will or energy to exercise, which can lead to loss of function. On the other hand, having a lot of pain and inflammation may make it harder to exercise and cause you to be depressed or anxious. Eventually, this vicious cycle harms your sleep, daily activity, ability to work, social interactions, treatment adherence and ability to self-manage. Therefore, treating emotional and mental health conditions should be regarded as a fundamental part of managing rheumatoid arthritis right from the point of diagnosis.

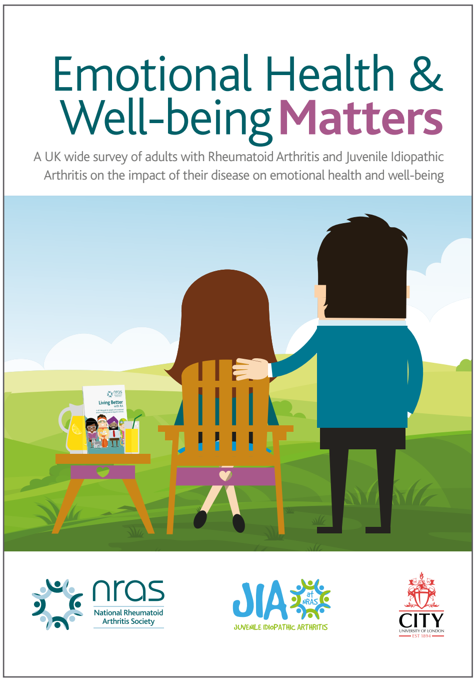
There is a huge amount of important data in this report, which I hope very much will convince rheumatology teams to sit down and put together a strategy to tackle mental health as well as physical health in routine clinical care. We feel that NRAS has a major role to play in supporting rheumatology teams in this respect. We have services and resources which we know provide the support people need, such as our helpline; there when people need it. Our peer support service exists as a tailored 1:1 telephone service and there is a moderated on-line peer support forum (NRAS/HealthUnlocked) available 24/7. Of course, those with serious mental health issues need the right professional support at the right time, which is not always easily accessible in the NHS. However, for people who are experiencing anxiety, isolation, low mood and non-clinical depression, there are positive things we can do and we're ready to play our part.

You will find our new report in the publications section of our website: **www.nras.org.uk/publications/emotional-health-well-being-matters**

As we hurtle towards Christmas – another year gone in a flash – I hope that you will be kind to yourselves over the festive period. Take advantage of our Seasonal Tips and don't over-do it so you end up exhausted!

We wish you a very Merry Christmas and a Happy New Year to come.

Ailsa



Emotional Health & Well-being Matters

A UK wide survey of adults with Rheumatoid Arthritis and Juvenile Idiopathic Arthritis on the impact of their disease on emotional health and well-being

nras National Rheumatoid Arthritis Society

JIA at NRAS JUVENILE IDIOPATHIC ARTHRITIS

CITY UNIVERSITY OF LONDON

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

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

# Members' MAGAZINE

## Contents

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

Editors of this issue;
**Tracy Bracher & Clare Jacklin**

# Special introductory membership offer

## NRAS Membership for a friend or relative

If you are introducing a friend or relative, they can benefit from a special introductory offer of just £15 for the first year when paying by direct debit. As a thank you to you for recommending them we will send you either an NRAS Lapel Badge or NRAS Wristband which ever you prefer.

Call us on 0845 458 3969 or email us at membership@nras.org.uk

# Members E-Newsletters

As well as this lovely magazine, every month we send out an E-Newsletter to our members, to keep you up to date with all the latest news in between the magazines. It's a great and cost-effective way we can keep in touch with you on all the latest research, opportunities to get involved with events, campaigning and much more. If you haven't been receiving these E-Newsletters please email us at membership@nras.org.uk to check we have your current email address and also your updated contact preferences.

> *"Letter writing is the only device for combining solitude with good company"*
>
> Lord Byron

If you have an advert for a future edition, please send them to us or email **membership@nras.org.uk** or call Tracy on **01628 823524.**

# NRAS Pen Pals!

## Proof that pen to paper is preferred by people who pause for prose!

**Following the call out for NRAS Pen Pals in the spring magazine, we have been delighted to receive so many replies and been able to match up so many people who are now happily making new friendships via good ol' snail mail.**

If you'd like to connect with any of these people looking for a pen pal please send your letter c/o Tracy Bracher, NRAS, Ground Floor, 4 Switchback Office Park, Gardner Road, Maidenhead, Berkshire SL6 7RJ. Mark the envelope with the reference name and number and Tracy will forward your letter to the relevant person. Don't forget to include your address for them to respond to. ***Happy writing!***

### Bernadette 97966

I am 76 and live alone, but my son lives nearby. I trained to be an Illustrator. I have written and illustrated picture books for many publishers for over 50 years. I used to travel a lot. Since diagnosed with RA. I travel less. I still write and illustrate, as much as possible. I do a bit of gardening. I love reading and cooking. I enjoy meeting other people both socially and for work. I also have Osteopenia. I get very lonely, so it would be great to have a pen pal who could keep up a regular correspondence.

### Elizabeth 95258

Hi, I'm Elizabeth, I was diagnosed three years ago. I've tried five types of drug so far but to no avail, it seems that as soon as I manage to pronounce a drug, they take me off it! I enjoy art, socialising, dining out and doing voluntary work. I love my garden and find the wildlife a huge source of pleasure, I also have a beautiful cat that I adore. I pride myself in having a good sense of humour and would love to hear from like-minded people who also find laughter to be a good tonic.

### Lynda 12465

Hello, witty gregarious female in my 50's, North West area - seeks single male pen pals to correspond with. Age 50 to 65. My hobbies are voluntary work, dining out, music, gardening, TV, theatre/cinema. I also enjoy technology and the internet. I have had RA since childhood but maintain an active life and feel disability is no barrier to leading a successful and fulfilling life.

Let's hope all your letters to me keep my postman busy.

# World Arthritis Day

## Haywood Hospital host a series of events

**On Friday 12th October, The Haywood Hospital in Stoke-on-Trent was buzzing. To mark World Arthritis Day, the hospital hosted a series of events throughout the afternoon and into the evening.**

These events included 'soap box' sessions with the clinical experts, taster sessions of Tai Chi, yoga and dance, a variety of stands – including NRAS, of course – and refreshments. The aim of the day was to provide as much information to those affected by arthritis as possible with emphasis on self-management of the condition.

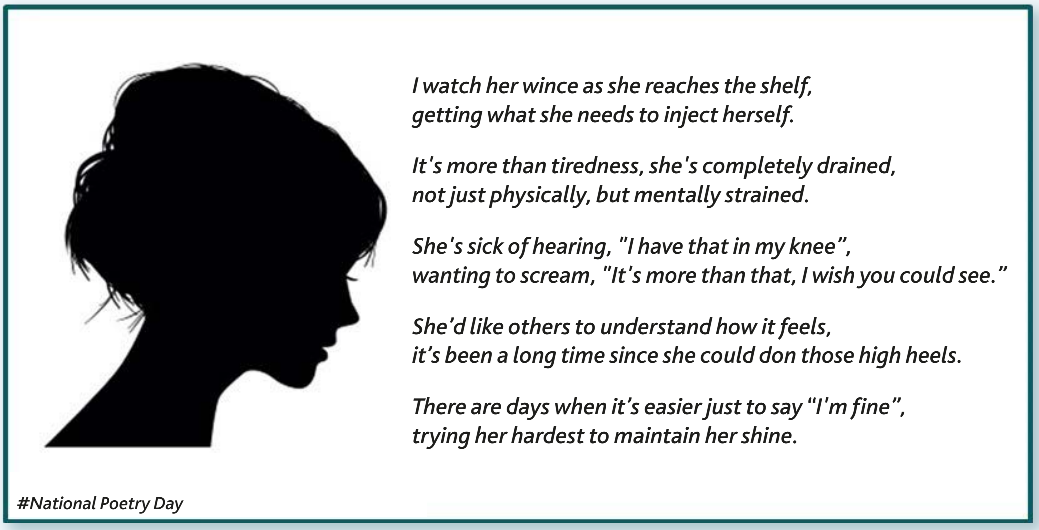
The event was sponsored by The Haywood Foundation, a charity founded in 1977, which is dedicated to helping local people affected by arthritis and related conditions. Over 140 people attended the event – a wonderful result for a wet, windy Friday afternoon in October! The success of this event could be seen as evidence of the growing desire of those living with arthritis to be armed with knowledge and to be involved with the self-management of these conditions.

The NRAS stand, complete with the new eye-catching literature, proved very popular. Local group coordinators Brig Batten and Trina Rule were delighted at the enthusiastic response of so many people from the local community.

The local NRAS group holds its meetings at this community hospital every other month and receives excellent support and encouragement from both staff and patients. Anybody interested in attending the meetings would be most welcome. Please visit the NRAS Website **www.nras.org.uk/groups/nras-stoke-on-trent** or email **groups@nras.org.uk** or call **01628 823524** for details of a local contact.

# #National Poetry Day

**Our lovely social media guru Katie, looks after all our posts on Facebook, Twitter and Instagram. If you follow us on social media you will have seen her informative posts, polls and latest news from NRAS. For National Poetry Day on 4th October she wrote this poem about Rheumatoid Arthritis.**



*I watch her wince as she reaches the shelf,*
*getting what she needs to inject herself.*

*It's more than tiredness, she's completely drained,*
*not just physically, but mentally strained.*

*She's sick of hearing, "I have that in my knee",*
*wanting to scream, "It's more than that, I wish you could see."*

*She'd like others to understand how it feels,*
*it's been a long time since she could don those high heels.*

*There are days when it's easier just to say "I'm fine",*
*trying her hardest to maintain her shine.*

*#National Poetry Day*

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**By Ailsa Bosworth, MBE**

Chief Executive

# The Future of Immunology

## Parliamentary Launch, 16th October, Palace of Westminster

Immune-mediated inflammatory diseases, such as rheumatoid arthritis, lupus, psoriasis, Crohn's disease and axial spondyloarthropathies, are characterised by common inflammatory pathways which lead to inflammation which may result from, or be triggered by, a dysregulation of the normal immune system response.

This means that the immune system that usually attacks only unwelcome invaders – like bacteria or viruses – for reasons not yet fully understood, attack healthy tissue, causing inflammation, pain and damage in different parts of the body, including a person's eyes, joints, gut, and skin. Over the past 70 years the UK's outstanding academic institutions and dynamic life sciences industry have led the field in immunological research. Not only has the UK provided its brightest minds with the support and funding they need to push the boundaries of medical knowledge, it has also consistently ensured that the fruits of their work reach and improve the lives of patients. This has led to scientific breakthroughs in the treatment of immune-mediated inflammatory diseases, helping the thousands of people in the UK and millions worldwide affected by these conditions to lead healthier and more active lives.

I have personally seen and experienced, and most importantly benefitted, from the results of all this amazing research. Just in the last 20 years research has revolutionised the field of rheumatology, and diseases like rheumatoid and juvenile idiopathic arthritis, so that outpatients' clinics are no longer full of people in wheelchairs. We have also seen the abolition in the vast majority of hospitals throughout the UK of 'rheumatology' in-patient wards.

NRAS has been pleased to be part of an alliance established earlier this year with the British Society for Immunology, The UK Bioindustry Association and AbbVie, with the aim to foster continued investment in immunological research for the benefit of patients in the UK who live with immune-mediated inflammatory disease. This aim is also critical for the Government to meet the ambitions it has set out in its Industrial Strategy for the UK to become a top-tier global hub for biomedical and clinical research and medical innovation. The launch of the alliance to

# The Prescription Prepayment Certificate:

## Paying by Direct Debit

In our last magazine, we mentioned that some people were having problems with not getting notification when their prescription prepayment certificate (PPC) was up for review. The PPC is a way of paying for your prescriptions in advance, with a one-off 3 month or yearly payment, which can work out cheaper than paying for individual prescriptions, when you are on regular medication.

In the article, we suggested that it might be worth setting a reminder in your phone or on your calendar of when the payment is due to come out. One of our Members got in touch to point out that you can also pay by direct debit, so that the payment is automatic and you won't risk a fine. This is a great idea. It may still be worth setting up that reminder, perhaps a month in advance if you have an annual PPC, just to help you to budget and remind you that the money will be going out next month.

NHS Prescription Prepayment Certificate

NHS

Certificate No: 10109572718

Name:

Valid From: 01/06/2018

Expires End: 31/05/2019

celebrate 70 years of research into immunology was held on October 16th at the Palace of Westminster.

The UK has developed the infrastructure for experimental medicine that is arguably the best in the world. Much of this has been made possible by the National Institute of Health Research, along with the major charities such as the British Society for Immunology, the Wellcome Trust and the Medical Research Council.

Professor Sir Robert Lechler PMedSci (President, The Academy of Medical Sciences, Vice Principal (Health), King's College London) said at the launch:

"*The therapeutic dividend of many decades of fundamental immunological research is now being realised at an astonishing pace, touching every aspect of health and well-being.*

*... it is essential that the UK continues to invest in the people and platforms that drive translation into the clinic and that we take all possible steps to strengthen the biotech sector that has such an important role to play in commercialising novel therapies*".

Our call to action following the event which members of the Alliance will be promoting wherever and whenever possible is as follows:

## Together we're calling for:

- Increase funding for immunology research, especially in areas of immune-mediated inflammatory diseases, in line with the Government's 2.4% GDP research investment target to ensure the UK remains a competitive and leading destination for research and clinical application in this area
- The government to recognise that without access to high level researchers and clinicians, the UK's position as a world leader in immunological research will be under threat. Ensuring that the new immigration system will support our ability to recruit and retain talent
- Maximise the research potential of our unique MNHS. Encourage a research strategy that embeds research and innovation at the heart of the health system
- Strengthen relationships between academia and industry – target and encourage partnerships at the early stages of the R&D pipeline through to scaling and clinical application
- Raise awareness of immune-related inflammatory diseases to enhance understanding of the symptoms with the general public and clinicians
- Expand the use of shared-decision making between patients and clinicians on care and treatment for inflammatory conditions
- Timely diagnosis
- Invest in the clinical and nursing workforce to ensure that it is equipped to provide patients affected by an immune-mediated inflammatory disease and their families with timely access to the services and support they need
- Develop appropriate training tools for clinicians and healthcare professionals to recognise the early signs of immune-related inflammatory diseases to enable early diagnosis and enhance the understanding of the interconnected nature of this group of conditions
- Ensure that clinicians and healthcare professionals understand the need for rapid referral to specialist care following diagnosis
- Implement improved measurement of early diagnosis rates with commissioners to enable action to be targeted to those areas most in need
- Patient access to innovation
- Accelerate the introduction of new advances in treatment for immune-mediated inflammatory diseases so that patients are able to benefit at the earliest opportunity, including through the establishment of accelerated medicines pathways
- Introduce adaptable health technology assessment processes that allow patients to access promising treatments whilst the data is still maturing and ensure a value-based approach to treatment assessment that fully recognises the voice of the patient and clinical community
- Adopt new approaches to pricing and reimbursement that support as many patients as possible to benefit from advances in treatment while delivering value for the NHS

NRAS is already acting on a number of the above calls to action and will continue to work with the Alliance towards achieving these aims.

**Sponsoring MP Melanie Onn**

*It is essential that the UK continues to invest in the people and platforms that drive translation into the clinic*

# Celebrating some of our amazing fundraisers of 2018

**2018 has seen some amazing youngsters fundraising for NRAS this year. They have taken part in a whole range of activities from cutting off their hair, to climbing the Three Peaks, showing their support for friends and family with RA and JIA.**

Milly Hartley braved the chop and had her beautiful locks cut to raise funds for our JIA Services. She raised an amazing £650.20 for NRAS and donated her hair to the Little Princess Trust.

To celebrate his 11th birthday young Finley Davies did a truly amazing challenge and climbed Ben Nevis and Snowdon with his Dad Gareth. Finley made it to the top of Ben Nevis at 6pm, having started out at 9:30am. It was very snowy on Ben Nevis but he battled on through snow storms and ice. Finley was doing his climb to support his Mum, Lesley who was diagnosed with JIA at age 15. He raised over £700.

Suzy Holding did the incredible 100K South Coast Challenge and raised an amazing £2,285. Suzy herself has RA and was diagnosed 10 years ago. Also, thank you to Anne O'Neill who ran in yet another event to raise money for NRAS, a 5K in Woking, which was on the day her Mum, who had RA, would have been 101! Anne raised £302.

Big thanks as well to some of our awesome JIA families who organised larger Community events. Hannah Gotts and family organised a fabulous family fun day in Pakefield in Suffolk and raised an amazing £1,902. The Mann family raised £2,307 with their fun filled day and Anna-Maria Walker, whose daughter has JIA, held a charity Gig night in Worcester, bringing together the families love of music and some great local musicians. They raised a fantastic £1,050.

These are just a few of our amazing fundraisers. Our thanks go out to everyone who has taken the time to raise funds for NRAS in 2018. Without your effort, time, support and creativity we would not be able to support all those who rely on our services.

Thank you!

# My Story ~
# Harry Bhamrah

**I was born in Kenya and moved to London when I was 16. I am married with two daughters, one is a GP (which is handy) and the other an orthodontist consultant. I am also blessed with a 10 month old grandson.**

I worked for 30 years in IT and then 10 years in Community Engagement, which involved encouraging communities to engage with providers of local health and social care services. Little did I know then that I would be needing to do the same myself one day.

In September 2016 I was on a walking holiday in Italy and I found that my eyes were very irritable - this was I believe the start of my rheumatoid arthritis with secondary Sjogren's syndrome!

I had to cut short my Italian vacation and upon my return saw my GP immediately. It took endless tests, at various hospitals (Western Eye Hospital, Kings College Hospital for my dry mouth and then Hillingdon Hospital) before I finally got a diagnosis. This was a very distressing time.

The consultant at Hillingdon advised me to contact the NRAS Helpline and thank heavens he did. In the beginning, I used to call them [the helpline] every few days because they were the only people who had time to listen to me and offered me guidance as to what I could do next - they were truly a Godsend! When I was depressed and worried I really don't know what I would have done without their friendly support!

It was a long time before I was prescribed a 'biological' treatment – which thank God means I am now in remission. This enabled me to rekindle my love of travel and earlier this year to take a tour of Israel where I walked on the very long wall of Old Jerusalem!

At the moment my current bugbear is fatigue, so I'm grateful to have just received the "Fatigue Matters" booklet. I find all the NRAS booklets helpful and easy to read. They are good to have around to refer back to and offer great supportive information.

My way of dealing with RA is I try and ignore it and get on with life! I have discovered spirituality and meditation in the form of 'Brahma Kumaris' which has transformed my life, teaching me how to have a good life. My very helpful GP recommended I attend a 'mindfulness for health' course this year which I found really helpful. I also attend an exercise class on Monday mornings, and we have tea and chat afterwards - this is a great start to my week! I believe the key is keeping busy and staying interested in many activities. I also belong to two walking groups and regularly walk in the Chess Valley which keeps me fit.

I also keep involved in the local community activities. Four years ago, I went along to a U3A (University of the Third Age) meeting as I was interested if they had a group near me, they didn't so asked me If I would start one. This is my 4th year as Group Leader of The Visits Group and we have a growing membership of 177. In addition, I have started my second term as secretary of the local Lions club with which I have been involved for 30 years.

I am currently on two WEA (Workers of Educational Association) courses, 'Art Appreciation through visiting London art galleries' and 'History of London through walks' and now feel like a knowledgeable Londoner!

In October 2017, I travelled with an uncle from the Punjab in the north to Kerala in the south of India - it was so hot and humid, just like this summer in the UK. I did find the weather made my RA more tolerable which was a bonus. I am already booked on a grand tour of China including walking the Great Wall of China which I am really looking forward to. One day I hope to visit Chennai (Madras) and Goa but one day at a time.

My advice to anyone newly diagnosed with RA is to keep positive, 'walk on the sunny side of the road', have faith and be grateful for what you have - and use the NRAS Helpline, they have been my lifeline and I consider them my friends on the end of a telephone line. Thank you!

By George Metsios

# Sarcopenia and Rheumatoid Cachexia

Rheumatoid arthritis (RA) is a chronic inflammatory condition with symptoms that have debilitating effects on the daily activities of those diagnosed, including functional disability, pain and fatigue. Importantly, RA is a condition that is characterised by long-term inflammation, which, in turn, can cause a variety of other health complications, such as an increased risk of heart disease, but also a condition that has been termed 'rheumatoid cachexia'.

Cachexia is a wasting syndrome that is seen in advanced cancer and other conditions, and is characterised by loss of weight and particularly, muscle mass, fatigue, weakness and loss of appetite. In contrast, 'rheumatoid cachexia' is different to cachexia. Rheumatoid cachexia, is specific to RA and is a 'syndrome' in which we don't see changes in weight. While retaining their weight, RA patients lose their muscle mass while at the same time, increasing their fat mass.

This significant change in body composition is thought to cause a deterioration in symptoms of RA as well as placing people at further increased risk of heart and vascular diseases. There are no official diagnostic criteria for this condition, however, recent studies in this field reveal loss of muscle in about 50% of RA patients, while the prevalence of sarcopenia (established syndrome characterized by loss of muscle mass and strength) and rheumatoid cachexia in RA, are reported to be about 37% and 29%, respectively. It is important to note, that as we age, we tend to lose more muscle compared to when we are younger, and this is the reason we see that above 65 years of age, studies on RA patients report loss of muscle mass at around 60%.

## What causes low muscle mass in RA?

Research findings suggest that rheumatoid cachexia is caused by a combination of two factors: a) the excessive amount of inflammation, and particularly a small protein called tumour necrosis factor alpha (TNFa); high levels of TNFa are thought to stimulate muscle mass breakdown via specific biological pathways and b) physical inactivity, as avoiding physical activity means that we do not use our muscles as much, and thus our muscles tend to become smaller and weaker. The combination of these factors, but not loss of appetite, are the two main factors contributing to this RA-specific syndrome. Other factors, however, have been implicated in the observed prevalence of low muscle mass in RA, such as smoking as well as high dosages of intramuscular steroids, which are often necessary for the treatment of RA, particularly to alleviate the symptoms of unpredicted flares and/or high disease activity , when other dmard medications are not tolerated or ineffective.

## Ways to reverse muscle mass loss in RA

Researchers have tried to identify interventions that can reverse loss of muscle mass in RA and have mainly focused on three different interventions: anti-TNFa medication, supplementation, and exercise. Although anti-TNFa medication (biological medication that is used to treat RA) blocks the actions of TNFa, and thus it was reasonably hypothesized that it can stop loss of muscle mass breakdown. This has been found not to be the case. Studies have, unfortunately, shown that anti-TNFa medication on its own, cannot stop the enhanced loss of muscle mass that we see in RA.

Studies have also used supplements to increase muscle mass in RA patients and reverse rheumatoid cachexia. Creatine is an organic compound that can stimulate muscle growth, but for some individuals, creatine supplementation can have adverse effects, such as water retention, cramps and upset stomach. Creatine has been found to increase muscle mass in RA. However, the observed increases in muscle mass, do not translate into beneficial effects on symptoms of RA, such as functional ability. **Presently, the safest and most effective intervention to increase muscle mass in RA, is exercise.**

Exercise not only increases muscle mass, but it can also reduce body fat, and thus, this intervention can address both characteristics of rheumatoid cachexia (i.e. it increases muscle mass and it reduces fat mass). Exercise also has, at the same time, many other benefits for people with RA, such as improved functional ability, improved mood as well as reduced fatigue, pain and risk of heart disease. Importantly, increasing exercise results in a reduction in inflammation, a fact that can benefit the overall symptoms of RA significantly. Other studies have shown that exercise can also significantly improve the cardiovascular function of people with RA, reducing their risk of developing heart disease. Moreover, the largest study to date, the RAPIT trial, has also shown that even in people with extensive damage in big and small joints, exercise can slow the progression of the damage caused by RA.

It is also worth noting, that no studies in the literature report any adverse effects for people with RA engaging in exercise (such as increased injury incidence or damage to joints), even if the exercise programme contains high-intensity exercises (such as walking uphill on a treadmill and/or cycling). Of course, specific care has to be taken when people with RA start exercising and physiotherapists and other health professionals involved in advising on exercise should take into account: a) the preferences of the person that wishes to start exercising and b) the functional limitations of the person with RA in order to develop a tailored exercise programme. Moreover, the intensity of the exercise has to gradually go up, starting from low intensities and increasing the intensity in a safe manner, always taking into account the feedback from the person with RA.

In general, it seems that exercise is a very promising intervention for RA to reverse not only loss of muscle mass, but also benefit many RA symptoms.

Important information and tips on how to safely increase your physical activity levels appear in the NRAS "Love Your Heart' interactive online video programme.

**www.nras.org.uk/loveyourheart**

Muscle Mass Loss is seen in ~ 50% of RA patients

Sarcopenia: in ~ 37% of RA

Rheumatoid Cachexia: in ~ 29% of RA

↓

**Causes of low muscle mass in RA**

- ❖ Physical inactivity
- ❖ Inflammation
- ❖ Steroids
- ❖ Smoking

**EXERCISE** is currently the best intervention to reverse low muscle mass in RA

Body scan of a 250lb woman and a 120lb woman. White color indicates fat deposition, while red color indicates muscles

By Michaela Davies

# Occupational Therapy for the hands

Hand therapy has become a specialisation for occupational therapists (OTs); some of you will already be aware of what we do and how we do it: but for those who aren't, our Royal College of Occupational Therapy describes occupational therapy as:

> "….*a science degree-based, health and social care profession, regulated by the Health and Care Professions Council who take a "whole-person approach" to both mental and physical health and wellbeing and enables individuals to achieve their full potential…providing practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them. This support increases people's independence and satisfaction in all aspects of life.*"

As the hand is such a complex part of the body, to become a specialist requires additional post-graduate education and clinical experience: and is the non-surgical management of hand disorders and injuries using physical methods such as exercise, splinting and wound care as a result of trauma, surgery or a rheumatology condition i.e. rheumatoid arthritis. So what does that actually mean when it comes to hand therapy when function is affected by rheumatoid arthritis? What do my team and I do with our patients to "overcome barriers" and how do we provide "practical support"? How do we help you engage in everyday activities when pain and swelling are a common occurrence?

We are a small team of Occupational Therapists with many years of experience

## Who are we and what do we do?

We are a small team of Occupational Therapists with many years of experience between us, working for the Northampton Healthcare Foundation Trust who have recently been categorised as "Outstanding" by our latest CQC inspection this year. Currently we work from three clinics based at St Mary's Hospital in Kettering, Corby Community Hospital and Rectory Road clinic in Rushden and accept referrals from qualified professionals including GPs, consultants, A&E and Allied Health Professionals.

## What aspects of therapy is covered?

Therapy concentrates on three areas:

- Exercises:

A tailor-made program will be put together with you to do at home on a regular basis. This is to maintain your range of movement and grip strength – some patients report an increase in these areas.

- Splinting:

These are either for resting inflamed joints or to provide support when engaging in everyday tasks such as gardening, shopping, hoovering, ironing or making the bed. These may be an off the shelf commercial variety or fabricated and tailor made for you dependent on your level of pain and the position of your fingers.

- Joint Protection, Pacing and planning (JPPP)

This can be covered either in a group discussion or on a one to one with your clinician depending on a person's physical or wellbeing needs. Having gathered and actioned upon each group's feedback, I have tailored the delivery of this session and it is an informal, fun, frank exchange of ideas, strategies and methods that help you to retain an active range of movement and grip strength, and manage your symptoms. Primarily though, it's about discussing and providing practical ideas to address some of the most common problems when faced with poor hand function.

***For example:***

**Food preparation**- including filling and lifting pots and pans with water or food, using kitchen equipment such as knives and graters, opening jars and bottles, turning controls on the oven, carrying plates or hot drinks.

**Washing** - including using small items such as toothbrushes and razors, squeezing tubes and bottles or turning on taps and showers.

**Dressing and undressing** - involving zips, buttons and fastenings, or putting on socks or tights.

**Tips from hobbies and interests** - like gardening, craftwork or even hanging Christmas decorations and baking mince pies!

Patients often bring in gadgets that they have found to be useful, which is great for me as it can be difficult to keep up with this ever-developing area.

Ultimately, we cannot possibly cover everyone's different activities, after all we are all individuals with different ages, interests, cultures and accountabilities, but the aim of the group is to empower you to recognise the common strategies that you can employ to protect your joints. Often patients are so motivated and intent on keeping their range of movement they are actually engaging in methods that are having a detrimental long-term affect. But by adopting the methods discussed in therapy, patients are reassured they are doing the right thing for themselves long term.

## Holistic approach

As OTs, looking at you holistically we also often refer onto other services like Age UK, Community OTs for home assessments, Physiotherapists, Extended Scope Practitioners, Podiatry, Orthotics and signpost on to other services and charities that may help with mental wellbeing. Together with other health professionals you come into contact with, hand therapy is part of that "toolbox" used to help manage your rheumatoid arthritis symptoms. To access hand therapy services please do have a chat with your health professional to request a referral. Ultimately though, after that professional input, "therapy" takes place in the comfort of your home at your leisure. New practices take time to become habitual, but the strategies we recommend soon become instinctive and I encourage patients to find a routine to embrace them, that fits into their daily routines and responsibilities. Even doing a little bit, regularly, helps keep the hands functional.

# NRAS Diwali Dinner & Dance Event

Saturday 10th November 2018 Baylis House, Slough

What a fantastic evening with a very good turnout, over 200 people attended the Diwali event and thoroughly enjoined the authentic Indian meal and entertainment throughout the night…not to mention the endless dancing!

## A huge thank you to the following:

Ritzy Music - Djs on the night, Elite Drummers – Dhol Players, Neha & Neeru – Professional henna artists

Simon Chainey – Fire performer, Baldip Jabble – Live singer (a.k.a Deep's Sangeets) accompanied by Mubarak Ali

Joti Reehal for sharing her story of her experience having RA and how it has affected her and her family over the years

Dr Kanta Kumar for sharing her knowledge from a medical professional point of view and her continuing work with NRAS

## We would also like to thank all who donated raffle prizes for the event;

- Great Rail Journeys
- Michelin star Indian chef Atul Kochhar
- Citizen Watch UK
- RajPall working Jewellers, Leeds
- Royal Windsor Racecourse
- Baggage Outlet, Queensmere Shopping Centre, Slough

**NRAS raised over £9,000 from ticket sales, a raffle and donations on the night!**

**The money raised from this event will help NRAS to continue supporting people living with Rheumatoid Arthritis (RA) in the UK, including the South Asian communities.**

# It's a family affair

**Fundraising is a great way to get involved with helping to raise awareness about RA or JIA and vital funds to support others who benefit from NRAS services. To have a loved one with RA or JIA can have a huge impact on family life. Organising or taking part in fundraising is a great way to come together. Family fundraising is fun and gives a great sense of family achievement. Recently we have had several families that have pooled all their skills and resources to help fund the NRAS services those with RA or JIA and their families rely on.**

## *Meet the Osbornes*

Tina Osborne from Ashbourne in Kent contacted NRAS this past Summer to say she would like to do some fundraising and help raise awareness about JIA. Tina has a young grandson, Jude, who was diagnosed with JIA in 2018. Tina, along with Jude, her friend Lady Jane Clark, Jude's parents Jodie and Daniel and her sister and nephew Carolyn and Rory, has really got behind raising awareness of JIA and raising funds to support JIA-at-NRAS services by engaging with both family and friends.

### *Open Day – Saltwood Castle*

Tina's friend Lady Jane Clark helped raise awareness of JIA and supported JIA-at-NRAS services by donating funds raised at a Charity Open Day at her family home, Saltwood Castle, in September. The Saltwood Castle Charity Open Day was fantastic, with glorious sun and lots of visitors. A fabulous £1,554 was raised for JIA-at-NRAS services from the gate entry on the day.

### *Fun Day – The Alfred Arms, Ashford, Kent*

Tina, Jodi, family and friends held Fun Day at The Alfred Arms in Ashford, Kent as part of #WearPurpleforJIA with an amazing £811 raised.

Tina's sister and nephew, Carolyn and Rory also ran in the Bournemouth Marathon at the beginning of October, raising a further £1936.25 on their Just Giving page.

If you would like to read more about Jude's journey with JIA, we invite you to read his blog called 'I am Jude' or to visit the 'Jude's JIA Journey' Just Giving page **http://iamjude.co.uk/ or www.justgiving.com/fundraising/judesjiajourney**

## *Meet the McCloskeys*

After 40 years of living with Chronic Juvenile Arthritis and the last 27 years of thoroughly enjoying being chief supporter for her husband and son's sporting events, Emma finally found a sport that she could get involved with and turn it into a family achievement at the same time.

Emma took on the 3km cycling element of her family's triathlon team, at the Superhero Tri-Para Triathlon in Windsor in August 2018. She was hoping for a good head start with her husband Paul taking on the swim and then a sprint finish from her son Tom in the run. This event would not have been possible for Emma without the support and commitment from the Conwy Freewheelers Adapted Cycling Club. They assisted Emma with her training at Eirias Park Race Track in North Wales every Sunday afternoon and loaned her a 4-wheel fixed gear bike for the event. They had a great day and all three of them enjoyed taking part in this unique event. Tom and Paul both finished in 5th place for their elements and The McCloskeys were, as a team, 58th out of 106 on their distance. They also raised an amazing £775.00 for support NRAS services.

# Patient Friendship and Support Group

## Ex-patients from the Canadian Red Cross Memorial Hospital in Taplow – please get in touch!

**A new Friendship & Support Group formed by ex-patients of the hospital has been formed and they are holding a reunion in 2019. Lynda Hesketh, Jackie Harvey and Sandra Watson are three of the reunion organisers and here's their message to you if you were a Juvenile Idiopathic Arthritis patient or, as it was referred to back in the day, Stills Disease patient - they'd like to hear from you. We are the Taplowites Friendship and Support Group, all ex-patients of the hospital who have kept in touch over the last 50 years.**

Do you remember Dr Barbara Ansell, Dr Anne Hall, Mrs Bobbie Jarvis, Miss Laughton, Mr Swann, Mrs Bolton, Sister Harris and Sister Lander? Do you remember the long walk from the physio department to the ward, tricycles and wheelchair convoys, the booming voice of Dr Ansell, the feared weekly ward round making your palms sweat?

Although back then we had to endure the distress of the plaster room, the overworked hydro pool hoist, hot wax therapy, prone lying couches, traction and back slabs, we did also have fun using syringes as water pistols, creeping into Sister's office to peak at blood results, playing jokes on unwitting doctors and nurses, getting up to mischief at the Youth Club, crafting wonky wicker baskets, playing 45s in the music room and baking with Mrs Lewendon. We savoured walks in the bluebell woods, treasured day trips, birthday teas, sparklers on Bonfire Night and celebrities visiting. All of which helped the time pass as we waited for, what seemed like endless months, the news you were being "sent home for good!"

Yes, they were times of pain and sadness, but also enduring cherished friendships. As children of Taplow, suffering the same pain and difficulties, we felt like a family. None of us chose to be there; many had to remain at Taplow as patients for years, seeing our family after intervals of many weeks. While, thankfully, treatments have improved tremendously for JIA, looking back we now realise we were the lucky ones to receive Taplow's world-renowned pioneering treatment - many were not so fortunate back then. The advances made at Taplow led to the revolution in treating JIA and as a result there is a far better understanding of JIA, enabling today's treatments to get the condition under control quickly. The Taplow patients of the 50s, 60s, 70s and 80s took part in medical trials, contributed to ground-breaking research and led the way in childhood joint replacement surgery.

We feel that our unique shared experience should not be consigned to the rubble of the derelict long hospital corridors, which is why we formed this friendship group. We currently have over 50 members of our friendship group and are holding a reunion on Saturday 8th June 2019 in The Midlands, and would really love to have more of you out there join us if you can. We mainly keep in touch using our closed Facebook Group - we reminisce about those years spent on Wards 2, 3 and 4, we share old photos, we support each other through our continuing health problems and we swap tips for coping with life's challenges.

Patients, family members and Taplow staff are all welcome at the reunion – the more the merrier.

**Patients may get in touch via our Facebook Group: www.facebook.com/groups/taplowites or Email: taplowites@gmail.com or Telephone Lynda on 07828 571952**

If you were a staff member, please email or ring us for further details. We'd like to think the determined, independent and fighting spirit of Dr Barbara Ansell and her amazing staff lives on in each one of us.

# If you can walk, you can "*Nordic*" walk

**There has been a wealth of research regarding the benefits of exercise for people with RA. Here we look at one unusual yet easy to do activity that might appeal to those who are looking to kickstart their exercise regime – it is called Nordic Walking.**

We talked to Julia Burdge (diagnosed with RA in 2006) who lives in Edinburgh, she took up Nordic Walking in 2017 because she was looking for an activity that would help her become fitter, take her out into the fresh air and participate in a very sociable activity.

Julia says that Nordic Walking; "helps with my RA as it keeps me moving and maintains flexibility in my joints, tones my muscles and is particularly beneficial for my posture. I work as a web designer so I am frequently sitting at my desk. And I'm told that it's also a great cardiovascular exercise. The biggest benefit I receive is remaining flexible which becomes harder as the years progress. I also love going out into the countryside and walking, we are especially lucky in Edinburgh as there are some great walks close by. However, you don't need to take on difficult walks as Nordic Walking works well in any open space."

## Some of the other benefits of Nordic Walking:

- It's a marvellous weight loss activity – as it uses up to 46% more calories than normal walking
- 90% of working muscles are used – upper as well as lower body
- Great for neck and shoulder tension and core strength
- Combines mental health benefits of exercise with those of being outdoors
- Can do it almost anywhere outdoors
- Sociable – go with friends and make new friends

## So what is Nordic Walking?

"Well!" said Julia, "you use a pair of special Nordic Walking poles and you have them angled behind you unlike in the trekking style where they are in front. You push back against the ground and this propels you forward therefore making it easier to walk. It also pushes your shoulders back and you walk with a much better posture – more upright!"

## How did you find out about Nordic Walking?

"A friend of mine has been doing it for a few years and tried to persuade me to join her. At first I was reluctant to get involved as I thought it might be too difficult. But she promised me that it wasn't too difficult to learn and do. She told me that its horses for courses – you work as hard or as easy as you like just like with ordinary walking. My friend learned with a qualified Nordic Walking instructor who runs course for beginners and also works with people with chronic conditions. I started with a free taster session so I could try it out before deciding whether to learn properly. I live in Edinburgh but most towns and cities will have people running courses - you would just have to google 'Nordic Walking' followed by the name of your city/area."

## Whereabouts do you Nordic Walk?

"You can go anywhere – in parks, on the beach, along woodland paths, in the hills – anywhere where people walk normally. Trevor Jones, the instructor, organises regular weekly walks and ensures that there is a good variety of walks from easy, flat, short walks to medium level slightly longer ones through to even harder walks for those who like a challenge. There are usually up to a dozen people on the walks so it's a good chance to meet new people and socialise whilst getting some exercise".

## Is it costly to do and do you need any equipment?

"No, you pay for the initial training and to join in organised walks but it's worth it because you have someone who is skilled in how to do it properly and guiding the walk. I don't have any specialist equipment – just a good pair of walking shoes – and because it's Scotland - wind and waterproofs! I haven't yet bought my own poles so I still use the ones provided by Trevor. But apparently you can get a pair of poles ranging from £30 - £80."

## What advice would you give to those thinking of trying it?

"Give it a go! You've nothing to lose by trying out and hopefully if you continue you'll learn a new activity very quickly, get fitter, lose weight, increase your strength, meet new friends and have some fun. What is stopping you?"

For more information see the link to the NHS website's Nordic Walking page:

**www.nhs.uk/live-well/exercise/nordic-walking-health-benefits/**

# Dear Helpline

## Should I have the flu vaccine?

**The flu vaccine is generally recommended to people with RA, who may be more susceptible to flu and may experience it more severely than people without the condition. We often get asked whether people with RA are 'entitled' to a free flu vaccine, and unfortunately, there isn't a clear-cut answer to this.**

On the face of it, as the guidance has always suggested that people who are immunosuppressed should have the flu vaccine, it looked as though this would apply to most RA patients, as the medications generally prescribed for this condition affect the immune system. However, the decision to give the flu vaccine has depended on the definition of level of immunosuppression, and this has been down to interpretation.

The Department of Health has previously suggested that, because levels of immunosuppression among RA patients will vary depending on the drugs and doses they are on, 'a clinical judgement from those responsible for the patient's care' is needed. Unfortunately, this has sometimes led to some GPs offering a free flu vaccine to RA patients where others wouldn't.

The guidance for the flu vaccine this year has altered slightly, however. The government website (.gov) states that adults 'with a long-term health condition' are now eligible for the regular flu vaccine. Once again, on the face of it, this would mean that people with RA would be included. However, on the NHS Choices website, they list some of the conditions that would be covered (sadly, RA is not one of them), this time describing them as 'serious long-term health conditions'. Their list is not definitive, so RA could still be considered, but they state that 'it's always an issue of clinical judgement', which means that it is still open to different interpretations by different clinicians. This makes sense, as RA is a variable condition and the medications used to treat it vary in strength and dose. However, it does mean that the same patient could be told by one GP that they are eligible and could go to another practice and be told that they aren't. If you are not considered eligible in your area for a free flu vaccine, you can look at having one done privately, for example through your local pharmacy.

Further complicating this, if you are over 65 (or over 75 in Scotland), you will now be given a different flu vaccine. Recent news reports had concerned some people with RA, who contacted us, worried that the vaccine would boost their immune system and might therefore interfere with their immunosuppressant drugs. Our chief medical advisor has clarified this, confirming that "the new vaccine will not adversely affect their RA medication but only provide enhanced likelihood of immunity against influenza infection" as the new flu vaccine "boosts immunity to flu, rather than more generally boosting the immune system".

If you are unsure whether you should have a flu vaccine, ask your rheumatology team for further advice.

## NRAS Rheumatoid Arthritis Awareness Week (RAAW)

**17th -23rd June 2019**

With RAAW, our aim is to educate and inform the public about exactly what rheumatoid arthritis (RA) is and how it impacts those living with the condition. We also raise awareness of the importance of an early diagnosis. Throughout the week we share personal stories, raise awareness, challenge misconceptions, and fundraise to support those living with RA.

To take part RAAW and receive a fundraising pack for 2019 please contact the fundraising team using the contact details below.

RAAW Tea Party

RAAW BBQ

RAAW Quiz Night

# Dear Helpline

## I notice that NRAS now cover JIA (juvenile idiopathic arthritis) as well as RA (rheumatoid arthritis). Is JIA the childhood form of RA?

**The word 'arthritis' means 'inflammation of the joints', so all types of arthritis will have symptoms in common. In JIA, because there are a number of different types of JIA which can vary greatly from one to another, the ways in which they also vary from RA are equally varied and numerous. However, there is one form of JIA which is indeed the junior form of RA. This usually affects girls around secondary school age, involves several smaller joints, symmetrically and the blood tests show the same results as adults with RA. Juvenile idiopathic arthritis (JIA) is an umbrella term for 7 types of arthritis that may occur in children.**

Several changes in the terminology of juvenile arthritis have occurred in the last 20 years. The older terms juvenile rheumatoid arthritis (JRA, used commonly in the United States) and juvenile chronic arthritis (JCA, preferred in Europe) were replaced by the term juvenile idiopathic arthritis (JIA) at meetings of the International League of Associations for Rheumatology (ILAR) in the late 1990s. JIA incorporates all of what was called JRA in the past and also includes all other forms of "idiopathic" arthritis in childhood. It is important to know that since this time JIA has been the recommended terminology by the world-wide paediatric rheumatology community. Thus, clinicians who diagnose and treat children with arthritis should at least be familiar with the JIA terminology, which is broadly used in textbooks and journal articles. Within the last 20 years it has been quite common to find that a young person with JIA has been re-classified as having RA after the age of 16. This practice has been primarily to do with the fact that NICE guidance did not cover/permit the use of biologic therapies in adults with JIA. If diagnosed with JIA as a child, and you take the disease into adulthood, it doesn't change into RA at age 16 or 18, it remains JIA, but becomes 'adult' JIA and there are distinct differences and potential complexities between adult JIA and RA.

To arrive at a diagnosis of JIA, many of the same investigations would be carried out as in RA, including testing for inflammatory markers in the blood (ESR and CRP), scans such as X-ray or ultrasound and examination of the joints/discussion of symptoms and any possible family history etc. JIA can occur at any age in childhood and can vary in severity in the number and type of joints that are affected. Some children's arthritis will go into remission before the child reaches adulthood, whilst others will continue with it into adulthood. It's also possible that a child gaining remission, could find that the disease flares again, sometimes many years later in adulthood. Symptoms and possible complications will also vary. One such complication is uveitis, inflammation within the eye(s), which occurs in between 10-30% of children with JIA and often carries no symptoms in the early stages. Eye examinations are therefore very important for children with JIA.

Like RA, JIA can often be mistaken for other conditions. In the case of JIA, 'growing pains' or injuries might be suspected or a child might not be believed at all when they say they are too tired or in too much pain to go to school or do a particular activity. Diagnosis can be even harder in younger children who might not have the speech capabilities to articulate their symptoms to their parent or a healthcare professional. Parents, of course, will often just have a sense that their little one is not behaving normally but may not understand why. A GP examining the child may be looking for subtle signs, such as 'guarding' which means the child finding ways to avoid using a specific joint when they walk, stand up or play. Swollen joints may not always be as visible on a young child with their 'baby fat', but there can be other signs of swelling, such as heat and a spongy feeling on examination. The immune system's response in the body, which causes this inflammation, increases blood flow to the area. This can lead to physical changes in a growing child's skeleton and is the reason why speedy referral to a paediatric rheumatologist is essential.

Not all the medications given in RA are approved for use in JIA, but many are. DMARDs (disease modifying drugs) such as methotrexate and biologic DMARDs will therefore, be common to both conditions, as are steroids, anti-inflammatories and painkillers, although the doses and the circumstances in which they are given will vary. Whilst it would not be true to say that most forms of JIA are a juvenile form of RA, adult patients with JIA will often find they have a lot in common in terms of symptoms and treatment, to adults with RA. Therefore, even before we set up our JIA service, which primarily focuses on parents of children and on young people with the condition, we have had contact with JIA patients, particularly the adults, who benefit from our many resources and services including attending RA groups and discussing life with JIA on our RA forums.

# Depression and anxiety

## In early RA, they may be linked to higher levels of disease activity

**A study, examining 848 patients with RA in Scotland has shown that rates of anxiety and depression seemed to match levels of disease activity in the first year of diagnosis.**

It is not surprising, of course, that many patients experience depression and anxiety after being diagnosed with RA. These symptoms can be linked to the diagnosis in a number of ways. Coming to terms with having a long-term condition and looking at how this will affect the person's future can naturally cause both depression and anxiety. However, there is also a potential link to other symptoms, such as pain, fatigue and inflammation.

Levels of depression and anxiety were seen to drop significantly for patients one year after diagnosis. Depression dropped from 12% to 8%, while anxiety dropped from 19% to 13%. The blood test for C-reactive protein (CRP), which measures levels of inflammation in the blood, was seen to be higher in patients reporting higher levels of depression, which adds to the view that patients with higher levels of inflammation also experience greater levels of depression.

# New gene identified

## Linked to disease severity in RA

**Researchers at the Icahn School of Medicine at Mount Sinai, Egypt have discovered a new gene which they believe is linked to disease severity in rheumatoid arthritis.**

The gene was discovered in a region of chromosomes containing 41 genes and is called HIP1, a gene that had not previously been associated with rheumatoid arthritis or levels of inflammation. In examining the genes within this region, the researchers found a mutation in the HIP1 gene, and further analysis showed its link with levels of inflammation.

These findings are important for the future of RA, both in diagnosis and in treatment. In diagnosis, it may be possible for a blood test to be developed, for HIP1, which could indicate the likely severity of rheumatoid arthritis. In treatment, this gene gives a new potential target for pharmaceutical companies to look at.

Of course, it would take a long time before any such blood tests or treatments could be developed and tested ready for use, but this discovery could be another important milestone in our understanding of and better ability to treat and diagnose RA.

# Rheumatoid arthritis patients no longer face higher mortality rates

The word 'arthritis' means 'inflammation of the joints'. In the case of RA this is due to the immune system attacking those joints. However, rheumatoid arthritis is not just a disease of the joints. It can cause problems in many areas outside of the joints, including the heart, lungs and eyes. Complications from RA, especially when it is poorly controlled, have previously been associated with an overall increased mortality rate for people with the condition, with the biggest risk coming from heart disease (it should be pointed out that these mortality rates are still low, but just increased compared to the general population).

A study at the University of British Columbia, however, now suggests that the previous higher level of mortality in rheumatoid arthritis no longer exists. The study looked at almost 25,000 patients diagnosed between 1996 and 2000. Whilst there was a statistically significant increase in mortality levels for those diagnosed at the earlier end of this patient group, it was found that after 2000, there was no difference in mortality levels for RA patients, compared to the general population.

The study did not investigate the reasons for this reduction, but it is thought that new treatments (in particular since the biologic medications were introduced), advances in RA research and earlier detection and subsequent diagnosis of RA are likely to be factors.

This is obviously very good news for the future of people being diagnosed with RA, but of course, the increased mortality rates for those diagnosed prior to 2000 could be a worry for some. It is important to know that these are only general statistics and will not necessarily have any affect on you. However, anyone diagnosed with RA should be aware of the increased overall risks of heart disease in people with RA. For more about this and how you can keep your heart healthy, take a look at our interactive online video programme, 'Love your Heart'. **www.nras.org.uk/loveyourheart**

# Passive smoking in childhood can increase RA risk later in life

It has long been known that smoking is bad for people with RA. It can make people more susceptible to getting the condition and, if they continue smoking after diagnosis, can make medication less effective and disease symptoms worse. The risk of cardiovascular disease is increased in those with RA if they continue to smoke, making later complications of stroke and heart disease more likely.

Now, a study in France, which analysed 321 cases of RA, has discovered that patients who had had exposure to passive smoking during childhood were more likely to develop the condition, even if they had never actively smoked themselves. Perhaps more surprisingly, they also discovered that childhood exposure to passive smoking was associated with a marginally higher risk for RA than adult active smoking.

The study specifically looked at women and started in 1990. Those taking part completed questionnaires every few years, the results of which were then analysed by the researchers.

# Why you could be asked to switch to a biosimilar medicine

**The NHS has introduced many life-saving innovations in its 70-year history. Antibiotics, medicines to control diabetes and heart disease, and specialist treatments for cancer are some of many revolutionary advances.**

## Biological medicines

One of the most recent innovations has been the development of biological medicines. They have been available since 2000 and are becoming much more widespread. These medicines treat conditions which were previously very difficult to treat, such as certain cancers, rheumatoid arthritis, Crohn's disease and psoriasis.

Until biologicals were developed, almost all medicines were made by mixing chemicals together. Biological medicines are grown from living organisms which means living cells are used to make large, complex, molecule-like proteins and other substances produced by the body, which can then be used as medicines. The complex processes needed to make biological medicines often involve the latest DNA technology and can be very expensive.

Biologic medicines are already making a difference to thousands of people's lives including Ailsa, NRAS CEO, who says; "Without access to biologic drugs for the last 18 years, I would be in a wheelchair and unable to work".

## Biosimilar medicines

Now that the patents are beginning to expire for the original biological medicines, another generation of biological medicines is becoming available enabling valuable savings to be made for the NHS.

It is not possible to make an exact copy of an originator biological medicine; because they are made from living cells so there will always be some natural and slight differences between them. Therefore, the new versions are known as biosimilars, which means they are highly similar, and as safe and effective as the originals, but they are not an identical copy.

## Patient safety and biosimilars

Biosimilars are thoroughly tested and analysed in the laboratory and in clinical trials to ensure they are as safe and effective as the originator biological medicine. They have also gained the regulatory approvals from, and been licenced by, the authorities in the UK and Europe in the same way as all medicines.

Where the National Institute for Health and Care Excellence (NICE) has recommended the originator biological medicine in its guidance, they have stated that the same guidance will normally apply to a biosimilar version of that medicine.

## Are biosimilars safe?

Biosimilars are only available on the NHS once the European Medicines Agency has looked at the evidence and decided that they are just as safe and effective as the original medicine. Steve Brown, regional pharmacist for NHS England and NHS Improvement, is confident that biosimilars are safe:

"There have been a number of research studies looking at how well biosimilars work and their safety," he says. "There appear to be no significant differences in efficacy between the originator biologicals and the new biosimilars. Where patients switch to a biosimilar we expect them to remain stable, as if they had stayed on the originator biological medicine."

NRAS has been working in the field of biosimilars to provide patient information and support since 2014 and are familiar with the evidence to date which reinforces the fact that they are as safe and effective as the reference products. The vast majority of patients have been switched successfully and we believe are happy to see savings being made which can be reinvested in improving patient care and services. Relatively few patients have been switched back to the originator product.

## What next with biological medicines?

Biosimilar medicines represent very good value for the NHS since they are often much less costly than the originator medicine. Therefore the NHS is asking clinical teams, in discussion with individual patients, to ensure they are using the best value biological medicines – whether that is the originator biological medicine or a new biosimilar medicine – so that the money saved can be reinvested in other medicines and treatments for patients. In 2017-18, the NHS saved an estimated £210 million with this approach.

## What does this mean for me?

Any switching to a new medicine should involve a consultation between you and your clinical team and should take into account your needs, preferences and values as well as all the available clinical evidence. This is known as 'shared decision making' and will be vital if the best value, clinically effective medicines are to be used. In discussion with your clinical team you can agree on the most appropriate medicine. In some cases, it may continue to be the originator biological medicine.

## Adalimumab (Humira®) biosimilars

Since its patent expired on 16 October 2018, the NHS is expecting four biosimilar versions of Humira® (adalimumab) to become available from January 2019. Adalimumab is used to treat immune-mediated inflammatory conditions such as:

- Rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and juvenile idiopathic arthritis
- Inflammatory bowel disease
- Psoriasis
- Uveitis.

Adalimumab costs the NHS over £400 million annually and is the single medicine on which we spend most in hospitals. If patients with the support of their clinical teams take up the best value biological versions of adalimumab, then the NHS has the potential to make substantial savings, money that can be reinvested into helping other people access much needed treatments.

> Today, more than ever with stretched resources, it's vital that we use NHS resources wisely and carefully and so we should be using best value biologics, wherever possible. When switching patients from an originator biologic to its biosimilar, it's important that commissioners and health professionals proactively adopt the principles of shared decision making.
>
> Ailsa, NRAS CEO

To find out more about what the changes mean for you, you can download a FAQ document from **https:www.sps.nhs.uk/wp-content/uploads/2018/08/Adalimumab-Patient-FAQ-Final-9-August3.pdf**

If you have any questions or concerns around biologics or biosimilars you can call our helpline on **0800 2987650** or email **helpline@nras.org.uk**. There is also a wealth of information including an in-depth interview with Prof. Peter Taylor on the topic. **www.nras.org.uk/biosimilars**

# Big Data

## Real World Evidence – Population Health Management

**You may recall back in our Spring Members' magazine issue we ran an article entitled "use MY data" so you're already familiar with how data can play an important role in transforming the future of health care. If you'd like to read that article again it can be found at: www.nras.org.uk/get-involved-research**

designed by freepik

You may have heard of these terms in recent times and have wondered what they mean in relation to use of your own personal health data. Or, you may not be aware of the debate and discussion going on in the health industry about use of data. Either way, we at NRAS would like to explain why we think it's important to embrace technology and the opportunities sharing data and real-world evidence offer in order to improve outcomes, save money and transform health and social care. The potential of cutting-edge technologies to support preventative, predictive and personalised care is huge.

## Population Health Management

### What is it?

Population Health Management is the aggregation of patient data across multiple health information technology resources, the analysis of that data into a single, actionable patient record, and the actions through which care providers can improve both clinical and financial outcomes.

In other words, when you think about how your data is currently held and used by health and social care systems, there is information about you, your health and social care needs and use which sits in different computer systems in different organisations and these systems don't talk to each other, so your GP can't necessarily see or access the information about you which your hospital team may have on their systems, or your social care record or information about past procedures which may sit in another hospital where you used to attend before you moved to your current address. It's entirely possible for these systems to talk to each other but for reasons which lag well behind the times, in most places, they don't. This means that someone who is engaged in your health care at the moment, doesn't necessarily have access to the whole picture about your health and social care needs. The state of online services, basic IT and clinical tools in health and care is far behind where it needs to be. Despite much good practice and some pockets of excellence, for many people – patients, service users, carers and staff – we still need to sort the basics.

Technology systems used daily across hospitals, GP surgeries, care homes, pharmacies and community care facilities as stated above, don't talk to each other, fail frequently and do not follow modern cyber security practices. As a result, some people are getting suboptimal care, staff are frustrated and money could be saved and released for the front line.

Just being able to make the best use of mainstream products and services would transform health and social care in this country.

## Big Health Data

### What is it?

Big Data in healthcare refers to the abundant health data amassed from numerous sources including electronic health records (EHRs), medical imaging, genomic sequencing, payor records, pharmaceutical research, wearables (FitBit etc.), and medical devices, to name a few.

Big Data has been attributed as having "transformative potential" in healthcare systems, with benefits across the entire pathway of care delivery for all stakeholders, but the opportunities this affords will only materialise when healthcare systems move beyond the mere collection of large amounts of data. Linkage of previously separated data sets and their analysis using appropriate Big Data analytics offer new ways to accelerate research and to identify the right treatment for individual patients (personalised medicine). Access to large data sets gives a more comprehensive picture of patients, allows patient-related outcomes to be measured more accurately, and supports decision-makers in shaping healthcare systems.

However, the notion of Big Data goes beyond the characteristics of data itself and includes how data are used, as is captured in the following definition from a recent European Commission funded study:

"Big Data in Health refers to largely routinely or automatically collected datasets, which are electronically captured and stored. It is reusable in the sense of multipurpose data and compromises the fusion and connection of existing databases for the purpose of improving health and health system performance. It does not refer to data collected for a specific study." (European Commission, Study on Big Data in Public Health, Telemedicine and Healthcare. 2016.)

## Real World Evidence

### What is it?

Real world evidence (RWE) in medicine means evidence obtained from real world data (RWD), which are observational data obtained outside the context of randomized controlled trials (RCTs) and generated during routine clinical practice or gathered through other means such as the kind of data which is obtained by patient organisations relating to burden of disease, quality of life and other psycho-social aspects of living with a chronic disease.

Real World Evidence comes into play when clinical trials cannot really account for the entire patient population of a particular disease. Patients suffering from comorbidities or belonging to a distant geographic region or age limit who did not participate in any clinical trial may not respond to the treatment in question as expected. RWE provides answers to these problems and can also analyse effects of drugs and other treatments over a longer period. Pharmaceutical companies and Health Insurance Payers study RWE to understand patient pathways to deliver appropriate care for appropriate individuals and to minimise their own financial risk by investing on drugs that work for patients.

## So how is NRAS proposing to use data?

For all the above reasons and because, going forward, we want to focus on providing better and new resources which match the real needs of individuals with RA and JIA, we shall be seeking funded opportunities with trusted technology partners to tailor our services and resources to people in a more personalised way which matches expressed need.

We shall be holding focus groups to explore the opportunities offered by supporting use of real-world evidence for people with RA and Adult JIA in January, and in January. If you would like to participate and live within reach of Maidenhead or London, please get in touch - (iain@nras.org.uk)

We firmly believe that big data and use of real-world evidence will increase the development of personalised care, improving treatment and outcomes for the RA and JIA community and others with long term conditions.

# FUNDRAISING THANK YOU

## Carillion Communications

**The fantastic Carillion Communications, based in Maidenhead, have continued to support NRAS in 2018. The team there are full of ideas and enthusiasm.**

Amongst some of the many fundraising events they have organised this year - were a Charity Car Wash on one of the hottest days in July when an amazing £350 was raised and a BBQ at their offices in August where some very delicious sausages and burgers were served and more money raised. Two members of their staff called Tom (Team Tom-Tom!) have also supported NRAS by taking part in the Royal Parks Marathon in London on 14th October raising £610.

Their Halloween events included guess the weight of a very large pumpkin (which they bought into our offices for us to have a guess!). They also sold home made cakes and sweets raising a whopping £450!

Human

How can I pass on something wonderful?

NRAS plays a vital role in helping those living with RA and JIA to take control of their disease and have a voice. Each year thousands of people rely on NRAS for information and support.

Leaving a gift in your Will to NRAS can make a lasting difference, and these gifts are a vital part of our income. Gifts in Wills enable NRAS to continue to grow and develop services in meaningful ways which benefit those who need our support for years to come.

If you have benefited from the services NRAS provides and you would like to support others living with RA and JIA, please consider leaving a gift in your Will to NRAS. This gift will have a positive impact on the lives and future of others living with RA and JIA.

To talk to someone about leaving a gift to NRAS in your Will or to find out more about the difference such a gift can make please contact Cara Brandi, Head of Fundraising by email to **cara@nras.org.uk** or by phone on **01628 823524**.

**REMEMBER A CHARITY IN YOUR WILL**
**Help the work live on...**

# Launch of Emotional Health and Well-being Matters

**The beginning of November saw NRAS launch its new report, 'Emotional Health and Well-being Matters'. Guests included NRAS Members and volunteers, consultants and healthcare professionals, professional bodies, industry representatives and charity partners.**

The event began with the Shadow Minister for Mental Health and Social Care, Barbara Keeley MP, discussing the importance of the report and how the Government must properly support and fund services for people with musculoskeletal conditions. Dr Hayley McBain, the lead author of the report from City University, discussed the methodology behind the survey and the importance of using validated questionnaires, which enabled City University and NRAS to compare data collected from this survey to other national data sets. The British Society for Rheumatology (BSR), which is the UK's leading specialist medical society for rheumatology and musculoskeletal professionals, also attended the event and Dr Elizabeth Price, President of the BSR, spoke about the importance of health professionals ensuring that they have conversations with people about their mental health and the types of psychological interventions that can be delivered by health professionals when upskilled, such as cognitive behavioural therapy (CBT).

A number of MPs attended the event, following almost 300 emails being sent to the MP in their locality from NRAS Members. Some of these MPs have pledged to help the charity and their constituents with RA and JIA in a number of ways, which is great for NRAS to raise awareness and push for policy change. A big thank you to all who emailed their MPs asking them to attend the event!

The campaign to implement the recommendations from the report will now begin. NRAS relies on volunteers to help influence decision-makers across the country, and if you would like to help, please get in touch! **campaigns@nras.org.uk**.

# Rheum for You

**We were so delighted just how far people were prepared to travel to join us in Cardiff for our last Rheum for You event of the year. Braving a very cold snap, we had attendees from as far as Bristol, Gloucester and beyond.**

Clare Jacklin, Director of External Affairs opened the event with an update on what NRAS have been up to in the last few months; our new resources including publications, apps, videos and our very popular webinars. She also presented on key news such as the updated NICE guidelines, leading the way on biosimilars information, and our major landmark survey on emotional health and wellbeing as mentioned in the article above. The keynote speaker was Dr Maddy Piper, recently retired Consultant Rheumatologist from Ysbyty Ystrad Fawr Hospital. She presented 'An update on the latest treatments for rheumatoid arthritis'. It was a very frank and honest account of rheumatology services through the last thirty years bringing us right up to date with the advances in treatment and medication. One of our Welsh Ambassadors, Carl Harrison then spoke about how the Ambassador network makes an impact in Wales to support and campaign for those living with RA and JIA. Sarah Collins, Psychotherapeutic Counsellor ended the day with a presentation on: 'Mental Health – who cares?' Sarah has been living with RA for many years and spoke about the struggles of developing the condition after the birth of her first child. It was a hard hitting and emotional account that some almost forty years later still saw her overcome with emotion at some points when recounting her experiences.

Attendees appreciated the opportunity to meet others with RA, re-connect with old friends and make some new friends. Zoë, an attendee posted on HealthUnlocked about the event; "This afternoon I went to an event called "Rheum for You" organised by NRAS, with speakers Dr Maddie Piper and Sarah Collins. The afternoon was so well run and the speakers pitched their talks perfectly. The atmosphere was warm and welcoming."

We are busy planning for 2019 and the next Rheum for You conference is taking place in Cheadle, near Manchester on Saturday 23rd March 2019. To register your interest, please email **groups@nras.org.uk.**

# A successful first year of webinars!

Exceptional with the content and delivery

**2018 saw a new service launch at NRAS, informative webinars with expert speakers: 'RA Matters Online'. In this year we have hosted four webinars and also co-hosted a webinar with pharmaceutical company, Lilly UK. Here's a look at the topics we've covered during 2018:**

## May: 'Current questions and future directions - an update on research in RA' By Dr Catherine Swales

This webinar was presented by Dr Catherine Swales FRCP PhD, Senior Fellow and Honorary Consultant in Rheumatology, NIHR Clinical Trials Unit. Dr Swales has a wealth of experience and knowledge of clinical studies and research at the University of Oxford Medical School, and talked through current trials taking place and what may be coming in the future.

## June: 'How to get the best out of your rheumatology service' by Dr James Galloway

Dr James Galloway, clinical lecturer at King's College London and an honorary consultant in rheumatology at King's College Hospital was the expert speaker for this webinar. Dr Galloway covered the subjects – 'Shared Decision Making: making the most out of your rheumatologist' and statistics from the 'National Early Arthritis Audit: measuring quality in the NHS'.

## September: 'The importance of physical activity in rheumatoid arthritis' by Prof. George Metsios

The expert speaker for this webinar was Professor George Metsios, Professor in Clinical Exercise Physiology, Faculty of Health Education and Wellbeing at the University of Wolverhampton. His work evolves around physical activity, exercise and health and specifically how physical activity and/or exercise can be used to improve disease symptoms in patients with different chronic diseases, such as rheumatoid arthritis. He spoke about research studies into physical activity in RA and what those living with the condition could do to help themselves.

## October: 'RA Matters to Me'

For this webinar, Lilly UK and NRAS hosted a panel discussion around the subject 'RA Matters to Me'. Lilly and NRAS collaborated on the RA Matters campaign, seeking to improve the understanding of RA to support people with RA to live the best lives possible. As part of the campaign, this webinar showcased a new film highlighting NRAS volunteer Rachael's personal experience of RA. The panellists then discussed some of the themes in the film, including the impact of RA on work, relationships and aspirations. The panel members on this webinar were: Cathy Boys, a Senior Rheumatology Specialist Practitioner at Basingstoke and North Hampshire Hospital, Ailsa Bosworth, Chief Executive and founder of NRAS, who has lived with RA for over 30 years and Rachael Till, a Science Teacher who was diagnosed with RA at 22.

## November: 'An update on the latest medicines for rheumatoid arthritis' by Prof. Peter Taylor

The final webinar of the year was presented by Professor Peter Taylor, Norman Collisson Professor of Musculoskeletal Sciences, at the Kennedy Institute of Rheumatology in Oxford. Professor Taylor has specialist clinical interests in rheumatoid arthritis and early inflammatory arthritis. He has over 20 years' experience in clinical trial design and international leadership in studies of biologic and small molecular therapies in RA. Professor Taylor spoke in depth about the new biologic and small molecule medications for RA, how they work to treat the condition and statistics on success rates of these medicines so far.

In total, with these webinars, we have reached just over 1,000 people! The recordings of the webinars have in total been watched over 700 times and that number continues to grow. We are thrilled with how well the first year of webinars has gone and we will be hard at work planning an equally excellent webinar programme for 2019.

If you would like to watch any of the webinar recordings you can find the links on our website at **www.nras.org.uk/webinar.**

NRAS would like to extend a huge thank you to each of the expert speakers and panellists that took part in our webinar programme this year, we couldn't have done it without you! Here's just a small number of the many lovely comments we have received from those who have watched the webinars so far:

*'Can you ask Prof. Metsios if he wants a new patient?! His attitude to exercise and the 'you know your body best' approach is inspiring.'*

*Thank you for the recording of the webinar from Professor Peter Taylor. I was sorry I was unable to log on live, but the recording was excellent. So much information discussed in a very understandable way. Thank you.*

*'How can I get a Rheumatologist like you Dr Swales? You sound great for patients and very good at explaining.'*

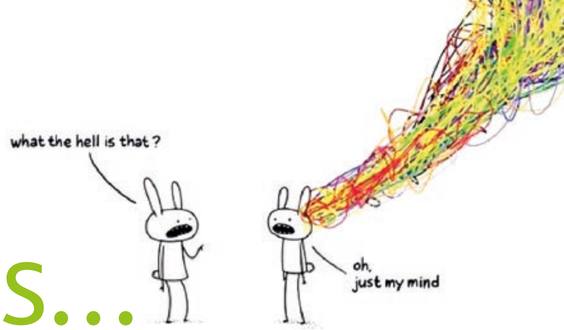
*'I write to thank all concerned and most especially Professor Taylor for this enormously impressive and helpful presentation'.*

*'Dr Galloway was exceptional with the content and delivery; such honesty and reassurance from a specialist consultant!'*

*'I have really enjoyed this webinar it has been extremely interesting, thank you Dr Swales.'*

*'Thank you for giving me the opportunity to take part in this webinar, one could not help but to warm to Dr Galloway for his obvious kindness and his apparent genuine concern for his patients'.*

*'I just saw the exercise webinar recording with Professor Metsios, it was very good and boy did it prompt me to get up. I was there on my wobble board as well as walking machine! Can't wait for the next one!'*



# Mindfulness...

## ...and Progressive Relaxation with your child

**Everyone is talking about it and the benefits can include focussed attention, creativity, immune function, compassion and resilience. So why wouldn't you want to practise mindfulness with your little bundle of joy!**

Practise makes perfect and although it can seem quite straightforward, finding the time and quiet space can be a bit of a challenge sometimes. However, there are countless ways through music and stories you can teach mindfulness. Search the internet and source a good resource that works for you; but after all my research into this topic, practising mindfulness yourself is a great start. Not only will it help you understand your triggers and your habits, it also role models this healthy behaviour and you will find it much easier for your little one to engage in it.Here are some ideas I came across for you to practise with your child.

**Mindful Breathing** – sit or lie down, close your eyes and focus on each breath as it comes in and goes out. You can focus on your chest going up and down or on the sensation through your nostrils.

**Breath Star** – Spread out the fingers on one hand and trace around that hand with the index finger of your other hand. Breathe in as you trace up a finger and out as you trace down.

**Belly Buddy** – Lie down with a soft toy or cushion on your belly. Just focus on the weight on your belly as you breathe in and out and notice how the object moves.

**Back to Back** – Sit back to back with a friend or family member. Repeat the Mindful Breathing exercise together but notice your partner's breathing too. Are you 'in sync'?

**Mindful Eating** – Next time you eat an apple or a snack, take your time. Breathe slowly and focus on the smell of the snack, the texture and the taste. Which parts of your body are you using to chew and swallow each mouthful?

Most people experience stress and anxiety physiologically as tension in their body. It might be that you clench your jaw more or suffer with back ache or a sore neck. Your sleep, pain levels and immune function can also be affected. Progressive relaxation takes a lot of practice. Your child first tightens a muscle group for about 7 seconds, then relaxes it for about 4/5 seconds. – muscle groups include muscles in the face, shoulders, neck, arms, legs, back, hands and feet. You can help coach your child to breathe deeply and relax during this technique. Most people do this lying down in a comfy, relaxing place. This technique is sometimes recommended for children and young people who have a fear of needles and injections.

# The JIA-at-NRAS team start to plan for 2019

**October and November are always a busy couple of months as we start to pull together our plans for next year. This includes when and where we will host our family fun days, bush craft days and what JIA resources we want to create.**

Throughout the year we hold several events to bring families and healthcare professionals together and following these we always receive numerous requests from other paediatric rheumatology departments around the country. My wish list for 2019 includes fun days across the UK from Yorkshire to Exeter and an additional Teen bush craft day. The bush-craft days are so much fun and provide an excellent opportunity to get teens together, have some good old-fashioned outdoor fun, learn some new skills and make new friends.

This year we produced two short animated films for parents/carers and young people. The first covered the basics of when a young person moves from paediatric to adult care. The second was all about the importance of problem solving and how much easier it is to navigate life's challenges when you can problem solve effectively. 2019 will see two new animations created, which we hope will cover mental health in young people and JIA and fatigue.

Our two JIA booklets produced in 2016 are as popular as ever with both healthcare professionals and parents/carers. We will be reviewing these in 2019, making sure they are updated with any new information. It would be wonderful if we could produce a book for younger children, explaining in age appropriate language and pictures what JIA is; another project on my wish list for next year, watch this space!

Ane x

# What is resilience?

## And why is it an essential life skill?

**Resilience is the ability to cope with challenging situations. Resilience is something that is learnt, usually from our parents or carers; it grows with us and it enables us to "bounce back" from upset and challenging situations.**

### What do children and young people find challenging?

- Sudden changes
- Serious challenges
- Feelings of isolation
- Friendship difficulties
- Stressful situations

Teaching someone how to be more resilient can be incorporated into everyday life. Structure and routine are important, especially in younger children because fear of the unknown, whether it's a new vegetable on their dinner plate, starting a new school or being told they have a long-term condition, can be a scary prospect. Structure and routine help children and young people to learn self-discipline, and this can result in a child/young person being able to cope better. In addition, routine provides security. Change is handled best if it's expected and predictable; family routines help children and young people grasp how to handle life. Change is not always expected, but the foundations laid down with structure and routine will help them to rise above it.

### Making friends

Building and maintaining relationships makes you more resilient. Friends generally make you happier, they can inspire you to reach goals and they can help you make more friends. People who have the ability to empathise generally have good friendships; this is because they are genuinely able to understand the needs of others.

Encourage your child to listen and understand what it's like to be in someone else's shoes and think about what they have in common with that person. Expressing an interest in what someone else is saying and not jumping to conclusions are both skills that encourage empathy. If your child is shy you can practise with them in a fun way how to say hello and tell others their name. Music and dance groups are great at bringing little ones out of their shell.

When friendships go wrong, and children and young people fall out, it's important not to try to rescue them if you can avoid it; you will help them far better by observing, listening and coaching. It's so painful to watch our children suffer hurt and rejection, but it is part of the growing- up experience. You can help by believing in them and offering support; for example, saying you can help by brainstorming some ideas or just sitting quietly with them listening. Often relationships are fixed quickly and it's we as parents who get the most upset!

Be a role model and let them see you resolve problems in your own life.

# Events Diary

| | |
|---|---|
| 9 March | **JIA Family Fun Day**. Newmarket |
| 23 March | **Rheum for You**. Manchester |
| 6 April | **JIA Family Fun Day**. Cheltenham |
| 18 May | **JIA Family Fun Day**. Leicester |
| 7 June | **#WearPurpleforJIA** |
| 17-23 June | **NRAS Rheumatoid Arthritis Awareness Week (RAAW)** |

## Looking for a Challenge for 2019?

Order your Events brochure at
**fundraising@nras.org.uk**

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National Rheumatoid Arthritis Society

Helpline: **0800 298 7650**
General: **01628 823 524**
e: **helpline@nras.org.uk**
w: **www.nras.org.uk**

Ground Floor
4 Switchback Office Park
Gardner Road
Maidenhead Berkshire
SL6 7RJ

/nationalrheumatoidarthritissociety
/jiaatnras
@NRAS_UK
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