

# Members' MAGAZINE

WINTER 2019



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National Rheumatoid  
Arthritis Society

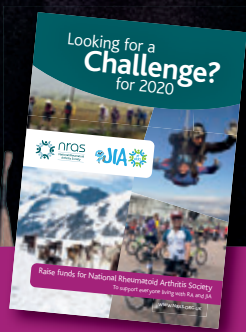
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By Clare Jacklin

NRAS CEO

# Dear Members

I am thrilled to be writing my first 'Dear Members' section of the magazine as your newly appointed CEO. Ailsa, founder of NRAS, handed over the reins to me at the end of June but I'm so pleased that I still have her by my side as NRAS' National Patient Champion.

As it is still early days for me in my new role as CEO, I will wait until the spring issue of the magazine to share with you in more detail my hopes and vision for NRAS. To help me, however, I really do want to hear from you, the NRAS Members. What would you like from YOUR society? Are there any resources that we are not providing that you would like to have access to? If so, please let me know specifically what you would like to see. Also, would you like to be more involved in your society? If so, how? I look forward to hearing from you – you can email me directly at [clare@nras.org.uk](mailto:clare@nras.org.uk)

We've had a very successful year on all fronts, amazing fundraising activities, JIA family days, Bushcraft days, Rheum for You events, launch of the New2RA RightStart service (which is flourishing), great campaigning activity, a very successful RA Awareness week and Wear Purple in June as well as over 2000 people registered to watch our webinars during 2019. If you haven't managed to watch the webinars live you can catch them again on [www.nras.org.uk/webinar](http://www.nras.org.uk/webinar)

As I sit down to write this message to you all, we are busily preparing for the 2019 NRAS National Healthcare Champions' Awards which you will read about later in this winter issue of the NRAS magazine. This will be our sixth award ceremony and it is such a wonderful occasion because people just like you, have taken the time to nominate professionals involved in their healthcare who have, in their eyes, gone above and beyond the call of duty, and that has meant a great deal to so many patients. It was a real struggle to wade through the many, many nominations to whittle it down to just 9 incredibly well deserving winners. I'd like to take this opportunity to say a huge thank you to so many of you who did send nominations and in the event that your nominee didn't win on this occasion, they have all been notified that they had been recognised for their excellent patient care and support.

If you didn't have an opportunity this time around to send in your nomination but you feel one or a number of your health professionals deserve a 'pat on the back', a 'well done' but more especially, a 'thank you for all you do'....don't wait until the next NRAS Healthcare Champions' Awards to tell them .... tell them now!

Once the awards ceremony is over, we'll then be hurtling towards the silly season that is Christmas. Don't panic if you haven't bought your NRAS Charity Christmas Cards there are still some in stock! Perhaps you're cutting back this year and not sending cards but sending e-messages instead, then perhaps the money you save on postage could be donated to your favourite charity ... NRAS?

We're also preparing for our annual Christmas extravaganza, the NRAS Christmas Concert, taking place in Maidenhead on Friday 6th December, in St Peter's Church. Everyone is welcome!

As much as many of us look forward to Christmas and spending time with family and friends, it can also be a very stressful, and for some, isolating time especially when dealing with a long-term condition like RA or JIA. So, don't forget you can visit our online community HealthUnlocked and Facebook 24/7 to talk to others and get some support. Our helpline is open right up to 12.30 pm on Christmas Eve as well. If you would like a pre-Christmas peer support call from one of our wonderful volunteers, please get in touch with Kim at [volunteers@nras.org.uk](mailto:volunteers@nras.org.uk).

On that note, I do hope that you have a happy Christmas and keep as healthy as possible through what can be a very busy time, and all my colleagues in NRAS join me in wishing you the very best for the coming year.

Warmest regards

Clare  
Chief Executive

# Members' MAGAZINE

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To comment on this issue or to submit a story or article for a future issue please email [editor@nras.org.uk](mailto:editor@nras.org.uk)

Editor of this issue:  
Tracy Bracher

## Christmas Gift NRAS Membership

**Not a fan of Christmas Shopping? We have the perfect solution, avoid the crowds and start your Christmas shopping early by giving the gift that lasts all year.**

If you have a family member or friend who lives with rheumatoid arthritis or juvenile idiopathic arthritis, why not consider buying them a gift NRAS Membership? For just £25 for the whole year, they will receive all the benefits of Membership plus a gift card which has a space for a personal message from you. We can arrange for it to be sent directly to the recipient or we can send it to you, so you can gift it to them yourself.

If you are interested in Gift Membership, then please call Tracy on **01628 823524** or visit [www.nras.org.uk/gift-membership](http://www.nras.org.uk/gift-membership) to print off the Gift Membership form.



## 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 campaigning and much much more. If you haven't been receiving the E-Newsletters do email us at [membership@nras.org.uk](mailto:membership@nras.org.uk) to check we have your up to date email address and contact preferences.



Jess Swallow with her Nan

Right: Jess Swallow with her Nan, mother and sister (left to right)

# QBE Foundation Nomination and Award

## £50,000 for NRAS from QBE European Operations Foundation



**"Your charity has been nominated by one of our staff at QBE Insurance and we're very pleased to tell you that you have been chosen and will be receiving £50,000."**

What a way to end the week. On Friday 26th July at 4.30 pm Helen Saich (Trust & Company Giving Fundraiser at NRAS) took a call from the QBE Foundation Chairman with the wonderful news that the QBE Foundation (the charitable arm of QBE Business Insurance) had awarded NRAS £50,000. This grant will help NRAS make a difference and continue to deliver our services to all those who need our help.

We were so lucky to have been nominated by QBE employee, Jess Swallow, whose mother and grandmother are RA sufferers. There were a large number of nominations from QBE staff across the UK and Europe and luckily for NRAS, Jess's story from the heart, moved the judges and we were thrilled to receive the funds on 16th August.

We would like to share the nomination written by Jess below:

"My grandmother developed rheumatoid arthritis when she was aged 50. As with many diseases, one of the main factors that causes RA is stress, and when my grandmother was diagnosed, she was looking after my grandfather 24/7, who had suffered from a stroke and soon after passed away. Growing up, she tried where possible to look after us when my mum needed a babysitter, however due to her lack of mobility as the RA became more debilitating and things such as driving, picking us up, mowing the lawn, etc had to stop - this became hard. Watching her joints flare up and become misshapen over the years, and then watching her toes fold over so she is unable to walk properly is hard - we want to help

her, but other than the many drugs she is on (which they never seem to be able to get right to suit her) which then causes other problems, I feel useless. Despite this, she never moans to us and also greets us with a hug and a huge smile.

RA is also hereditary, and my mother was diagnosed 10 years ago - I want to do everything I can to prevent mum's RA following the same pattern as Nan's...we do everything we can; remaining active where possible, practising yoga and eating a healthy and nutritious diet. She loves gardening and I really hope she can continue gardening for a very long time. It is hard to watch as those you love most struggle with this degenerative disease and I want to do everything I can to protect them, and others that it affects daily.

I don't feel as many people know about RA, and so it is unlikely people would donate to their charity. I want to spread this awareness and help boost the morale of those with the disease. Thank you for the opportunity to apply for funding."

Jess, her mum and nan came to visit us at our offices in Maidenhead in November. It was so lovely to meet them and find out more about their experiences of RA and the time together just flew by.

We are delighted that we are going to be working with Jess as she is very keen to help us raise awareness of RA and what it means to cope daily with this disease and the impact on the whole family.

Thank you Jess.



Jess, her mum and Nan visiting NRAS offices in November

# World Arthritis Day 2019



World Arthritis Day is a campaign started by European League Against Rheumatism, (EULAR) which is the organisation that represents the people with arthritis/rheumatism, health professionals (HPR) and scientific societies of rheumatology of all the European nations. The aims of EULAR are to reduce the burden of rheumatic diseases on the individual and society and to improve the treatment, prevention and rehabilitation of musculoskeletal diseases which of course includes rheumatoid arthritis and juvenile idiopathic arthritis. NRAS works closely with EULAR and collaborates with the other patient organisations across Europe.

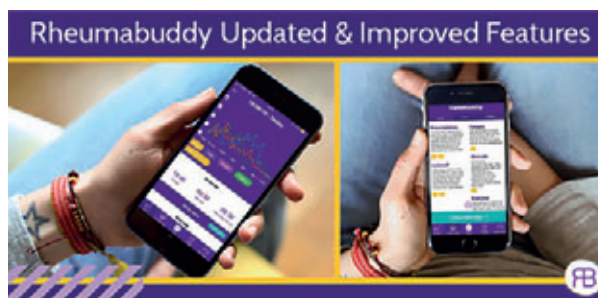


The theme of this year's campaign and part of the Don't Delay Connect Today theme is **Time2Work**, and we report separately in this issue about our Time2Work event held at the King's Fund in London on 18th September.

However, in addition to launching our Time2Work videos and video highlights we also launched a new version of **RheumaBuddy** for both iOS and Android smart phones developed by DAMAN.

You can get the full information about the new version with new features by visiting [www.nras.org.uk/rheumabuddy](http://www.nras.org.uk/rheumabuddy) where you can also download the app. We shall be looking for people to pilot and feedback on the new version so if you are interested, please contact Emma Bartlett – [emmab@nras.org.uk](mailto:emmab@nras.org.uk)

We also launched a new app developed by Ampersand, **My Arthritis**, which contains NRAS information and content in addition to the many features to help you self-manage your disease. My Arthritis has a clinical as well as patient interface and so if adopted by your hospital, you will have the ability to share your data with your clinical team.



The My Arthritis app is available for iOS and Android smart phones and is downloadable from iTunes or the App Store. It is also available to download from our website. Visit the My Arthritis page on our website for more information.

We shall, in due course, be re-branding our DAS app which many of you will be familiar with so watch the website for more information.

If you haven't ever tried using an app, do have a look at both of these great resources and find one that suits your needs. We'd love to hear how you get on. Email any feedback to [emmab@nras.org.uk](mailto:emmab@nras.org.uk)





By Anne Crichton

Senior Trainer  
Tai Chi for Health Institute

# Tai Chi

## This low-impact, slow-motion exercise also emphasises breathing and mental focus

People often joke about Tai Chi. "Is it wax on – wax off from The Karate Kid?" they say with a laugh. "Isn't it just waving your arms about?" or "it's all that leaping and kicking stuff," or "oh, it's too slow and boring for me, only for very old people!"

In my twenties I too joked, "I'll need a new hip sometime". In my sixties osteoarthritis set in, with its good friend pain! I realised that arthritis was no laughing matter!

Eventually came a hip replacement. But guess what? Up till the week of the operation I continued to teach Tai Chi, and five weeks later was again practising daily, much to the astonishment of the consultant surgeon!

Tai Chi had helped manage my pain and speeded my recovery.

Today medical professionals are beginning to recommend Tai Chi. An excerpt from a Harvard Medical School report states:

*'With origins in Chinese martial arts, this low-impact, slow-motion exercise also emphasises breathing and mental focus. A number of small studies suggest Tai Chi helps people with different forms of arthritis, mainly by increasing flexibility and improving muscle strength in the lower body, as well as aiding gait and balance.'*

Tai Chi can be easy to learn with a good teacher; specially developed short Tai Chi forms are safe and can be modified or practised seated.

But, "Oh dear", I hear you say, "that sounds too much like hard work!" Well... yes, but it is worth the effort. Persevere and you will get the hang of it.

Soon you will begin to be aware of your movements. Where is your weight? Can you transfer it slowly from one foot to the other? Are you moving mindfully, thinking of your posture, the width of your stance?

Now with your mind becoming more focused, your attention is not on pain, but on the feel of the movements. You become more confident; you are now part of a group. Classes are fun, you are getting out and about more.

And then there is the scientific research – one recent study shows that mindfulness soothes the brain patterns. Over time, these changes alter the structure of the brain itself so that patients no longer feel pain with the same intensity.

So how can this help manage your arthritis? It is well known that gentle exercise is beneficial for arthritis, however, not everyone feels comfortable in a gym. Joining a community Tai Chi class can certainly improve strength and balance, but the added bonus is enjoying good company, sharing experiences and having fun. You need no special equipment, just an open mind and positive thinking.

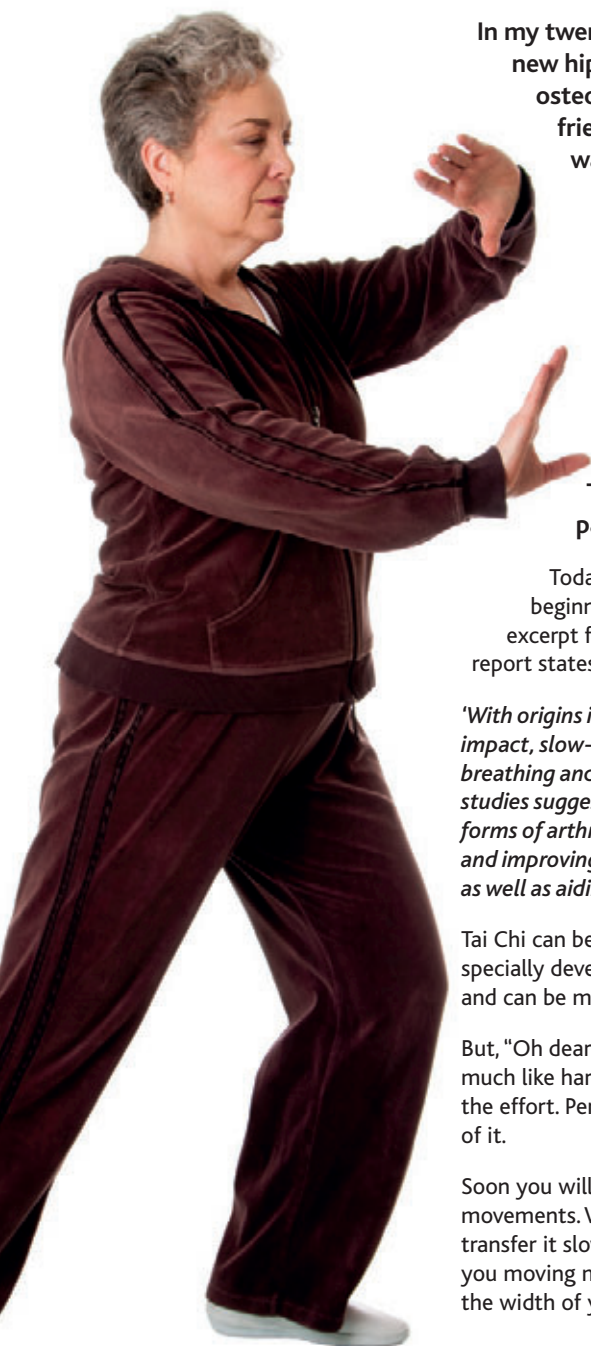
I am fortunate to have been teaching Tai Chi to wonderful students for many years. My inspiration is Dr Paul Lam, originator of the Tai Chi for Arthritis programme.

Having developed arthritis as a child in China, Dr Lam graduated from Medical School in Sydney. By now his osteoarthritis had become debilitating. His father-in-law suggested Tai Chi might alleviate the symptoms. It worked – Dr Lam later proceeded to win several international Tai Chi competitions!

This began 30 years of dedication to his GP practice in Sydney, and a mission to make Tai Chi accessible to all, to improve health and quality of life and, in particular, for those who have arthritis.

Recently retired and now in his early seventies, Dr Lam teaches workshops and seminars worldwide. This year I witnessed his Chen 36 Sword demonstration at the USA annual conference – truly amazing and totally inspiring. Although he still suffers from arthritis, it is controlled by daily practice. Dr Lam is living proof of the effectiveness of Tai Chi.

Why not give it a try? It might change your life too!



# The essential principles of Tai Chi

## Movement

Make your movements slow smooth and continuous like water flowing in a river. Imagine you are moving against a gentle resistance, like moving in water.

## Body Structure

Keep an upright posture. A golden thread connects your head to the sky. Knees slightly bent and pelvis tucked under. Ear, shoulder and hip should align. Be aware of weight transference in all parts of a movement.

## Internal

'Song' – gently stretch your joints from within. Think of internally expanding each joint.

'Jing' – pay attention to your body and the movements you are making.

Be aware of your surroundings – yet focused on what you are doing.



## Tai Chi starting position and order of moves

### 1. Start position 2. Commencing movement

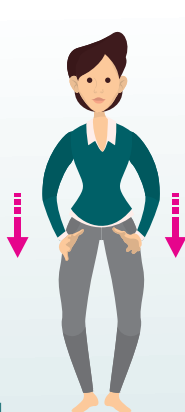


Stand with your body upright but relaxed: feet slightly apart, knees loose, eyes looking forward, chin tucked in, shoulders relaxed.

Cleanse your mind.



**a.** Breathing in, lift both arms in a wide curve.



**b.** Breathing out, lower arms and bend knees slightly.



**c.** Lift arms, elbows bent. Step forward with left heel.

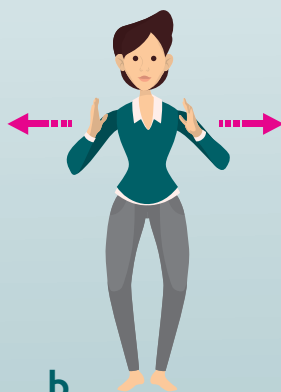


**d.** Pushing hands forward, bring right foot forward, in line with the left.

### 3. Opening and closing hands



**a.** Bring hands to front of chest



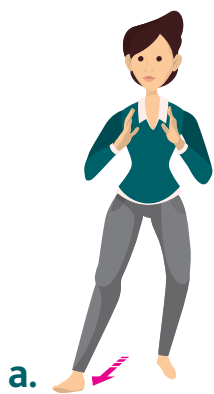
**b.** Breathing in, open hands



**c.** Breathing out, push hands towards each other

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## 4. Single whip



**a.** Step to right and slightly forward with right heel.



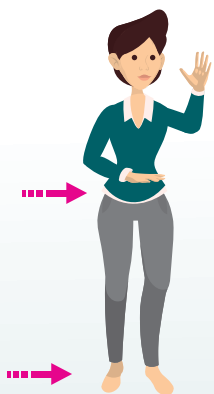
**b.** Shifting weight onto right leg, push palms forward.



**c.** Turn palms to face forward and extend arms outward, watching left hand.

Tai Chi can be easy to learn with a good teacher; specially developed short Tai Chi forms are safe and can be modified or practised seated.

## 5. Waving hands in the clouds



**a.** Bring right arm inwards toward the left, right hand to left elbow. Step in with the right foot.



**b.** Move right hand upwards and left hand downward. Extend right foot and prepare to step sideways to the right.



**c.** Step to the right, turning upper body and arms to the right. Transfer weight to right foot. Then bring left foot in closer.



**d.** Move right hand down and left hand up.



**e.** Turn upper body and arms to the left, transferring weight to left foot. Feet remain still.

To find out more about Tai Chi for Arthritis or a class near you, go to the Tai Chi for Health Institute website:

[taichiforhealthinstitute.org](http://taichiforhealthinstitute.org)

Tai Chi for Arthritis by Dr Paul Lam – Introduction and first lesson:

[www.youtube.com/watch?v=tAOuEpa01j4](http://www.youtube.com/watch?v=tAOuEpa01j4)

Front view demonstration of the entire Tai Chi for Arthritis – Part 1 performed by Jane Tan:

[www.youtube.com/watch?v=q9vdlCJZGtA](http://www.youtube.com/watch?v=q9vdlCJZGtA)



# Healthcare at Home

Charity of the Year – NRAS chosen as one of their Charities of the Year

**Healthcare at Home, the UK's leading full service, clinical provider of healthcare out-of-hospital, at home, at work and in communities, chose the National Rheumatoid Arthritis Society as one of their charities to support in 2019 during the months of May to August.**

As part of their fundraising Healthcare at Home:

- Held a Summer Fair at their offices on 22nd June. Members of our lovely Chesterfield NRAS group attended and had a very successful day fundraising and raising awareness.
- Hannah, Emily and Amy, 3 colleagues from Healthcare at Home, took part together in the Birmingham 10K challenge and raised over **£200**.
- From January to June, Healthcare at Home colleagues raised money through a car share scheme, NRAS were very pleased to receive an amazing sum in August as a result of this.
- Healthcare at Home employees donated through their salary using the Pennies from Heaven employee payroll scheme.

Cara Brandi and Helen Saich (from the NRAS fundraising team) visited Healthcare at Home's offices in Burton on Trent on 24th June and were pleased to meet Jessica Bell and Bethany Reed. Cara and Helen enjoyed meeting other members of staff too, having a tour around the offices and also whilst they were there, making a video to tell their staff all about NRAS.

At the time of going to print, the amazing amount of **£5,709** has been raised through all their fundraising efforts. Thank you so much Healthcare at Home, you have been a pleasure to work with and we are so grateful for your support.

To speak to us about nominating NRAS as your organisation's or club's Charity of the Year, contact us at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk) or call **01628 823524**.



Cara and Helen on their visit to Healthcare at Home pictured with Jessica Bell



Chesterfield NRAS Group pictured at the Summer Fair on 22nd June



Hannah, Emily and Amy taking part in Birmingham 10K



## Professor Christopher Buckley

Director of Clinical Research  
Kennedy Institute of  
Rheumatology  
University of Oxford

Director of the Birmingham  
NIHR Wellcome Trust Clinical  
Research Facility  
Rheumatology  
Research Group  
Institute of  
Inflammation and Ageing  
University of Birmingham

# Arthritis Therapy Acceleration Programme

## Targeting the right drug to the right disease at the right time

**In recent years many exciting new targets, including TNF, have been identified for a range of immune-mediated-inflammatory diseases (IMIDs) such as rheumatoid arthritis and inflammatory bowel disease. However, there is often a lag between scientific discovery in the laboratory and translation into the clinic, with many potentially relevant drug targets remaining untested in patients.**

We launched the Arthritis Therapy Acceleration Programme (A-TAP) two years ago to help overcome the barriers that slow down drug development for IMIDs. A-TAP brings together the Universities of Birmingham and Oxford and seven NHS Trusts across the Midlands and Warwickshire and Oxfordshire, led by myself and Director of the Kennedy Institute of Rheumatology (University of Oxford) Professor Fiona Powrie. This unique partnership between discovery scientists, clinicians and other healthcare professionals, with access to more than five million patients combined, has spearheaded a new attempt to develop treatments that target the underlying cellular causes and not just the symptoms of disease.

A-TAP initially focuses on four IMIDs that affect the joints, eye, skin and gut namely rheumatoid arthritis, inflammatory bowel disease, Sjogren's syndrome and seronegative forms of joint disease such as psoriatic arthritis and ankylosing spondylitis. Each of these conditions is characterised by too much inflammation caused by either the immune system mistakenly attacking the body's own tissues or from a failure of the natural processes that inhibit the inflammatory response. The activity of the cells and proteins that trigger and sustain inflammation varies between patients, yet many of the culprits driving inflammation are common across different types of IMIDs; they share something in common and we need to identify what cell that is.

A-TAP will therefore pioneer innovative clinical trials that test one or a combination of drugs across a range of IMIDs at the same time.

Importantly, new treatments will be assessed based on their success in altering proteins or cells that drive inflammation in tissues rather than on a reduction in clinical symptoms alone. This approach of testing novel therapies in small trials across a range of different disease types will speed up decision-making and progression to larger scale clinical trials. Moreover, because the endpoints being used in these studies are based on quantifying the amount of protein or number of cells in a tissue, the number of participants in such clinical trials will be much smaller than in traditional trials, making the studies much faster. Such an approach has been very successful in oncology, and the ATAP will extend this to IMIDs.

Ultimately, through the A-TAP pipeline, we hope to develop a framework where biological markers of inflammation can be used to match the appropriate therapy to those patients most likely to benefit. For rheumatoid arthritis, this could help limit irreversible damage to joint tissues by effectively treating patients during the early stages of disease.

We are also pushing for a "bedside-to-bedside" approach to treating IMIDs where consultants with different specialities closely collaborate in the treatment of patients, so that their primary interest becomes inflammation rather their own discipline. This approach will improve patient care and is essential for clinical trials that operate across different types of IMIDs.

Since launching A-TAP our efforts have focused on bringing together the people and technologies necessary to establish a process for rapidly testing new drug targets in the clinic. As we move to the



NRAS Team visiting Chris at the Kennedy Institute

next phase, we intend to work closely with our colleagues at the National Rheumatoid Arthritis Society, and hopefully with some of the readers of this magazine, as we expand our portfolio of translational and clinic research in Oxford and Birmingham. This is an exciting time for research into the treatment of IMIDs, and we believe A-TAP will be a driving force for the delivery of new therapies that change the lives of patients.

A-TAP is supported by £7 million investment from the Kennedy Trust for Rheumatology Research.

The delivery of A-TAP crucially depends on patient participation in experimental medicine studies that tell us more about the disease process and how it is affected by different types of therapy. In Birmingham we have had great success working with patients at the time when they first show symptoms of disease. The Birmingham Early Arthritis Cohort (BEACON), run by Prof Karim Raza and Dr Andrew Filer at the University of Birmingham, has pioneered such an approach in which clinical, imaging and histology studies have all been used to study patients at different stages in the development of RA.

## The benefits of a Mediterranean diet

**A Mediterranean diet has been known to give health benefits for all kinds of health conditions, including cardiovascular (heart) disease. Though the main dietary advice to people with RA has always been to keep to a healthy, balanced diet and try to avoid any foods which worsen their RA symptoms (which foods these are, if any, will vary from person to person), there has also been evidence that overall people with RA do better on a Mediterranean diet. Benefits of this diet have included reduced swelling and tenderness and reduced duration of morning stiffness in joints.**

So, what is a Mediterranean diet? Well, as the name suggests, this diet is based on the foods eaten in Mediterranean countries, such as Greece or Italy. It includes foods such as fresh fruits and vegetables, nuts, beans and pulses, olive

oil, wholegrain cereals and regular oily fish and poultry consumption.

In a recent study, researchers looked at nearly 100,000 healthy women in France, recruited between the years of 1990-91, and had followed their health since then, aiming to see whether or not a Mediterranean diet could help to prevent someone developing RA, as well as reducing symptoms in existing RA patients.

The study found that there was no preventative effect of this diet on RA overall. However, interestingly, they found that for any of the women who had ever smoked, a Mediterranean diet was seen to reduce their risks of developing RA. Those who had never smoked saw no reduction in risk based on whether or not they followed this diet, but it is well established that smoking is in itself a major risk factor in developing RA.



# NRAS Groups

## Edinburgh and Lothians NRAS Group



On 3rd September the launch meeting of the Edinburgh & Lothians NRAS Group took place in the Scottish Health Services Centre (SHSC). It had taken some time to get to this point but, with the enthusiastic support of the NHS Lothian Rheumatology Team and three of the NRAS Scottish Ambassadors based in the area, it proved to be a great success. Over 80 people attended, including Naomi Scott, Lead Rheumatology Pharmacist who gave the keynote talk; 'What's new in Rheumatoid Arthritis?' plus staff from the Rheumatology Team who assisted with the Q & A session. Sheila MacLeod, Chair of the NRAS Scottish Campaigns Network also presented an important update; 'Working with the rheumatology service in Scotland - the patient voice' to inform everyone of the excellent work that has taken place so far.

Several attendees volunteered to become Group Coordinators with the aim of taking the group forward. These volunteers have now met and agreed that the first open meeting will take place early next year once a suitable venue has been found. Keep an eye on the Groups page of our website for more information [www.nras.org.uk/groups](http://www.nras.org.uk/groups) or to be added to the email mailing list, please send your details to [groups@nras.org.uk](mailto:groups@nras.org.uk).

NRAS would like to extend a huge thank you to the three NRAS Scottish Ambassadors based in the Edinburgh area; Sheila Terry, Sheila MacLeod and John Paton, who were all integral in organising and facilitating the launch of this new group, we wouldn't have been able to do it without them!

## Worcester NRAS Group

Donna Saunders, Volunteer Coordinator of the Worcester NRAS Group, (pictured left), enjoyed a lively day at Worcester Pride in September where she had a stand selling NRAS merchandise and raising the profile of the local Group and NRAS.



## West Wales NRAS Group

Yvonne Spencer, Volunteer Coordinator of the West Wales NRAS Group, is seen here welcoming Sarah Roberts who ran in the Cardiff half marathon at the beginning of October. Group members donated £72 to Sarah and her husband Steve who raised a total of £412 in sponsorship for NRAS.





## NRAS Group Fundraising

The Fundraising team would like to thank some of our NRAS Groups who have been busy raising the profile of NRAS out in their local community, helping to raise funds and represent the charity on our behalf. By working together, we can meet and reach out to many more of our supporters that we might not be able to meet in person, being such a small team based at the NRAS offices in Maidenhead. Thank you.

### Hertfordshire NRAS Group

Teresa Shakespeare-Smith, Volunteer Coordinator of the Hertfordshire NRAS Group, pictured above with her daughter Steph and son Greg. Teresa has recently represented NRAS collecting cheques from Dunstable Bowls Club for **£1147.90** and the choir, Singing for Pleasure who are based in Welwyn Garden City, from their recent charity

concert that raised **£375.00**. Thanks goes to both of these organisations. Teresa herself has also raised **£1114.00** from her 'Reverse tombola' stalls at Walsworth Festival in Hitchin, Stevenage Day and Arlesey Summer Fete. Big thanks to Teresa's family, especially her Mum Joan, who has been busily knitting items for Teresa to sell.

# The Gathering

## Edinburgh

[www.nras.org.uk/the-gathering-scotland](http://www.nras.org.uk/the-gathering-scotland)

The NRAS Gathering is planned for May 2020. Similar to the NRAS 'Rheum for You' events, The Gathering will host expert keynote speakers and activities throughout the day. Some of the NRAS team will be there to welcome you along with representatives of the NRAS Scottish Campaigns Network. We are currently working on putting together an excellent programme for the day and we will announce further details in due course, but to secure your place in advance, please visit our website for more information and to book your place!



**The Gathering**  
**Saturday, 2nd May 2020**  
**Village Hotel, Edinburgh**  
**9:30am-5pm**





**Dr Patrick Kiely**  
PhD, FRCP

Consultant Rheumatologist,  
St George's University  
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Honorary Reader in  
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# The lung and rheumatoid arthritis

There are three situations in which the lung can be adversely affected in people with rheumatoid arthritis:

1. A direct effect of rheumatoid disease on the lungs
2. An adverse effect of treatment given for rheumatoid on lung tissue
3. Chest infections, as a consequence of rheumatoid itself or the immune suppressing therapies given to treat it, causing a further deterioration in lung function

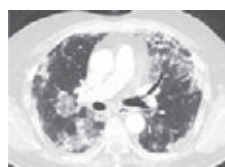
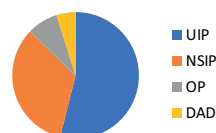
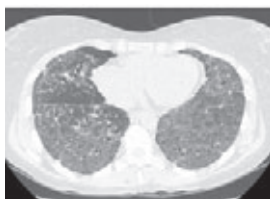
This article aims to give an overview of these three ways in which the lungs can be affected.

## HR CT types of RA-ILD

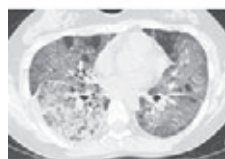
**UIP:** 44-66%  
Usual  
interstitial  
pneumonia



**NSIP:** 24-44%  
Non specific  
interstitial  
pneumonia



**OP:** <10%  
Organising  
pneumonia



**DAD:** <5%  
Diffuse  
alveolar  
damage

## 1. The direct effects of rheumatoid disease on lung tissue and pleura

People with RA can develop disease in their lungs as a consequence of their immune system attacking their joints and other tissues. Different types of lung disease can occur, including interstitial lung disease (ILD), bronchiectasis and bronchiolitis obliterans. In each of these, inflammation and damage can occur to the lung tissue, reducing the ability to absorb oxygen from the air we breathe into the blood stream and causing breathlessness in affected people. Often this is accompanied by a persistent cough, especially with exertion. Breathing tests (also called lung function or pulmonary function tests) and a CT scan of the lungs are used to confirm the diagnosis, and precise patterns of lung disease are described.

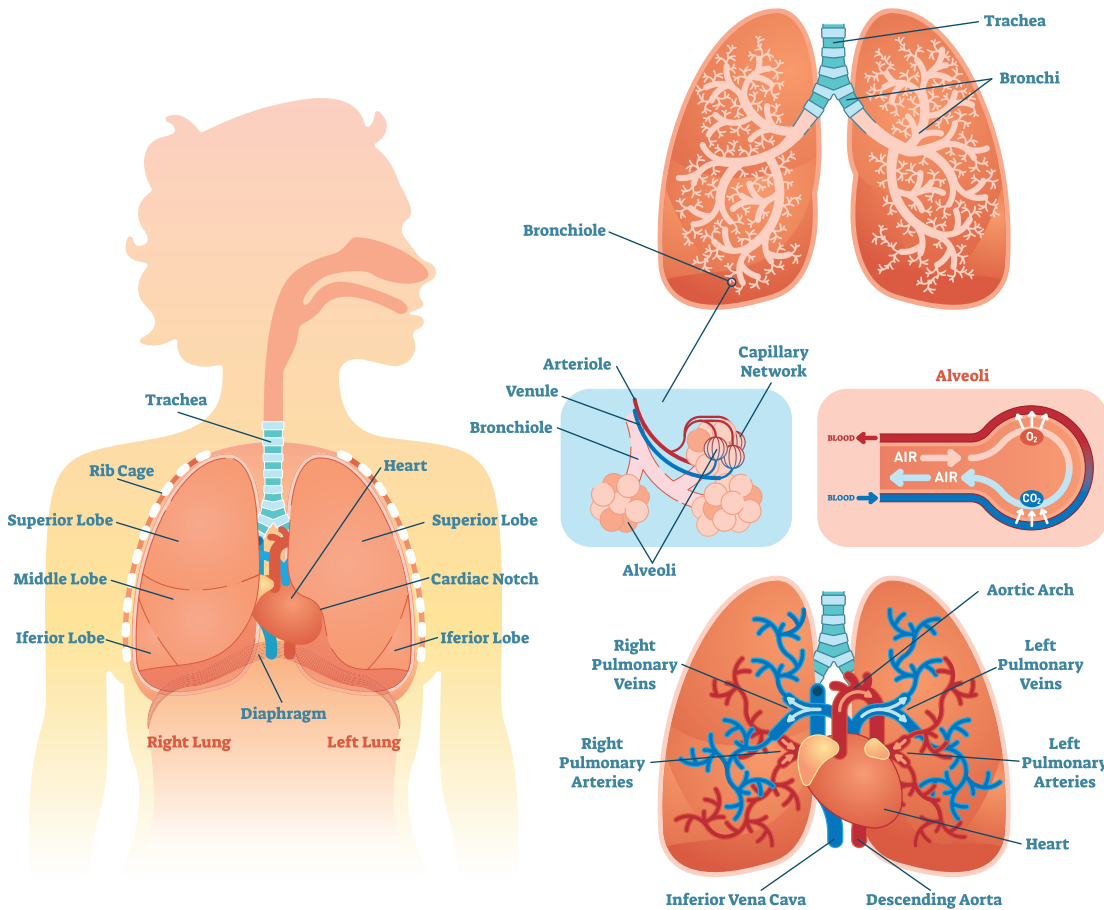
### Interstitial lung disease (ILD)

In interstitial lung disease (ILD) immune cells collect in the lung, accompanied by thickening or fibrosis of the tissues. This means the air sacs (alveoli) are less able to absorb the oxygen we breathe into the blood stream. Although CT scans show evidence of ILD in a high proportion of RA

patients (over half in some studies), this is not sufficiently extensive to cause breathlessness or cough in most, with symptoms estimated to occur in as few as 5% of RA patients. The CT appearances are so characteristic that radiologists are able to describe four patterns of ILD, listed below in order of how common they are:

- interstitial pneumonia (UIP) - the commonest form
- non-specific interstitial pneumonia (NSIP)
- organising pneumonia (OP) and diffuse alveolar damage (DAD) - much less frequent
- RA patients who are more likely to develop ILD include:
  - those that have smoked
  - have rheumatoid nodules
  - developed RA at a relatively older age
  - have rheumatoid factor and anti-CCP antibodies
  - are male

Usually ILD develops several years after the RA diagnosis, but up to a quarter of RA patients have ILD from when they first develop RA, or



even before their joints are affected. Historically there was no treatment for ILD and survival was poor, this being the second commonest cause of premature death (after cardiovascular problems such as heart attacks and strokes) in people with RA. However, more help is available now and there is evidence that some therapies, including mycophenolate mofetil, rituximab and abatacept, slow down or even prevent ILD progression.

**Bronchiectasis**

Bronchiectasis is a condition in which the branches of the airways are widened. This can occur as a consequence of recurrent infections or because they are pulled apart from fibrosis, as occurs in ILD. The consequence is that mucus and secretions collect within the airways, rather than being coughed up. Retention of secretions is a problem because this reduces the flow of air and hence oxygen absorption, making the affected person breathless on exertion. Retained secretions also encourage bacteria to grow, making chest infections more likely and in the most extensive cases these become a recurring problem. As in ILD, features are more commonly seen on CT than reported by patients, with up to 30% having areas of bronchiectasis but far fewer having symptoms. There are some chicken and egg theories concerning bronchiectasis and RA with thoughts that the bacteria in bronchiectasis are a cause of CCP antibodies which then trigger the onset of RA, and alternatively that the immune suppression used to treat RA leads to recurrent chest infections which ultimately result in bronchiectasis.

**Bronchiolitis obliterans**

Bronchiolitis obliterans is another inflammatory condition, in which the smallest airways (bronchioles) become blocked or obstructed. This means there is less air flow to the air sacs, and so less absorption of oxygen. The affected person feels breathless and may have a cough and be wheezy. This condition is more commonly seen as a result of inhaling chemicals, such as diacetyl used as a flavouring in microwave popcorn and e-cigarettes, but rarely may also occur in people with RA. In contrast to ILD, symptoms can commence over a short period of time, get worse quickly and in the absence of reversible treatment the most severe cases may require lung transplantation.

The pleura are a double layered envelope surrounding the lungs. In some people with RA the pleural layers can be affected by inflammation, leading to thickening of the pleural tissue and fluid collecting in the pleural space. This is more likely to occur in men and people with rheumatoid nodules. Pleural thickening and fluid may occur around one or both lungs, and whilst there are signs of this in over half of all RA patients on CT scans, in the majority the extent is mild and far less than 10% have pain or breathlessness from pleural disease. Often investigations have to be done to confirm the diagnosis, requiring the fluid to be sampled and a pleural biopsy taken to distinguish rheumatoid pleural fluid from infection (bacteria or tuberculosis) or cancer. Standard treatments for RA are usually effective for pleural disease, and only very rarely is surgery necessary to prevent fluid collecting.

People with RA can develop disease in their lungs as a consequence of their immune system attacking their joints and other tissues.

Nodules are a feature of RA and can occur within the lung or on the pleura. They are collections of immune cells, often found at the back of the elbow, and whilst a sign that the immune system is over-active (part of the RA disease process), the nodules themselves rarely cause symptoms and generally do no harm. When present in the lung they can be solitary or multiple and range in size from a few millimetres to several centimetres, when they can be visible on a chest X-ray. Although they have some characteristic features on CT and PET scans, sometimes a biopsy (small tissue sample) has to be taken to confirm the diagnosis, as they can look the same as cancer. Methotrexate treatment can make rheumatoid nodules larger and more numerous whereas other therapies, including rituximab and JAK inhibitors are effective in shrinking them.

## 2. The effects of RA treatment on lung tissue or the pleura

In principle any medication that effectively suppresses the immune driven inflammatory processes that cause RA should also be effective for all manifestations of the disease, in all organs. This is generally true, with many instances in which the early signs of lung or pleural disease on a CT scan never progress to an extent that the affected person becomes breathless or develops a cough, because of the effectiveness of the medications they are taking. Nonetheless, when RA lung disease is found to get worse it can be hard to decide if this is because the existing therapy is not completely effective at suppressing the inflammatory RA process or alternatively because the therapy itself is having a direct toxic effect on the lung or an indirect effect as a consequence of chest infections.

**Methotrexate (MTX)** is one of the most important disease modifying anti-rheumatic drugs (DMARDs) used to treat RA. It is very rarely associated with an allergic lung reaction, called hypersensitivity pneumonitis (in less than 1% of people). This often occurs early, well within the first year of treatment, but can be delayed up to 3 years after starting treatment. Patients become unwell over a few days, with breathlessness, fever and malaise. Stopping MTX and giving high dose steroid for a short while is sufficient for the majority of cases to recover. However, because hypersensitivity pneumonitis can be severe and even life threatening, people with pre-existing lung diseases (such as COPD) are not started on MTX if it is felt that they might not survive MTX pneumonitis, should it occur. Apart from this reaction, and the possibility of increasing rheumatoid nodules, there is no evidence that MTX makes it more likely that any of the other RA associated lung complications will occur, such as ILD, and on the contrary may be protective by so effectively treating the underlying RA disease process.

**Sulfasalazine** has been associated with a lupus like syndrome where pleural disease is seen, and

also a hypersensitivity 'eosinophilic' pneumonia. These are not common events, and are usually reversible after stopping treatment.

**Leflunomide** has been associated very infrequently with the development of ILD, particularly in Asian people.

Early reports of **TNF inhibitors** (TNFi) suggested a link with progressive ILD and death. However, it has been difficult to determine if this link was caused by the drugs, as TNFi were initially given to people with advanced severe ILD with a high risk of chest infections and a poor likelihood of survival. This class of biologic agent has not been found to cause ILD in people with other immune driven diseases not in themselves associated with lung disease (eg psoriasis, colitis), but caution is still important when starting a patient with severe lung disease and high risk of chest infection, on a biologic therapy.

Currently **rituximab**, **abatacept** and **mycophenolate mofetil** are favoured options over TNFi, partly because of a somewhat lower risk of chest infections.

## 3. Chest infections

People with RA and lung disease have several reasons to be at an increased risk of chest infections (bronchitis and pneumonia). Firstly, because the lung is damaged, the natural defences from infection are curtailed. This is made worse in people who smoke, or are exposed to fumes or other lung toxins, and every effort must be made to stop smoking. This is over and above the fact that smoking reduces the effectiveness of DMARDs and TNFi. Secondly, the treatments for RA (all DMARDs and biologics) work by suppressing the immune system. In doing so they reduce the body's defence against infection and increase the risk of infections. Furthermore, an unwanted cycle can develop in which DMARD and biologic therapies have to be interrupted to enable recovery from chest infections, which in turn result in flare of the RA and its lung disease, leading to more lung damage and even greater susceptibility to infection.

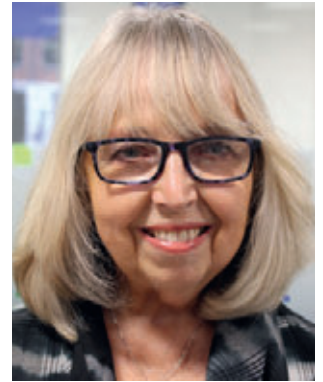
A balance between risk of infection and treatment of the underlying rheumatoid process needs to be struck. Helpful measures include avoiding contact with sources of infection such as crowded spaces, keeping up to date with vaccines (influenza yearly, pneumococcal polysaccharide vaccine PPV once) and respiratory exercises to aid natural ways of clearing lung secretions. **Stopping smoking is very important.**

Whilst all DMARDs and biologic therapies carry an increased risk of infection, it is becoming increasingly clear that steroids (prednisolone) confer the greatest risk of all, and every effort should be made to stop oral steroid (prednisolone) treatment in people with rheumatoid lung disease.



# EULAR Recommendations

for the implementation of self-management strategies in patients with Inflammatory Arthritis (IA)



**By Ailsa Bosworth, MBE**  
National Patient Champion for NRAS



**If you are a Member of NRAS or a follower of our work, you will know that much of what we do is to champion the importance of supported self-management for people with RA and Adult JIA and to support families, children and young people affected by JIA.**

The recognition of the importance of supported self-management is becoming more widespread and recommendations for the self-management of patients with IA are thus necessary to guide more holistic and patient-centred care, tailored to the individual's needs. In spite of a greater recognition by government, professional bodies and health professionals of the need to involve patients in their own care and provide education and opportunities to access self-management resources, the reality for many is that outpatient consultations remain very medically and clinically focused and when services are audited, this is often an area which underperforms.

As a consequence, in 2017 at a meeting of European patient organisation Chief Executives supported by EULAR (European League against Rheumatism), I raised the issue of incorporating recommendations for health professionals for the implementation of self-management strategies in the routine care of patients with inflammatory

arthritis, in the EULAR guidelines for the treatment of adults with RA. This resulted in my being encouraged to be the convenor of a new EULAR project and apply for funding from EULAR to develop a European Taskforce to research the subject and publish recommendations. I am delighted to say that with the help of my wonderful co-convenor, Dr Elena Nikiphorou (King's), we put a proposal together and funding was granted in March 2019. We recruited a Taskforce to help us to deliver this project comprising 20 health professionals and patients representing the entire multi-disciplinary team (including consultants) from 11 European countries, and we held our first face to face meeting at a Heathrow Hotel in September. Our work will span a further 12 months before the recommendations are finalised and published. This is a further important step in ensuring that patients are treated in a more holistic way and self-management is at the centre of their care pathway alongside the clinical, medical aspects of their care.





# Dear Helpline

My family don't seem to understand my RA. How can I help them to understand what I'm going through and how my condition affects me?

There is no right or wrong way to tell your family about your RA. It will depend on various factors including their age, relationship to you etc. However, feeling that nobody understands your RA is a common experience and, whilst nobody will ever truly understand without going through this themselves, there are ways that you can help to bridge the gap between their knowledge and yours. Remember people like to receive information in different ways.

## For children:

Where possible, involve your children in what's happening and allow them to support you in any way they can. This could mean that they need to help more around the home, or it could just be that you want them to understand that some activities will be harder for you to do with them than they may have been before.

It can be tempting to try to shield children from what's going on in a family, but remember, kids pick up on things, so if you don't have a conversation with them this could cause more worry if they notice that something is going on.

Medikidz publish books on various health conditions and have a great book called *What's up with Eloise?*. This is a comic book aimed at explaining a parent's RA to their child. This is available on Amazon and various other book sites for around £8.99. The book was first published with input from NRAS in 2012.

## For adults:

### Information

If you feel that your family shut down conversations about your RA or you find it difficult starting a conversation about it, why not order some of our booklets such as *New2RA*.

You could give the booklet to them and say that it would mean a lot to you if they read it, or just leave it around the home so that they can choose to read it when they are ready.

### Questions

Your family may prefer to speak about your condition with someone rather than read about it. They may also have some questions about your RA that they don't like to raise with you, so you could always suggest that they ring the NRAS Helpline. We are here for all people affected by RA, not just those who have the condition themselves, so are more than happy to speak to them generally about the condition.

### Mindreading

Your family won't know what you don't tell them! In time, they may pick up on the signs that you are having a bad day and will know how best to help you, but when you feel ready, have some honest discussions with them. Talk about how your RA can affect you and what level of physical and emotional help you need. If they get it wrong, and you feel they're not doing enough for you, or doing too much and making you feel claustrophobic, tell them.

### Guilt

Guilt is something we hear about all too often in speaking to people with RA. It is only human for you to feel bad that your condition impacts not just on you, but on those around you as well. However, to balance this you must remember two things: 1. It is not your fault that you have this condition, and it affects you most of all, so there is no reason for you to feel guilty. 2. If the tables were turned, would you feel less love for your family member if they got diagnosed with RA? If not, then remember to give them the benefit of the doubt on that one as well, just be honest about how you all feel, which will help you to find a way to manage your RA together.



My dog is due to have a kennel cough vaccination, and I've been told it's a live vaccine. Would that put me at any risk?



This is a question that's come up a couple of times before, and it's not necessarily something that everyone with RA would have considered to be a risk. We found what looks to be a very good, common sense approach article on this on the 'Worms and Germs Blog' website, which aims to promote safe pet ownership.

Live vaccines for your pets can be a risk to you as a pet owner if the bacterium that causes the condition being vaccinated against can infect people. Many bacteria would not pass to humans, so are not an issue, but 'kennel cough' can cause occasional infections in people. If you came into contact with the live vaccine, this could therefore put you at risk, but if your dog contracted kennel cough because they weren't vaccinated against it, that could also put you at risk, so this needs to be weighed up.

As with all animals, dogs carry various bacteria on them, which can pose just as much, if not more of a risk to owners, yet often this gets taken for granted. As the author of the article puts it:

"This often doesn't get considered. If you show me a dog vaccinated with a modified live vaccine and ask me to list the top things with which the dog is likely to infect a person, the modified live bug won't even crack the top 10 (or 20)"

So, what should you do if your dog needs a kennel cough vaccine? The author offers up a few common sense suggestions. If at all possible, get someone else to take your dog to get vaccinated. Dogs can sometimes sneeze when the vaccine is squirted up their nostrils, so this is the time that you are most likely to come into contact with the live vaccine. It might also be an idea for you (or someone else) to wipe your dog's face after they have been vaccinated. You should also minimise close contact with their face and wash your hands after petting them, especially around the face.

To anyone considering becoming a dog owner, the good news is that the risks of getting an infection from a dog, particularly through their live vaccines, are pretty small. Being a dog owner can of course offer many benefits, including regular exercise, lower blood pressure, reduced stress and of course companionship.

The good news is that the risks of getting an infection from a dog, particularly through their live vaccines, are pretty small

# Community Fundraisers

Thank you to our fabulous fundraisers who always go the extra mile to make a difference! Here are just some of our wonderful supporters and the amazing things they have been up to...

## Swimmers



**Shona Fowlie** swam Loch Tay and took part in the Beast Race raising **£1,468** in sponsorship – Shona and her Mum have RA.



**Darcey Lucas** who was diagnosed with JIA aged 8, raised an amazing **£2,280** swimming from Albania to Corfu in August. In 2018 Darcey suffered a flare-up of her RA, so this was a huge mental and physical challenge.

## Runners



**Philip Oliver** ran a 5km Park run and raised **£120!** Running is not his preferred sport, but he was set a challenge by his new secondary school to take part in an activity he would not normally do and raise money for charity. Philip did a brilliant job and came in 3rd in his age category. Go Philip!



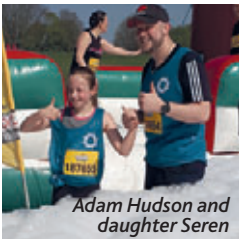
**Bryony Hobden** was inspired to support NRAS as her Dad has RA and he has found the support he has received from NRAS to be very helpful. Bryony has raised a fantastic **£320!**

Adam Hudson and his daughter Seren took part in the Gung Ho event in Swansea. Adam has also run in two other events this year to highlight JIA, as his son has this condition. Adam has raised **£215** so far. Well done!

### Challenge events



Heather Moore



Adam Hudson and daughter Seren



Mark Webb & Mel Moore

NRAS had 3 runners in this year's Yorkshire Tough Mudder – **Heather Moore** raised **£298** and **Mark Webb** and **Mel Moore** raised **£150**. They had a muddy but exhilarating time!



Eight-year-old **Hana Veal** climbed Scafell Pike to show support for her Mum, who has RA. Hana doesn't like walking, and prefers horse riding and swimming, so this was a big challenge. Well done Hana for completing the climb and for raising **£243**.

### Cycling



**John and Lynne Gleedwood** cycled the iconic London to Brighton route for NRAS in September and raised **£499**.

We are very fortunate to have a network of Groups up and down the country who are able to represent NRAS in the local community, as well as supporting NRAS with their own fundraising initiatives. **Teresa Shakespeare-Smith** our NRAS Hertfordshire Group Coordinator has been out and about in the local community.

The Singing for Pleasure choir chose to support NRAS with one of their fantastic charity Concerts back in the Summer. Seen in the photo is Teresa receiving a cheque for **£375** from Glynis Rogers, Musical Director and Founder Member of the most successful charity Choir in Hertfordshire.



On Sunday 29th September, Teresa collected a cheque for **£1147** from the Dunstable Town Bowling Club. The bowling club had chosen us as their charity of the year and pictured with Teresa is Philip Bell, who is the Captain of the Club. NRAS are very grateful for the support of the Dunstable Town Bowling Club and the fantastic amount raised to help people living with RA and JIA.



*Thank you.*

# NRAS Challenge Events

## Marathon

A huge thank you to all the NRAS runners for taking part in the Brighton Marathon, London Marathon and Vitality 10k earlier this year. The total amount raised for all 3 events an amazing

**£11,285**



**Brighton marathon:** Fraulein Smith, Matthue Levitt, Nadia Muncey | **London Marathon:** Toby Jarvis | **Vitality 10k:** Kelly-Marie Staunton

## RideLondon 100 4th August 2019

'I am excited to be riding my first RideLondon event which happens to be on the day of my 35th (coral) wedding anniversary (4th August). My lovely wife Heather suffers from rheumatoid arthritis which is a debilitating long-term condition.'

*Merv Wyeth pictured on his wedding day with his wife Heather and at the finish with his bike*



## South Coast Challenge 4th August 2019

A big thank you to Duane, Heather, Jeanette and Arnie, a.k.a. The Thornham Marina Worriers!! who took part in the South Coast Challenge and raised amazing total of

**£2,045**



## Katherine Dixon – Skydive 11th August 2019

'Being scared of heights and putting too much faith in a stranger, I am sky diving for JIA at NRAS!'

Katherine raised a fantastic **£410**



## Thames Bridges Challenge

7th September 2019

On Saturday 7th September, Helen and Bronwen are took part in the Thames Bridges Trek; 25km & 16 bridges, with some unrivalled views of London. 'We both work as fundraisers for the National Rheumatoid Arthritis Society and see first-hand every day the difference this charity makes to adults living with rheumatoid arthritis (RA) and children living with juvenile idiopathic arthritis (JIA)'.

Helen Saich & Bronwen Cranfield raised a fantastic **£1,021**



## Lucy Drew – Great Wall of China Discovery Challenge

'Just over 5 years ago I was diagnosed with rheumatoid arthritis and since then have battled with the pain and destruction that this disease can cause. However, I am determined to not let it beat me and instead have decided to embark on a challenge to trek the Great Wall of China to raise money for the National Rheumatoid Arthritis Society'



## Thames Path Challenge 8th September 2019

The 'Lightning Lake' sisters, Mandy, Libby and Sarah, walked a total of 106km between them, in the Thames Path Challenge on September 8th.

'Mandy celebrated a big birthday earlier this year and we decided to mark the occasion by completing this challenge and raising money and awareness for the National Rheumatoid Arthritis Society (NRAS), a charity which our family has found a great support over the last 10 years.'



## Great North Run 8th September 2019

'This is a bucket list race of mine and to be able to run this on behalf of NRAS means a lot to me'

Jamie Mills raised an amazing **£260**



'I'm running the Great North Run in memory of my Nan, Florence Hartley, a wonderful lady who battled through her pain every day to try and keep living a normal life. She was an inspiration and such a positive influence on me as a little girl.'

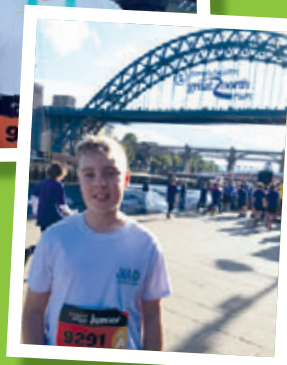
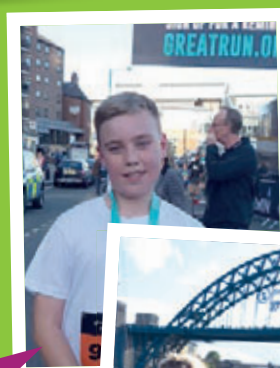
Carron Holmes raised an amazing **£740**



## Great North Mini Run 7th September 2019

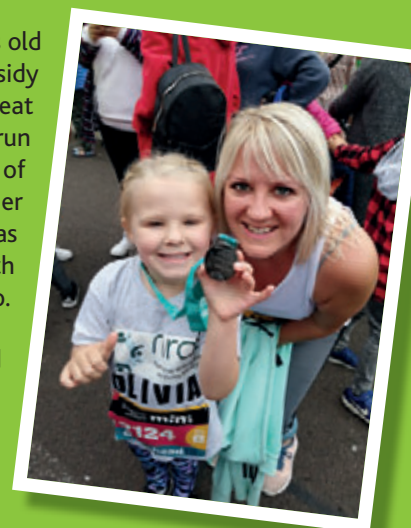
'Charlie Wray has recently been diagnosed with Juvenile Idiopathic Arthritis (JIA) of the spine. Charlie has given himself a goal to complete the Junior Great North Run and support the National Rheumatoid Arthritis Society 'NRAS'. Even though he knows he will struggle, he still wants to complete the run in the hope of raising money and awareness for this amazing charity.'

Charlie raised a fantastic **£1,155**



At 4 years old Olivia Cassidy ran the Great North Mini run in support of her grandmother who was diagnosed with RA 7 years ago.

Olivia raised an amazing **£240**



# Early inflammatory arthritis patients waiting too long for specialist support

A new report reveals that patients with suspected early inflammatory arthritis are waiting too long to see a specialist.

The National Early Inflammatory Arthritis Audit, conducted by the British Society for Rheumatology (BSR), is the largest and most comprehensive study into the condition. It aims to improve patient care and treatment and has recorded the data of over 20,600 patients with 98% of trusts and health boards in England and Wales participating.

Data is measured against NICE quality standards. These highlight key areas to help services improve, such as prompt referral from a GP, seeing a specialist within three weeks and getting treatment within 12 weeks of symptom onset.

The report reveals that only 41% of patients met the 3-day standard for referral from their GP and only 38% referred to a rheumatology unit were seen within the 3-week guidelines. The average wait for the first appointment was 28 days.

Ali Rivett, Chief Executive of the British Society for Rheumatology, said: "A prompt diagnosis of early inflammatory arthritis can make the difference between developing life-long disabilities or actually going into remission.

"As the leading organisation representing rheumatology professionals throughout the UK, we know how hard they are working to meet the needs of the growing number of people who need their help. However, we recognise that more needs to be done so that all units reach the standards."

BSR said many reasons are causing these issues, but that a shortage of staff was a factor.

Ali went on to say: "There's no doubt that staff shortages are part of the problem and contributing to longer waiting times. The NHS simply doesn't have enough rheumatology staff and some units are stretched."

On a positive note, BSR says the audit helps to show the true impact of early inflammatory arthritis on people's lives and the importance of prompt treatment; patients who accessed appropriate treatment within three months were much more likely to get back to work and less likely to suffer from depression or anxiety.

The audit data also shows considerable variation across England and Wales and identifies 51 Trusts or Health Boards performing less well than the rest. These 'outliers' are being encouraged to use their data to lobby for additional resources as well as to look at how processes can be improved.

The audit plays a vital role in identifying where the problems are. It's not just about resources but also units making better use of the resources they have. Reconfiguring services and sharing learning amongst units can make a real difference.

The report shows that there many good examples across England and Wales where units are performing well, and regional champions have been set up to help others learn from their good practice.

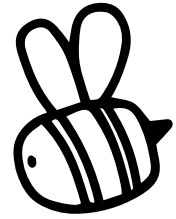
Although things won't change overnight there are improvements being made so that all units can reach the [NICE Quality] standards. Doing this audit really raises awareness of the condition, gets it on people's radars and encourages Trusts to strive for more. BSR will be working hard with the rheumatology community in the coming months and have developed a Quality Improvement Plan to drive real change across the UK.

For more information, visit [www.rheumatology.org.uk/neia-audit](http://www.rheumatology.org.uk/neia-audit)

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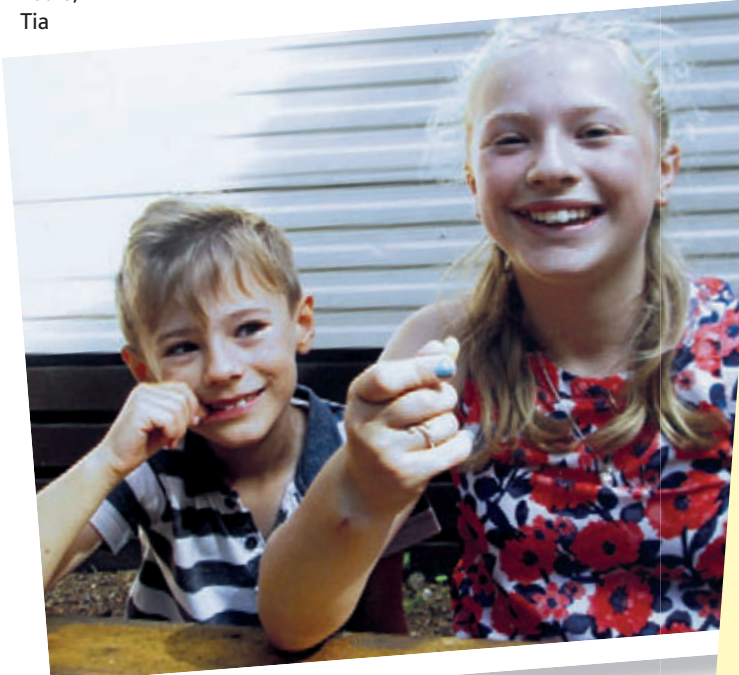
# Poems by Justine



Dear Tracy

Thank you for publishing my daughter, Justine's poems in your magazine. Her JIA is up and down but its manageable with her medicine. I know when she's in pain with her joints, she doesn't always like to let me know, she knows I'll worry but I suppose that's all part of being a mum! Justine has been getting support and help from her Rheumatology team at The Jenny Lind Children's Hospital since she was 4 and soon when she's 16 she'll be moved onto the adults arthritis department.

Yours,  
Tia



Justine who wrote two poems pictured with her brother Jack

## Friends

by Justine age 14

Friends are like bees  
they never sting unless they are scared  
when they sting they get scared  
But when they sting they hurt  
and when they hurt it hurts  
and when it hurts you get angry  
and when you get angry you hate them.

But friends are also like walls  
they are always there, always waiting  
but one day someone comes  
you don't know but they come.  
They come & take all that away  
when it happens you're sad  
then somebody else comes  
they start building  
building where the wall was.  
The wall, your wall  
Another wall appears  
all new & all warm  
you go up for it & sit on it



It feels all lovely like your friend  
but you know nothing will ever replace the wall.  
It gives you a look of sadness  
you look around but nothing  
you see nothing  
Over the years you become close to the wall  
and soon it becomes your friend  
you secretly hope the wall doesn't disappear again  
That's what I think about friends!

## My dad

by Justine age 14



My dad was a clever man & he liked to  
drive to work in his big white van,

He was a plumber & liked to fix taps,  
and when he was at home he liked to  
fix taps!

He also liked cars that were quite old  
He spent most of his free time in the cold

He used to be funny & make us laugh  
When he dressed up as mum & borrowed  
her scarf

When he made us laugh he was quite mad  
I will miss him but he was the  
worlds best dad !!x



By Professor Frances Williams

# The IMRABIOME Study at King's College London

## The Influence of Methotrexate on the RA microBIOME

Rheumatoid Arthritis (RA) is a long term systemic autoimmune disease which affects the joints and other organ systems. Both genetic and environmental factors cause the development of RA. In recent years, research has turned its attention to the role of the human microbiome – the bugs living in and on us - in the development of RA.



Image courtesy of the artist MURUGIAH

### RA and the gut microbiota

The human gut plays host to a complex make up of bugs known as the microbiota. The vastness of the system has led to it being dubbed the "second genome", or to be considered as another organ within the human digestive system. The gut bugs' genetic material, or microbiome, contains an estimated 3 million genes, dwarfing the approximate human host genome of 19,000 genes. An extensive catalogue has already been compiled from a collection of over 1,000 stool samples. These genes produce metabolites, and the thousands of metabolites produced by the gut microbiome are recognised as contributing to a range of important gut functions. Previous work has found that the gut microbiome has a unique "signature" of metabolites that varies from person to person, although everyone studied seems to have the same set of core, functional bacterial genes present.

### Drugs and bugs

RA is commonly treated with disease modifying anti-rheumatic drugs (DMARDs), which include methotrexate amongst others. These drugs are used to slow the progression of damage to the bones of the joints that are affected by RA.

Prof Frances Williams is leading the IMRABIOME Study (the Influence of Methotrexate on the Rheumatoid Arthritis Microbiome) which is recruiting patients at 12 NHS sites across the UK. The study is co-sponsored by Guy's and St Thomas' NHS Trust and King's College London and is funded by Versus Arthritis.

We have recruited over 160 patients newly diagnosed with RA who have never had DMARD treatment but are due to start soon on methotrexate or sulfasalazine. The study collects stool samples at baseline before DMARD treatment begins, then at 3-month and 6-month follow-up visits after treatment has started. The study also collects other samples including saliva,

blood, urine and extensive information on diet, general health history and other medication. The goal of the study is to understand the changes to the gut microbiota as RA treatment progresses, identifying whether there is any difference in those treated with different DMARD drugs. For example, the gut microbiome might influence how successful treatment is – we know some patients have marked improvement in their joints on just methotrexate 10mg per week while others need higher doses and combination therapy.

### The Study So Far

We closed recruitment of new patients at the end of July 2019, so the last follow-up visits are scheduled for February 2020. In total, we aim to recruit 150 patients with stool samples collected successfully at 3 time points. So far, we have obtained 68 complete sets of 3 stool samples. The study is challenged by patients dropping out or being lost to follow up when self-collection of stool samples is required, with an approximate 17% of patients dropping out before completing the study.

Efforts are currently underway to set up a sub study, also funded by Versus Arthritis, in which we will collect stool samples and clinical information from patients who have long

term RA and are part of the Norfolk Arthritis Registrar held by University of East Anglia, in collaboration with Prof A MacGregor. This small addition to the project will lead to a nationally important bioresource for the study of RA and its relationship with the gut microbiome.

### Early results on the RA microbiome

Work so far carried out in TwinsUK at King's College London indicates that some of the bugs reported as increased in the gut microbiome in RA are driven by human genetic factors. That is, having the genes for RA even without having the disease itself can lead to a different microbiome profile. Further work is under way to understand how this is occurring by studying the influence of the immune system in RA.

Research has indicated that the DMARD methotrexate is metabolised by certain gut bacteria. It is also an antimicrobial agent as well as an immunosuppressive drug. The insight provided by the IMRABIOME study could increase our understanding of how DMARD drugs treat RA, as well as the development and disease progression of RA itself. In turn this could shape prevention and future treatment guidelines.



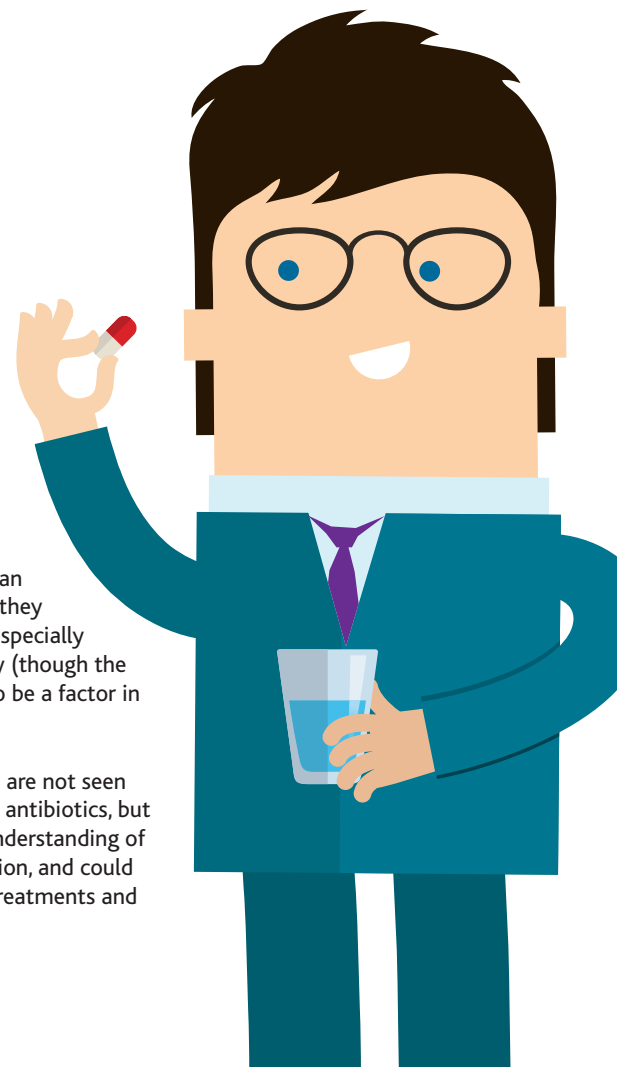
## Study finds link between exposure to Antibiotics and RA onset

**A study by Keele University has found that people with RA who had previously been exposed to antibiotics were 60% more likely to develop rheumatoid arthritis than those who had not. Those who had taken more antibiotics or more recently had a course of antibiotics were at an even greater risk for RA, the study found.**

The study was unable to say with certainty whether it was the antibiotic use or the infection that the antibiotic was used to treat, that caused the increased likelihood of RA, and they did see a difference between the type of infection and the level of risk. Upper respiratory tract infections treated with antibiotics, for example, increased the risk of developing RA, yet for patients who had this type of infection but did not receive antibiotics, this increased risk was not present.

A similar link has been seen in studies looking at other autoimmune conditions, including type 1 diabetes and juvenile idiopathic arthritis (JIA). One study, in 2015, for example, found that children had an increased risk of developing JIA if they had taken antibiotics, and again, especially if in higher doses or more recently (though the type of infection was not found to be a factor in this study).

It is important that these findings are not seen as a reason not to take prescribed antibiotics, but they could be important to the understanding of the complex causes of this condition, and could therefore help us in finding new treatments and possibly even preventions.





# Shaping the Rheumatology Service in Scotland

By Sheila MacLeod

Scottish Ambassador

## Scottish Quality Registry (ScotQR) for Rheumatoid Arthritis



People with RA will be interested to know about a new initiative very soon to be trialled in two areas of Scotland, NHS Greater Glasgow and Clyde and NHS Lanarkshire. We announced its launch earlier in the year but, due to some technical problems, things have been delayed by a few months. Happily, all is now ready to go ahead! The project is being organised by Healthcare Improvement Scotland with the help of a grant from the Health Foundation. Throughout planning and implementation people with RA have been involved.

The system, inspired by arrangements used successfully in Sweden for some time, is designed to offer and strengthen patient-centred care, to make a reality of the doctor-patient partnership and shared decision-making, to support

informed self-management and to promote continuity of care through symptom-tracking and measurement of outcomes.

The focus of the consultation in clinic will be an online tool or 'dashboard' which will combine patient-reported wellbeing outcomes with validated clinical information. Patient and clinician will use this as the basis and framework for their conversation, matters raised and shared decisions will be logged, as well as printed out for the patient to retain. In a fully operational system this resource would be available to patients between routine appointments as a means of recording information and two-way communication; the pilot, being time-limited will not yet include this.

The pilot programme will run for four months from October 2019. Participants at the two pilot sites – both members of the clinical team and patients – will be asked for feedback. The testing of the ScotQR is designed to inform the construction and evaluation of a business case for the further roll out of the registry approach across Scotland within rheumatology as well as possible extension to other specialties.

The benefits to be gained from a quality registry approach – better communication, smoother continuity of care, more timely interventions when required, stronger patient voice both in individual care and in pathway redesign, availability of useful data and, above all, better outcomes (in Sweden a 50% reduction in the effects of disease has been claimed among people with RA) make this an exciting initiative. If you live in one of the pilot sites you will probably have received information already – or will be given all you need ahead of participation. Elsewhere, we will keep you in the picture in the hope that this scheme will be available to us all in Scotland in the near – or at least the foreseeable – future.

# Manchester Ambassadors Update

It's been an interesting year for the Manchester Ambassadors  
Chris Lowe, Ralph Bell, Clive Robinson



## Devolution Manchester

We have been involved in the programme of Devolution Manchester. This is about devolving the powers and health care budgets from National Government. Its aim is to have local decision making and targeting of resources. We are involved in the rheumatoid/MSK strand which is led by Ailsa Bosworth who is doing an amazing job at steering and pushing it forward. The aim is to improve outcomes for rheumatoid patients and standardise the pathways to care. It has been really interesting and hopefully will influence treatment for future generations.

## Rheum for You Manchester

The Manchester Ambassadors were in full force at this brilliant conference. We told the story of our diagnosis and treatment and what had been critical factors for us in our treatment. It was a thoroughly enjoyable conference with interesting sessions on pain relief, biosimilars and a session on Tai Chi which we creaked through. It was lovely to meet up with other NRAS members and Health Care Professionals.

## Daily Telegraph Brexit Medications

Jason Douglas, journalist, interviewed a Manchester Ambassador regarding the potential restriction to supply of medications through Brexit. He also interviewed two other people

with long term chronic illnesses (epilepsy and diabetes) regarding their concerns about getting hold of essential drugs and possible supply issues. As we know from a recent letter campaign by NRAS and responses from MPs, the Government are stockpiling medicines. For those with rheumatoid arthritis there are genuine concerns around the supply of essential medication and fears about any interruption to supply.

## Salford Hospitals Foot Health Survey

We have been involved in the Salford Hospitals Foot Health survey, that has utilised NRAS members and other patient groups to devise relevant and effective questions that health staff can use to more effectively diagnose and manage foot problems. We have the final meeting at the end of November before it goes live.

## Talk at Manchester University

We are giving a talk from the patient perspective of RA in November at the University of Manchester. It is on the Peripheral Joint Problems module of the MSc Clinical Rheumatology Course. We will talk to them from the human perspective about living with RA... it's always good fun and an eye opener for them! Learning about RA is one thing but living with it and its inherent challenges is another.

# Wales Ambassadors Update

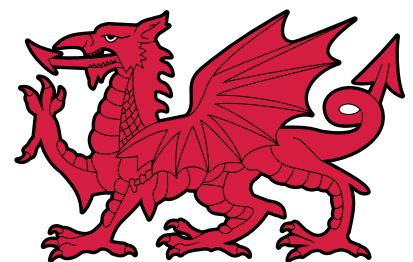
Richard Flowerdew, Carl Harrison

The last 12 months have been another busy year for the Welsh Ambassadors. Around this time last year we were preparing for the NRAS Rheum4you event at Village Hotel in Cardiff. The keynote speaker was Dr Maddie Piper, a Consultant Rheumatologist, who provided a fascinating insight into how treatment for RA has developed and improved over the years. Carl Harrison (Welsh Ambassador) gave a short presentation on the role of an Ambassador, including the importance of building good working relationships with politicians. This has continued in 2019.

In June, Nick Ramsey, Assembly Member (AM) for Monmouthshire, hosted an event on behalf of NRAS at the Welsh Assembly Pierhead Building on raising awareness about RA. This event was promoted by Nick Ramsey AM on the floor of the Senedd. The event itself was a great success. Those in attendance included those with RA

and their families, Assembly Members and an excellent turnout from the team at NRAS. Those Assembly Members who attended were able to get first-hand accounts from those with RA of their experiences living with the disease. We were particularly pleased that a number of people recently diagnosed with RA attended giving them an opportunity to meet others in a similar position and to explain to AMs the problems still persisting in Wales with delay between manifestation of symptoms and diagnosis. In many cases this is still far too long and is something we will be looking into further in 2020.

On a personal note, the event was tinged with some sadness as it was around this time that Ailsa stepped down as Chief Executive. We wish her all the best in her new role of National Patient Champion. We very much look forward to working with Clare in the future. **Roll on 2020!**



# My Story

Lauren O'Dwyer-Buckland



My journey starts at college when I was 18 years old. I was confused as to why my whole body ached and hurt from doing daily activities. My education was coming to an end and the freedom to travel was getting closer and my gosh was I excited to go and do whatever I pleased! Little did I know how trapped I would be feeling after that serious chat with my doctor a few weeks later. I have tested myself to lengths I can't explain. Physically, emotionally and mentally. I wish this wasn't a part of me, but I guess that's the beauty of it. How can the worst bring out the best in people?

My love for the sea and the snow is something that I feel defines me as a person. Keeping active keeps me sane and there is no better feeling than coming out of a good session on the water or snow. My life now consists of travelling the world, meeting fabulous people, taking photos, windsurfing and skiing. When I got diagnosed one thing was certain, I did not want rheumatoid arthritis getting in the way of anything. I am in no way saying getting to where I am now was easy. In fact it's been so hard that I have wanted to give up completely, stay at home, cry, sulk, sob. However, that wouldn't have gotten me here, where I am sitting and writing this now in the snowy mountains of New Zealand!

I was numb for the first couple months and I was in complete denial about having an illness, let alone RA which has no cure. Crying became one of my daily routines, both from the pain and the stress and anxiety of how it was controlling my life.

My original dosage of methotrexate was 15mg once a week and 200mg of hydroxychloroquine twice daily. I am currently on 12.5g of methotrexate and 5mg of folic acid 6 days a week. I've stopped taking hydroxychloroquine altogether which I'm so happy about. In the beginning I was put on to prednisolone, a steroid that essentially puts the 'emergency brakes' on the inflammation of the joints. This worked wonders, however it made me incredibly anxious and sad. I soon came off these after I was able to start MTX properly. There were a few initial side effects that I did struggle with, I was tired all the time and quickly realised I had no energy to do daily tasks, I found that vitamin B12 really helped with the fatigue. My hair also started to fall out quite rapidly which really upset me as I love my hair, but folic acid helped with that too.

MTX has changed my life for the better, it does just take time and patience! I now live my life pretty much pain free, and I feel stronger than I ever have before.

RA doesn't define me as a person, it rises me up.



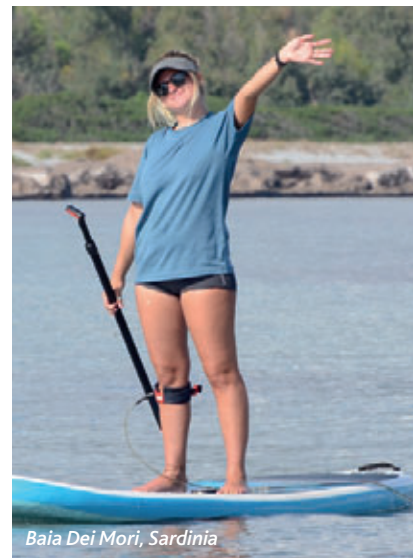
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Keeping active keeps me sane and there is no better feeling than coming out of a good session on the water or snow.

At the time I was diagnosed I was following my passion to become a windsurf and stand up paddle board instructor on a 5-week intensive course on the Isle of Wight. I wasn't completely confident that I would be able to do it, but the various different medications got me through, and I became qualified! This took me to Greece and Sardinia, where I worked for a British active holiday company. Since then I have travelled around and worked in Australia and New Zealand.

I wanted to travel, to meet people, go to crazy places and never want to leave them. To feel so free and full of love and happiness. Untouchable to the negative and to only radiate the positive. Well, I guess that all happened – here I am still

laughing, loving and living in places I could only have dreamed of. RA doesn't define me as a person, it raises me up. It helps me sleep at night knowing I've done myself proud and that I did not give up, and it should for anyone else, no matter what gender, size, age or condition you have. This isn't a sympathy story, because I don't want that. Instead I want to inspire, encourage others and heal. There is so much more to the human body, mind and soul than that of human degradation. We are all worth so much more than that!



Baia Dei Mori, Sardinia

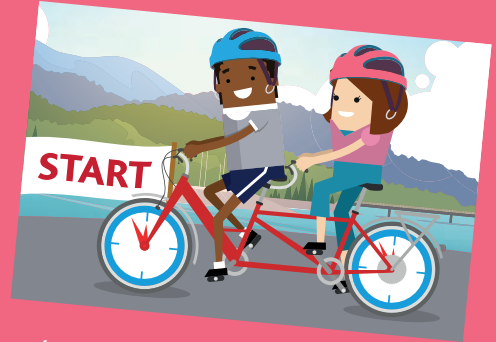


Baia Dei Mori, Sardinia

# Other ways to give

## Company Giving

No matter how big or small your company is, there are several ways it can support the National Rheumatoid Arthritis Society (NRAS) and the work we do to help all those in the UK living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA). With a charity partnership company colleagues can have fun and take part in fundraising, volunteering activities and sport/challenge events with charity places in prominent runs and cycle rides across the country including RideLondon100, Brighton Marathon and Royal Parks Half Marathon. To discuss becoming a corporate partner contact our fundraising team on 01628 823524 or email us at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk)



## Payroll Giving

Payroll giving is the most tax-efficient way to donate to NRAS. For example, a £10 a month donation would only cost you £8 because payroll giving donations are deducted before tax. You can donate any amount and can stop your donation whenever you like. To find out how you can sign up to payroll giving contact our fundraising team on 01628 823524 or email us at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk)



## NRAS Lottery

Tickets bought in the NRAS Lottery help the charity to continue supporting those with RA and JIA in the UK and give you a chance to win £25,000 each week! You can sign up to the NRAS Lottery online at [www.nras.org.uk/lottery](http://www.nras.org.uk/lottery) or call the Unity Helpline on 0370 050 9240.

**50p**  
from every  
pound comes  
directly to NRAS





# National Rheumatoid Arthritis Society's Healthcare Champions Awards 2019



**HEALTHCARE  
CHAMPIONS**

On 1st November we invited winners of our sixth Healthcare Champions Awards to a special reception at the magnificent Leathersellers' Hall in London where the awards were presented by NRAS Founder & National Patient Champion, Ailsa Bosworth MBE



*Pictured left to right, Nominator; Gabrielle Archer, Winners; Sarah Hartfree, Dr Alice Leahy, Anne Craig, Hayley Curme, Maggie Thorne, Dr Samir Patel, NRAS Patient Champion; Ailsa Bosworth MBE, Winners; Ruth Glynn, Stacy Ackerley, Nominator; Savia De Souza, Winner; Dr James Bateman, NRAS CEO; Clare Jacklin, and Winner; Sharon Pearson*

**Team Champions:** Hayley Curme, Maggie Thorne, Anne Craig, Specialist Nurses at the University Hospitals of Morecambe Bay NHS Foundation Trust

**Northern Ireland Champion:** Anne Quinn, Specialist Nurse at Royal Victoria Hospital, Belfast

**Consultant Champion:** Dr James Bateman, Consultant Rheumatologist at Wolverhampton New Cross Hospital

**Mental Health Champion:** Dr James Galloway, Consultant Rheumatologist at King's College Hospital, London

**Scotland Champion:** Rachel Campbell (JIA), Community Paediatrics Nurse at Royal Alexandra Hospital, Scotland

**Wales Champions:** Ruth Glynn and Stacy Ackerley, Specialist Nurses at Wrexham Clwyd Hospital

**JIA Champions:** Paediatric Rheumatology Team Southampton

**Nurse Champion:** Sharon Pearson, Specialist Nurse at Lister Hospital, Stevenage

**Healthcare Champion of Excellence:** Dr Samir Patel, Consultant Physician at Southmead Hospital, Bristol

A major priority for NRAS is to raise public awareness of rheumatoid arthritis and juvenile idiopathic arthritis while at the same time campaign for equal access to good care and services for all. The Healthcare Champions Awards are an important part of this work and provide the opportunity to celebrate the dedication, professionalism and excellent care given by those healthcare professionals that go 'the extra mile' to provide the best possible outcomes for their patients while working in the increasingly challenging environment that is the 21st century NHS.



*The Magnificent Leathersellers' Hall*



*Worcester Group Coordinator, Donna Saunders, eyeing up the tasty canapés*



Clare Jacklin, NRAS CEO talked about the importance of formally recognising the amazing work of so many rheumatology health professionals clinicians and nurses who go above and beyond the call of duty in the care of those living with RA or JIA.

People living with RA, and parents of children with JIA, were asked to nominate an individual or a team of health professionals who they felt had made a significant difference to them or their child, in particular when they did so by going beyond the call of duty. A special panel of judges was then convened to choose the entries that best met the following criteria:

- Provides a rheumatology service that *truly* meets patients' needs
- Treats patients holistically i.e. as individuals
- Involves their patients in decisions about their own care
- Goes that extra mile to listen, to care and to educate their patients about their disease, options and next steps in their care pathway
- Fights for their patients if they need treatment for which funding has become restricted.

In spite of the significant challenges that health professionals face in meeting, in full, all the NICE and BSR standards of care in the UK, there are many instances where high quality,

compassionate care is being delivered and the nominations for the 2019 Healthcare Champions Awards are testament to this.

Many NRAS Members spoke passionately of the care they received, such as:

"My son would not be here if it wasn't for him [Dr James Bateman], and what he did for me and my family."

"Sharon makes me feel like I'm a VIP – the sole focus of her attention and with genuine concern for my well-being."

Healthcare Champion of Excellence, Dr Samir Patel, gave a moving speech to a packed audience including his very proud son, Jack. "I love doing what I do. I enjoy my work looking after people and giving them everything that they need to live a full and rewarding life, so this is a great honour."

The winners and attendees also heard from Clare Jacklin, NRAS Chief Executive, who said, "We are proud and delighted to be honouring these health professionals this evening."





# HEALTHCARE CHAMPIONS 2019



Nominator Savia De Souza accepting the award on behalf of Dr James Galloway, Consultant Rheumatologist at King's College Hospital London



A very proud Dr James Bateman, Consultant Rheumatologist at Wolverhampton New Cross Hospital



Rheumatology Team Champions, Anne Craig, Maggie Thorne, Hayley Curme, Specialist Nurses at University Hospitals of Morecambe Bay NHS Foundation Trust



Healthcare Champion of Excellence, Dr Samir Patel, Consultant Physician at Southmead Hospital, Bristol



NRAS CEO Clare Jacklin and NRAS founder Ailsa Bosworth MBE with Wales Champions Stacy Ackerly & Ruth Glynn



Nurse Champion, Sharon Pearson was nominated by Hertfordshire Group Coordinator, Teresa Shakespeare Smith. "Sharon makes me feel like I'm a VIP, the sole focus of her attention and with genuine concern for my well being."



Sarah Hartfree and Dr Alice Leahy, picking up the JIA Champions Award for the Southampton Hospital Paediatric Rheumatology Team, pictured with their nominator, Gabrielle Archer



# Vitamin D deficiency

## linked to increased likelihood of uveitis in JIA

Studies have long shown a link between low vitamin D levels and a higher incidence rate and severity of autoimmune conditions. A new study, in Germany, has demonstrated that there is also a link between vitamin D levels and the likelihood of developing uveitis.

Interestingly, while 44% of JIA patients in this observational study were found to be vitamin D deficient, this was actually lower than the 62% of vitamin D deficient individuals in the healthy control group. However, it was found that lower vitamin D levels in the JIA group increased the

likelihood of uveitis, which is already known to be common in JIA patients. In addition to this, lower vitamin D levels were also linked to greater disease severity.

The researchers involved in this study have suggested that further studies are needed to investigate this link and to find whether increasing vitamin D levels could help to prevent uveitis and improve levels of disease activity in JIA patients.



## NRAS Pen Pals

“How wonderful it is to be able to write someone a letter! To feel like conveying your thoughts to a person, to sit at your desk and pick up a pen, to put your thoughts into words like this is truly marvellous.”

**Haruki Murakami, from the book Norwegian Wood**

Following the call out for NRAS Pen Pals in last year's Winter 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.

We understand that as a JIA parent, how difficult it can be to find others who understand, so we are asking in this edition if JIA parents would like to submit pen pal requests for the next magazine as Donna has done below.

If you'd like to connect with Donna or any future JIA parent pen pals 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!*

### Donna 104154

*Hi, I am Donna, I am 44 years old, married, and have two teenage sons, one with Autism and youngest has had JIA. I have had a RA and IBD for over 20 years, due to long term steroid use now also Osteopenia, and illness has affected my heart. I love animals, we have three rescue dogs, my house nearly became a zoo with rabbits, guinea pigs, hamsters, fish etc. Hence, I am known as the animal mad lady...Between the boys and dogs they keep me active, I also volunteer as a Rainbow and a Brownie Leader. Girlguiding has really helped over the years to keep me busy and the girls help make me forget my aches and pains. I used to be a Nursery Nurse, but sadly young children with all their cough/colds/bugs etc are no good for my poor immune system, but I am seeking work again with older children, but not finding it easy, as I am limited to the number of hours I can cope with. I would really love to hear from other parents, or animal lovers.*

If you have a pen pal request for a future edition, you can also send them to the address above, email [membership@nras.org.uk](mailto:membership@nras.org.uk) or call Tracy on 01628 823524.

I'm pretty sure people are going to start writing letters again once the email fad passes.

**Willie Geist**

# Facebook Fundraisers

NRAS has been incredibly grateful for the support shown for the charity on our Facebook pages. More and more of you are creating Facebook Fundraisers for birthdays, special anniversaries, in memory of a loved one, events you're participating in or just to raise awareness of RA and JIA.

This year we have already raised over £50,000 which is a fantastic achievement – thank you to you all. Don't forget you can raise funds on both the NRAS and JIA at NRAS pages. It's so easy to do and if it's your birthday Facebook will even donate on your behalf!

Below are some hints and tips to making the most of your Facebook Fundraiser:

### Tell your story

If you have a connection to RA/JIA or a personal reason for supporting NRAS, be sure to tell everyone about it. By sharing your story, your friends, family and supporters will be more likely to donate generously to your fundraiser.

### Ask generous friends and family first

Once your page is set up, ask a generous friend or family member to make the first donation. Studies have shown that people tend to match existing donations on the page.

### Tell people why they should care

Share statistics, videos, posts about how you close to your target you are, how your birthday/event went – anything to keep your supporters updated and make them feel connected to the cause.

### Thank people publicly

Make sure you say thank you to your generous friends and family publicly on your timeline, you can even tag them into the post itself. That way all your friends see it, as well as theirs, which could inspire and remind others to donate too! Besides, saying thank you never hurt anyone, it's just good manners!

If you need help creating a Facebook Fundraiser or other fundraising page, do contact the team at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk). You can find other ways to support NRAS's work on our website [www.nras.org.uk/get-involved](http://www.nras.org.uk/get-involved)



nras National Rheumatoid Arthritis Society

Sign-up Offer was £80 now £20

RideLondon 100 16 August 2020

To register visit [www.nras.org.uk/cycle](http://www.nras.org.uk/cycle)

FR Registered with FUNDRAISING REGULATOR

NRAS is a registered charity in England and Wales (1148578) and Scotland (SC039921). A company limited by guarantee. Registered company in England.

nras National Rheumatoid Arthritis Society

Great North Run | 13 September 2020

To register visit [www.nras.org.uk/runs](http://www.nras.org.uk/runs)

FR Registered with FUNDRAISING REGULATOR

NRAS is a registered charity in England and Wales (1148578) and Scotland (SC039921). A company limited by guarantee. Registered company in England.



# How Age UK can support people with rheumatoid arthritis



Even though receiving a diagnosis may feel lifechanging, it is not life-ending

Dealing with a long-term health condition such as RA later in life can come with its own challenges. The following article was written for NRAS by Age UK, to give our older members information on some of the support and services that may be available to them through this great charity.

## Receiving a diagnosis

Receiving a diagnosis of rheumatoid arthritis may seem overwhelming at first and your thoughts may turn to the impact it could have on your ability to remain active and independent. But it may be of comfort to know that many people manage their condition and live fulfilling lives for many years, and carry on doing things they enjoy, like keeping up interests and hobbies.

Even though receiving a diagnosis may feel lifechanging, getting an early diagnosis and receiving the appropriate medication will be beneficial in slowing the progress of the condition. There are also small changes you can make to your life to adapt how you carry out daily tasks which can ensure that you continue to live as well as possible and make plans for the future.

## Wellbeing and social interaction

It's perfectly natural to feel emotional following a diagnosis of any long-term condition, particularly if you live alone, but seeking support or speaking to friends and family about it can help you to adjust.

It's important to not sweep it under the carpet, and if speaking to friends and family for support is not an option, Age UK has a telephone friendship calling service, 'Call in Time' that can help. It is a national service where a volunteer befriender will phone an older person at an agreed time for a chat. Befrienders are matched with people who have similar interests, who provide friendly conversation and companionship on a regular basis over a long period of time.

[www.ageuk.org.uk/services/befriending-services/sign-up-for-telephone-befriending](http://www.ageuk.org.uk/services/befriending-services/sign-up-for-telephone-befriending)

It may also help to be able to talk to people who are in a similar situation which NRAS can help with. Local Age UKs provide groups, clubs or social occasions where you can meet new people or take up something new, and prevent you feeling isolated or alone. Your local Age UK can help you find an activity or group that will suit your interests. [www.ageuk.org.uk/services/](http://www.ageuk.org.uk/services/)

**in-your-area/social-activities** Social activities can be a great way to maintain self-esteem and confidence which can be critical in coping with pain and other symptoms of RA.

## Shopping

As rheumatoid arthritis causes pain and swelling of the joints, it may impact on activities such as being able to carry bags, or get to and from the shops. Being able to shop for food is an important part of staying well and independent and many local Age UKs offer a range of ways to support older people to be in control of what food they purchase with grocery deliveries and escorted supermarket shopping services. Some may offer services that help using supermarkets' online stores, whereby an order is placed on behalf of the older person and delivery is made to their home by the store at an agreed date and time. [www.ageuk.org.uk/services/in-your-area/shopping](http://www.ageuk.org.uk/services/in-your-area/shopping)

## How movement can help

Regular movement is recommended for everyone, not just people with long-term conditions like rheumatoid arthritis, and there are forms of movement that put less strain on joints, such as swimming, cycling, walking and aqua aerobics. Gentle stretches can be good and setting goals that can be slowly and steadily met is key.

Too much sitting and too little movement can make people feel worse in the long run so it's best to keep active, no matter your age or ability. Gentle regular movement can also help relieve stress, improve wellbeing, maintain joint mobility and strengthen the muscles which are supporting the joints. Lots of local Age UKs run movement classes tailored for older people. Find your local Age UK and get in touch to see what they can offer. [www.ageuk.org.uk/services/in-your-area/exercise](http://www.ageuk.org.uk/services/in-your-area/exercise)

Age UK and 14 other charities launched the campaign 'We are Undeatable' with Sport England this summer. The campaign website has lots of information which helps people to stay active at any age or ability with any health condition. <https://weareundefeatable.co.uk>

## A bit of extra help

If after a diagnosis, you do find yourself needing a bit of extra help; whether for shopping, gardening, house adaptations or advice on benefits, Age UK have a number of helpful fact sheets on their website, and a free telephone advice line for those not online. Experts give up-to-date, confidential information for older people, their families, friends, carers and professionals on a wide range of issues. Call on: **0800 678 1602** Lines are open 8am-7pm, 365 days a year.

Your local Age UK can help you find an activity or group that will suit your interests.

# Artist supports NRAS

Joanna Brendon was diagnosed with RA in 2013 and has been supporting NRAS since 2014.



Joanna has supported NRAS in various ways, including selling her handcrafted greetings cards to raise money. She has recently developed Interstitial Lung Disease but that didn't stop her hosting an Open Studio event in London in June which raised over **£380** for NRAS. She then set up a Facebook Fundraiser for her 75th Birthday and invited friends to donate to NRAS and raised another **£430**.

Thank you Joanna for all your support.

# JIA Happenings 2019

2019 has been a packed year for the JIA-at-NRAS Team, together we have welcomed 67 families to JIA-at-NRAS Family days at Cheltenham, Ilkley in Yorkshire and Exeter, and hosted 18 children at Bushcraft Days in Oxford and Castle Howard.



Clare Jacklin NRAS CEO welcomed the JIA families to Nell Bank and gave an update on NRAS

We sent out over 200 packs for Wear Purple for JIA which raised over **£47,600!** We hosted a visit from Maria Ekroth, CEO of The Finnish Rheumatism Association who joined the NRAS Team for one of the Wear Purple school events.



## Family Fun Day at Nell Bank





## Family Fun Day, Nell Bank

In June we hosted the 4th JIA-at-NRAS Ilkley Family Fun Day at Nell Bank, which is set in the beautiful countryside of Ilkley, West Yorkshire. Nell Bank is a purpose-built activity centre that provides day and residential experiences for children and teenagers of any age, ability and mobility range. We welcomed a number of new faces and many returning families, on what was one of the hottest days of the year!

Children and teenagers with JIA and their siblings, were able to enjoy pond dipping for water monsters, hut building, whilst their parents had the opportunity to listen to talks with healthcare professionals and ask questions during a dedicated Q&A section at the end of each presentation.

This year we were joined by rheumatology experts, Dr Mark Wood, a Consultant Paediatric and Adolescent Rheumatologist at The Leeds Teaching Hospitals, Georgia Hayward, Young Person Keyworker in Paediatric Rheumatology at Leeds Teaching Hospitals and Sandra Marshall, a Specialist Paediatric Rheumatology Nurse at Leeds Teaching Hospitals.

The fourth and final talk was from Chloe Scarlett, who has had JIA since she was 2 years old. Chloe is a qualified Drama Therapist and enthralled the audience with an inspirational presentation about her journey. Audience members were overwhelmed by her lust for life and her belief that a full life can be lived despite JIA.

## Bushcraft, Oxford

July saw us host Bushcraft Oxford, some of the children were attending for the third time so they must enjoy themselves to keep coming back for more. Everyone had to shelter most of the time under the camp tepee as the weather was truly horrendous, but there was not one grumble from anyone, and they got stuck in and made the best of it. Tom and Sam, our rangers, looked after and entertained us. They showed us how to make fire, which was very challenging when every stick in the wood was wet, even the cotton wool and wire wool were wet, resorting to matches didn't help either as they were wet too!! Weaving paracord to make survival bracelets proved popular with some of the children, making extra bracelets for their siblings which was really thoughtful! The rangers taught everyone about the art of camouflage and how to hide successfully in the woods, the children didn't need to be invited twice to use mud to camouflage themselves! One of the stand-out moments was a young girl who was so nervous about coming along saying, at the end of the day, on the walk out of camp, that she was definitely coming back next year and bringing her classmate with JIA. It was so lovely to see her and all the children having such fun, it made the day so special and I'm sure for Jo, the Occupational Therapist, having the opportunity to see them outside of the hospital environment.



*Cornbury Park – team flags made and everyone ready to hide and see if the camouflage worked*



*Cornbury Park – hard at work perfecting their survival bracelets*



*Cornbury Park muddied up and ready to hide*

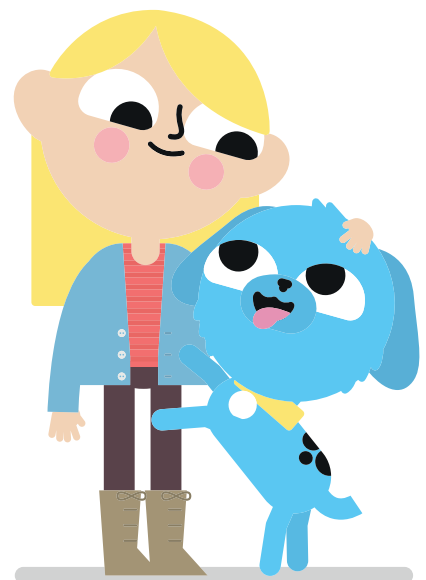


### Bushcraft, Castle Howard

In August we hosted another Bushcraft Day at Castle Howard in Yorkshire and we were looked after by camp rangers, Holly and Jason. They taught everyone how to make ground pegs perhaps from a piece of wood, for which a surprising amount of skill was needed! The team worked together gathering wood and learning how to make a fire. They did an excellent job and made a roaring fire. The Bushcraft rangers played games and managed to answer just about every question asked, no matter how random. Everyone felt welcome, involved and valued and a very tired team of Bushcrafters were duly returned to their parents at the end of the day!

In October Ian McNicol and Emma Bartlett from RA Services at NRAS, attended British Society of Paediatric & Adolescent Rheumatology (BSPAR) Conference in Birmingham. They spent a lot of time talking to Healthcare Professionals to find out what they think the gaps are in JIA Services and what NRAS can do to fill that gap. They also attended talks on transition, pain management, nutrition and how to motivate young people with JIA which were all very interesting. Hopefully with everything they learned and discussed with HCPs, we will be able to develop our JIA service further in the future.

So, a huge thank you to everyone who has attended JIA events or supported us by fundraising in 2019, and here's to an even bigger and better 2020.



# JIA Fundraisers



Our younger supporters have been star fundraisers this year helping to raise awareness about living with JIA as a young person and raise funds so that other children can benefit from our family days and other JIA family events.



*Jasmine and her NCS team friends*



*Jasmine having her infusion!*

## Jasmine is 16 years old and was diagnosed with JIA when she was seven years old

As part of the Social Action Project phase of the National Citizen Service (NCS), Jasmine and 15 others from her NCS group supported JIA-at-NRAS with a hugely successful Fun Day held on 21st July. They raised a phenomenal **£1,762!**

## Eleanor climbs Mount Snowdon

While on holiday in North Wales this summer, Eleanor (7), along with her friend Jess (6), sister Caitlin (3) and their families climbed to the top of Mount Snowdon to raise funds for JIA-at-NRAS Services.

Climbing 8.5 miles to a height of 1085 metres – no mean feat for little ones! Eleanor had decided she wanted to make this challenge a fundraiser and a way of telling more people about what really happens when you are diagnosed with JIA at just over 2 years old.

Eleanor has endured endless hospital appointments and steroid injections under general anaesthetic. She has been on Methotrexate from age 3, with regular blood tests, and orthotics for shoes and a physio to help with her joint movement. Eleanor has been in remission for the past 2 years but still gets regular eye checks after suspected uveitis. She loves dancing and gymnastics and, with a supportive school who provided special pencils and a writing board, she is now on par with all her peers. Eleanor is a very determined young lady and has raised an amazing **£375.**



*Eleanor pictured in pink and sister Caitlin at top of Snowdon*



*Eleanor with mum Nikola and dad Steve, with friends, Jess, Becca and Sam*



# Events Diary

19 April	<b>Brighton Marathon</b>
2 May	<b>The Gathering</b> , Edinburgh, Scotland
25 May	<b>Vitality 10K</b>
5 June	<b>#WearPurpleforJIA</b>
15-21 June	<b>NRAS Rheumatoid Arthritis Awareness Week (RAAW)</b>
16 August	<b>RideLondon – 100</b>
13 September	<b>Great North Run</b>
11 October	<b>Royal Parks Half Marathon</b>
12 October	<b>World Arthritis Day</b>

## Looking for a Challenge for 2020?

Order your Events brochure at [fundraising@nras.org.uk](mailto:fundraising@nras.org.uk)

Save the date



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

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