



nras
National Rheumatoid
Arthritis Society

WINTER 2015
Magazine



P30
FEATURE
Edgar Stene
Prize 2015

**NRAS TEAM WISHES YOU
ALL A HEALTHY AND
HAPPY CHRISTMAS**

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Dear Members...

As I write this, I have yet to clap eyes on a single Christmas tree or decoration, however, preparations for the festive season will be well underway by the time this lands on your doorstep! I cannot believe how rapidly this year has flown by. I've said that before but this year seems to have been the speediest yet. Clearly a sign I'm getting older!

I've just taken part in this year's GNR and would like to say a huge thank you to Chris, David, Donna, Dean, Cathy and Gemma for being my valiant pushers. The weather this year was fantastic which brought out the crowds who were incredibly supportive on our way round to South Shields from Newcastle city centre. Thank you also to everyone who supported us and the other runners who were running for NRAS (20 in total – amazing!). Jointly, and with funds still coming in as I write this, we have raised well over £13,000!



Chris, David, Donna, Cathy, Gemma and Dean my valiant pushers

We have just launched a new NRAS group in Glasgow which was well attended and our Londonderry group launch is 21st October. We are hugely grateful to our Group Co-ordinators who run our community groups as they are our NRAS representatives on

the ground across the UK, along with our supportive Members. We need you to help spread the word about NRAS and how we can help and support people with RA and childhood arthritis (JIA), especially at time of diagnosis when they may be feeling frightened and alone. We also rely on health professionals to sign-post their patients to NRAS so that we can be there when they need us right from the start and we've made it easier than ever for health professionals to sign-post now with helpline cards (business card size) which they can have on their desk in a natty holder. Please apply to tammy@nras.org.uk or phone her on 0845 458 3969 if you'd like a supply for your clinic desk. We have them for both RA and our JIA@NRAS service.

"If only someone had told me about NRAS when I was diagnosed, it would have made all the difference."

We've been doing a lot in Scotland lately including working with the Scottish Society for Rheumatology (SSR) on The Scottish Metrics for the Assessment of Rheumatoid Arthritis (SMART) project see page 7 for an outline of the project. For information on other great things we are up to in Scotland see our Policy & Public Affairs section on page 16.

We are also going to be doing a major patient survey across Wales which we



hope will be a major source of up to date information which will be useful in the run up to the elections in the devolved nations next year and help us to identify issues to be included in our manifesto, so if you live in Wales, I would urge you to fill in the questionnaire when it comes and let us know what matters to you about the services in your area.

The NRAS Christmas concert this year will be held on Friday 11th December in Maidenhead. It's always a lovely occasion and if you happen to live or be visiting near Maidenhead at this time I do hope you will come and join us to celebrate this special season. Full details on the website.

On behalf of the whole team here at NRAS we would like to thank you all, Members, Volunteers, health professionals and supporters for working with us this year and helping us to support all those living with RA and JIA. We wish you a very merry Christmas and good health and happiness for the coming year.

This year my family's Christmas will be very special as it's our grand-daughter's first ever Christmas and though it's still September as I write this, I can't wait to show her the tree and help her open her presents!

Arlisa

Welcome to new NRAS staff, Conn O'Neill & Anne Gilbert

Conn joined NRAS in June as Government Affairs Officer. Conn brings some first-hand political experience to the role having spent the last year in the Scottish Highlands as Campaign Manager for the late Charles Kennedy.

Conn grew up in Yorkshire before moving to Scotland first for university and then for work; he's enjoying being back in England but is still liable to be taken aback by just how many people there are everywhere having got used to the empty roads of the highlands!

Conn's parents both work in the health sector and so it was an area that always held his interest but it didn't prepare him for the baptism of fire that is the maze of acronyms used within the NHS and healthcare generally; CCG, MSK, NICE, RCN, BSR, BHPR, CSP, etc. etc. etc.

Conn fooled us all with his quiet manner and serious exterior but his quick turn of phrase and witty comebacks often take us by surprise and he has us in stitches laughing in the office on a regular basis! Welcome Conn, you've fitted in well to the NRAS team and we look forward to working with you to raise the flag for NRAS in Westminster, Cardiff, Edinburgh and Belfast.

Anne joined the team in May this year as Youth & Family Services Manager and she's settled in really well and has got up



Conn O'Neill and Anne Gilbert

to speed very quickly. JIA@NRAS is in great hands as Anne has over 15 years experience of working in Children's Services, supporting families, young people and schools, which will be hugely beneficial to her role leading a number of key young people's projects and NRAS' JIA strategy going forward.

Ann lives in Windsor with her two teenage boys, a snake and a crazy puppy and she regularly keeps the office entertained with the latest exciting instalment in the Gilbert family story. This November Anne is taking on the mammoth challenge of giving up alcohol for an entire month to support NRAS – we here in the office are all on tenterhooks to see if she can manage it! Good luck Anne.

www.justgiving.com/Anne-Gilbert1

NRAS Magazine

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Meet the Team...

Ailsa on Beverley

Beverley has been Information and Support Co-ordinator and a key member of our Helpline team since January, 2014. She completed her training and got to grips, very rapidly, with the huge amount of information, knowledge and sign-posting which is a key part of the job on helpline where you can be asked anything on any aspect of living with RA. She has a warm and friendly approach to supporting the thousands who contact us for help, whether it's by phone, email or in moderating the NRAS HealthUnlocked forum.

Beverley is also a keen fundraiser and is frequently coming up with ideas about how the NRAS team can fundraise but is also doing her own thing! She held a tea-party for NRAS during RA Awareness Week and is going to trek 100km across the Moroccan Sahara in November which is rather awe-inspiring from my perspective. Previously she has done Everest Base Camp, the Inca Trail in Peru and the last trek was to Mount Kilimanjaro!! She used to work in the health industry and has a science background in chemistry, having first worked for Kodak in their research labs, so came to NRAS with a great range of skills which has held her in good stead for the role she undertakes. She is married with two grown up daughters, Catherine and Rebecca, who are amazingly proud of their Mum's amazing fundraising feats! I wish her a successful crossing of the Sahara next month. www.justgiving.com/beverleyinthesahara



Phil on Denise

Denise Pointon is NRAS' Finance Director who, as well as being good with money, is a keen gardener with a particular fondness for roses and has enjoyed golf, tennis, skiing and canoeing among her 'off-duty' activities. Denise joined NRAS in May 2014 and describes the main element of her job as ensuring the sustainability of the charity, a phrase which encompasses a great deal from helping NRAS to get the best value from services we both use and provide, to making sure the paperwork gets done properly and on time. With a varied career background Denise brings a wealth of experience to the charity, from Flight Lieutenant in the RAF, General Manager of a company in Spain, spells of freelancing and working with Four Seasons Healthcare. Denise's background and experience in finance and management has enabled her to pretty rapidly become not only a valued member of the Senior Management Team, but be a huge support to the different teams within NRAS.



Farewell and a huge, big thank you to Ruth!

Ruth Grosart joined the NRAS family way back in 2011 working on the NRAS online & social media outreach but it wasn't long before she was the NRAS "IT Guru". In the four years Ruth spent with NRAS she honed her IT skills and kept NRAS' finger firmly on the pulse of the social media revolution. Facebook posts, tweets, web development, database reports, Thunderclaps, Health Unlocked and so much more were all part of the challenges thrown at Ruth on pretty much a daily basis. Never did she shy away from such challenges. We don't only miss her wonderful work ethic and IT knowledge we all miss her contagious laugh, her friendship and her willingness to help everyone. Ruth was a keen fundraiser too and got up to all sorts to raise much needed funds for NRAS. NRAS knows Ruth is ambitious and while we were so sad to say goodbye to her back in August, we were not surprised that she was ready to take the next step up to a bigger organisation to embrace the next progression in her career. We take pride in playing a part in her development and hope that one day when she is "top dog of the social media world" she won't forget her humble beginnings with NRAS. All of us here at NRAS office wish her all the very best in what promises to be a flourishing successful career with *Action for Children*.



Yellow Card App Launched

The Medicines and Healthcare products Regulatory Authority (MHRA) has launched an app for patients and healthcare professionals to report the side effects of medicines via the Yellow Card Scheme.

All medicines can occasionally cause unwanted side effects. Many side effects are mild, but some can be serious and even life-threatening. Occasionally, they can appear after a person has stopped taking a medicine. Some side effects, especially those associated with newer drugs, may not be recognised until many people have been taking the medicine for a long time. That's why it is important for people to report suspected side effects, especially if these are severe.

The Yellow Card Scheme collects information on suspected side effects from all types of medicines. These include prescription medicines or vaccines, medicines you can buy without a prescription, herbal and complementary remedies. Yellow Card reports are sent to the MHRA, the government agency responsible for ensuring that medicines and medical devices work, and are acceptably safe.

The new app supplements the existing website and is the only app that allows the reporting of side effects directly to the MHRA. The app is free to download on iOS and android. Key features of the app include:

- A convenient, paperless way to submit a report of a side effect of a drug
- The ability to create a 'watch list' of medications to receive official news and alerts. This means patients can keep an eye on any emerging safety concerns with their own medicines and promptly seek advice from a GP or pharmacist should they occur.
- The facility to view the numbers of Yellow Cards submitted for a particular medicine
- The power to view and submit updates to previously submitted Yellow Cards (for instance if the side effect has got worse or improved or gone away on stopping a medicine)

So what should I report?

It is especially useful for the MHRA to know about side effects that:



- Are not mentioned in the patient information leaflet supplied with the medicine
- Cause problems severe enough to interfere with everyday activities
- Occur when taking more than one medicine, since these could be caused by drug interactions.

"Sometimes, it is difficult to tell whether a symptom is a side effect of your medicine, or something else," said Sarah Smith, Senior Pharmacist Pharmacovigilance at Yellow Card Centre Northern and Yorkshire. "Even if you are not sure, please make a Yellow Card report if you think a medicine might have caused a side effect. Additional information such as what the medicine was used for, the dose, details of any other medicines that may have been taken and any relevant medical history can help us better understand the background to a report."

Side effects can also be reported by:

- Using the online Yellow Card at <https://yellowcard.mhra.gov.uk/>
- Picking up a patient Yellow Card form from a pharmacy or GP surgery
- Calling the Yellow Card hotline on 0808 100 3352 (weekdays 10am- 2pm).

What will happen after a report is made?

All reports are handled in strict confidence. If reported via the

app you will receive an immediate acknowledgement of your report. If reported via other means an email or letter will be sent to you. The information is added to the MHRA database, so that the reports can be analysed for emerging drug safety signals, and evaluated together with information from clinical trials and other medical literature.

If a new side effect is identified, it is carefully considered in the context of the overall side effect profile for the medicine, and how that compares with other medicines used to treat the same condition.

Sarah Smith added: "If a new side effect is found, the MHRA will review the way that the medicine can be used, and the warnings given to people taking it. In some cases, the medication may even be withdrawn from market. We want to ensure that medicines are used in a way that minimises risk, while maximising patient benefit. The information that you provide can ultimately improve the safe use of medicines."

If you are worried about a suspected side effect, contact a doctor or pharmacist, or call NHS 111 in England and Wales or NHS24 in Scotland also on 111. The MHRA cannot provide medical advice in individual cases.

For more information on Yellow Card reporting visit <https://yellowcard.mhra.gov.uk/the-yellow-card-scheme/>

Living with RA – My biggest regrets. Three things I wish I could do over

By Carol Eustice

Arthritis & Joint Conditions Expert

I have lived with rheumatoid arthritis for more than 4 decades. I experienced my first symptoms in September 1974 at the age of 19. As I look back over those decades and realize I have spent about twice as many years with a chronic disease as I did pre-diagnosis, I am proud of how I have managed my disease and lived my life. For the most part, that is. I mean, we all have regrets. I actually can point to three major regrets I have that are associated with my rheumatoid arthritis journey.

I decided to tell you about the regrets with the hope that some of you may learn from it and perhaps not repeat my mistakes. But, I also know that each of us with rheumatoid arthritis has our own journey. At the very least, I hope my experiences show you that it is important for us to be careful, thoughtful, and methodical with the decisions we make about our life with rheumatoid arthritis.

Regret #1 – Around 1975, a year after my initial symptoms had started and I was being treated by our family doctor, I requested a referral to a rheumatologist at The Cleveland Clinic. I lived in Cleveland at the time so it made sense to see what this world renowned medical facility and its doctors could offer me. To make a long story short, my rheumatologist recommended that I be admitted to the hospital for about a week for a course of three drugs, some to be administered intravenously. I didn't even give him a chance to explain his plan fully. I immediately said "I'm in college. I don't have time to miss classes and to be admitted to a hospital."

I know he didn't have a cure for me, since we know there is none to this day. But, he did speak of "dampening down the inflammation" and "gaining control". At age 19-20, I was clueless about the impact of rheumatoid arthritis. I simply saw it as an intruder in my life, and I decided that denial suited me. In my mind, there was a swirl of thoughts -- I don't need that. It won't. I won't. It can't.

I chose an oral course of methotrexate as my alternate treatment plan since I opted out of the suggested hospitalization. The rheumatologist was disappointed. To this day, I remember his face when I told him. And even then, I was fearful of the methotrexate, which at the time was still considered an experimental drug with potential consequences of liver toxicity. Feeling that methotrexate wasn't working, I went on and off the drug several times. We never tried raising my dose which can have good results for some people. **My regret is that I just didn't listen to my rheumatologist.** Perhaps I could have achieved remission early on. We will never know. We don't get do-overs.

Regret #2 – After I graduated from college in 1977, I was working in a hospital as a Registered Medical Technologist. I worked fulltime for 10 years but it was becoming increasingly difficult with my rheumatoid arthritis. I decided to go to part-time status and did that for 5 or 6 years when I decided I could no longer do my job. I quit and applied for Social. As my medical technologist career wound down, I had overlooked some important financial facts. If I had quit while I was still fulltime, I would have been entitled to a Long-term Disability benefit. I lost that benefit when I switched to part-time. Big Financial Mistake!

In my mind, I thought I would never quit working at the laboratory. I would go from full to part-time and when things got better, back to fulltime. It was denial steering the boat again. **My regret is that I was not more aware of the financial impact of my decisions and that I was not more realistic.** (Note: I actually only stayed on Social Security Disability a short time as I began my new writing career, which I do to this day.)

Regret #3 – I wish I knew then what I know now. Throughout my many years with rheumatoid arthritis, the importance of exercise and regular physical activity was never emphasized by any of my doctors. As a matter of fact, after one of my joint replacement surgeries, I remember asking



Carol Eustice

the surgeon about exercising beyond the 2 month stint of physical therapy that is typically required. The surgeon told me I didn't need more. He said I was young and would just "bounce back". It didn't happen that way.

More recently, I asked for a physical therapy referral from another orthopaedic surgeon. He said it wouldn't help. I felt I could rebuild and regain some strength I had lost after experiencing two stress fractures. This time, I knew better. I took it upon myself to find a great gym, get an evaluation by their physical therapist, and insist on the referral. It has made a huge difference. I still go to the gym regularly.

But, I regret that I missed out on years of exercise when it wasn't emphasized or recommended to me. Now, I realize the importance of exercise in managing rheumatoid arthritis.

The Bottom Line

Be fully aware of the impact of your decisions. Make sure you are being realistic and that denial is not masking the reality of your situation.

NRAS comment: Carol lives in America but we felt that her experience might be relatable to many of you on this side of the Atlantic too. You can read more of her blogs and tips on <http://arthritis.about.com/> and to find out more about exercise visit www.nras.org.uk/exercise

Scottish Metrics for the Assessment of Rheumatoid Arthritis Treatment (SMART) work in Scotland!



SMART approach to improve quality of Rheumatoid Arthritis (RA) care and treatment in Scotland

A new initiative launched this September aims to drive up quality of RA care and treatment in Scotland so that people with RA get their disease controlled as quickly and effectively as possible.

The Scottish Metrics for the Assessment of Rheumatoid Arthritis (SMART) project has asked rheumatology departments across the whole of Scotland to record what happens at key stages of the patient journey. This will provide a clear picture of current clinical practice at diagnosis and for the first 12 months, and help to identify aspects of care that could be improved.

People with RA in Scotland with a new diagnosis of RA have been asked to take part in the audit and a special on-line 'audit tool' has been developed to capture information about their diagnosis, care and treatment. This data will be analysed to find out how different rheumatology departments deliver patient services in relation to national guidance and to each other.

Led by the Scottish Society for Rheumatology (SSR), the audit has been developed by a partnership working group which includes clinicians who are members of the SSR as well as patient organisations, The National Rheumatoid Arthritis Society and Arthritis Care, and industry, Roche Products Limited. "The SMART project is very timely and vitally important," said Dr Elizabeth Murphy, SSR President. "While there are a host of guidelines for treatment of RA patients, NHS Scotland currently lacks measures that can be used to assess

how the health service is performing with regards to treatment of RA, and whether patients are being optimally managed according to these guidelines in order to maximise the likelihood of patients achieving disease remission," she explained.

Data from people with RA consenting to take part in the audit is being recorded at the start of the project and again at 6 and 12 months. This will provide a valuable overview of how people are managed in the first year of diagnosis – a time period where good control of RA is especially important for their outcomes in the long term. All patient information will be collected, processed and stored securely and anonymised before data analysis and publication of findings so that it will not be possible to identify individual patients.

"We will also be asking patients how their RA affects their lifestyle, day-to-day activities and work – it's essential that we focus not only on clinical information but also capture directly from patients the impact of RA on their lives and what matters most to them. Learning from this

audit will help Rheumatology teams to develop better patient services and care, and to optimise early treatment of RA," said Dr Murphy.

Ailsa Bosworth, CEO of NRAS said; "The Chair of our Scottish Campaigns Network, Sheila MacLeod, and I have been involved with this important project from the start because we believe that this will help to drive up standards of care for people with RA across Scotland. We shall be encouraging everyone being referred with a possible diagnosis of RA to take part in this audit. If anyone reading this article would like more information about the audit, do get in touch with me at NRAS [ailsa@nras.org.uk]

In future we shall be further collaborating with the Scottish Society for Rheumatology and Arthritis Care to design a survey for people with existing, established disease across Scotland, so rest assured that this population, whilst not involved in the current SMART audit is not being ignored.



My Story... *By Nicci Talbot*

I was diagnosed with rheumatoid arthritis (RA) at 38 after a viral infection caused joint inflammation that didn't go away. As a single parent juggling freelance journalism work with a part time job in a natural health centre it was a real wake up call to re-evaluate my lifestyle.

I was diagnosed with sero-positive RA, which came as a big shock, as there is no history of it in my family. I was offered Methotrexate and steroid injections by a rather old school GP and felt cornered so asked for a second opinion and referral to Brighton hospital which had a rheumatology research department. I spent six months on a gluten-free diet to reduce inflammation and tried various therapies: colonics, biofeedback, reflexology and massage. They helped to a point in terms of relaxation but the pain and swelling persisted and I was feeling exhausted from not sleeping well and finding it difficult to get out of bed with morning stiffness.

The second opinion was that if I didn't take medication I risked permanent joint damage, which may require surgery so I started on Methotrexate. My dosage has changed and I've seen several locums since (after bursting into tears about being unable to cope, a lovely Greek consultant offered me Biologics – a combination of entanercept (Enbrel) and methotrexate). I have been doing weekly injections for a few months now and feel pretty normal again, which is a revelation and something I don't take for granted (like childbirth it's easy to forget how bad joint pain is once it's over...) but when I have a flare up it is an instant reminder.

I still see medication as a temporary solution and my goal is to find out more about what causes RA and to get it into remission.

Exercise has been key in staying on top of my RA. My approach is to work from the 'inside out' – if I feel strong in my body and in a positive mindset (which endorphins create) I want to be out in the world and am more productive. Daily walks are non-negotiable and I have created a self-management routine, which includes massage, my eco Pranamats (an amazing acupressure mat), journaling, blogging, visualisation when

I inject meds and regular orgasms – yes! Orgasms are natural painkillers; make you feel happy and relaxed and I have made them part of my working day as a sex toy reviewer.

RA has been a valuable lesson in terms of self-care, priorities and looking after myself. It has forced me to consider how I spend my time, what nurtures and energises me and to set realistic goals for my work. Health is everything and our bodies are in a constant state of repair – their goal is homeostasis and it's helpful to keep this in mind when you have a long-term health condition like RA. I have lived in London for years, backpacked all over the world, carried shopping and a child with no car to lighten the load, juggled various jobs and been in debt throughout my 30s – all of which have no doubt contributed to my 'dis-ease'.

A positive way to think about pain is as a form of healing with your body shedding what needs to be expressed so



that you can move on. In the early days of RA I did a creativity course called The Mastery of Self-expression, which was a safe space to cry, laugh and something for myself – a spa weekend for the soul – and this helped me with self-acceptance and loving myself a little bit more.



Right to left, Nicci with her daughter Julieta with a friend Adriana in snowy Norway



Nicci says: *Ailsa has done an amazing job setting up NRAS and the society is doing wonderful work – it is fantastic to have access to research, courses, opportunities to get involved and support on the other end of the phone. I will do some charity events, join the NRAS Lottery (£25K would help towards moving somewhere warmer... which is one goal), use the Health Unlocked Forum and make use of initiatives like the Save at Sainsbury's Card which donates funds to NRAS from your weekly shop. It is well worth the annual membership fee as a gift to yourself.*

NRAS RA Awareness Week 2015 survey summary

As part of the society's aim to raise awareness of RA and its many varied impacts on the lives of those living with RA, we conducted an extensive survey during the awareness week in June.

There were 35 questions in total covering topics from family history, views on prescription charges to what sort of support people get, were given or would like to have been given but had not had access to.

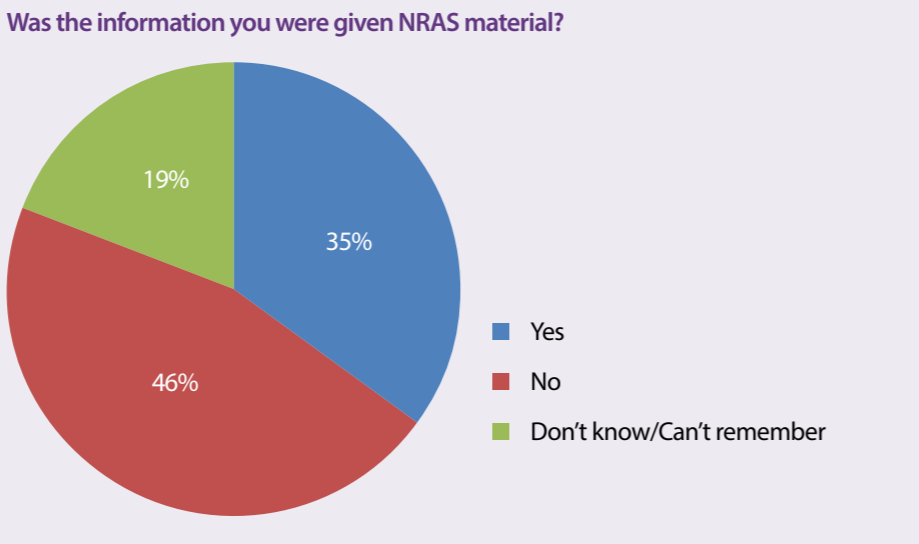
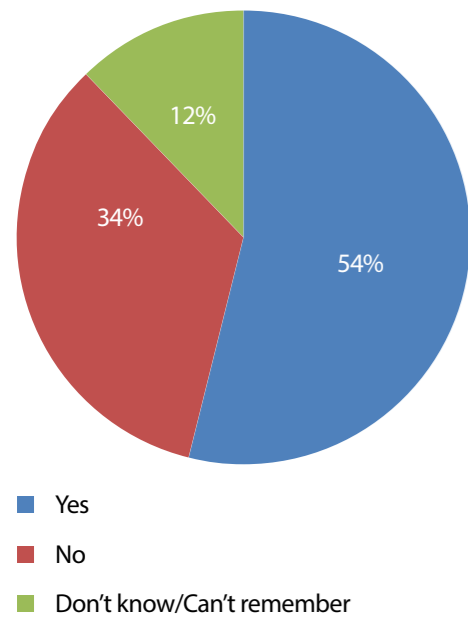
We were overwhelmed with the responses and would like to say a massive thank you to everyone who took the time to share their experience of living with RA by completing the questionnaire.

Here are some of the key highlights from the survey.

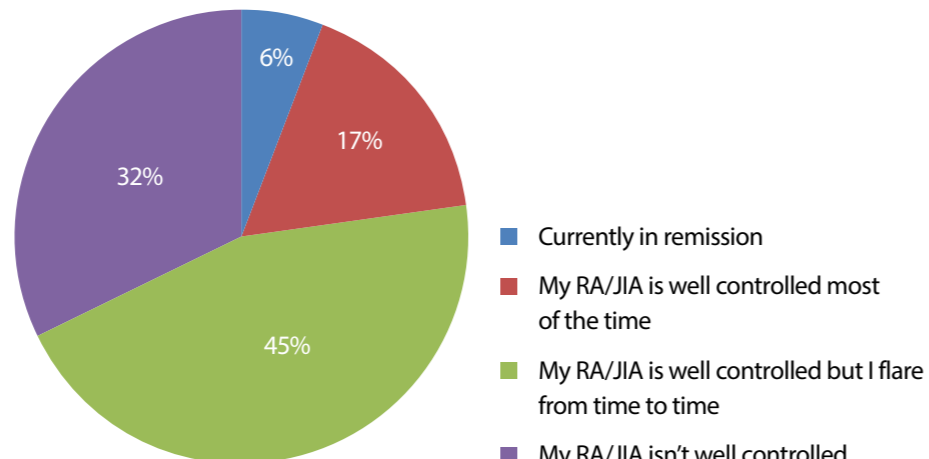
634 people participated in the survey.

Some of the key questions we asked are shared here.

When you were first diagnosed, did anyone give you any information about what RA or JIA was and what to expect? 619 responded to this question but the results were disappointing. Look how many people were not given vital information at such a crucial time.



When asked how people would rate their disease just under a third (173 of the 549 who responded to this question) said their disease was NOT well controlled.



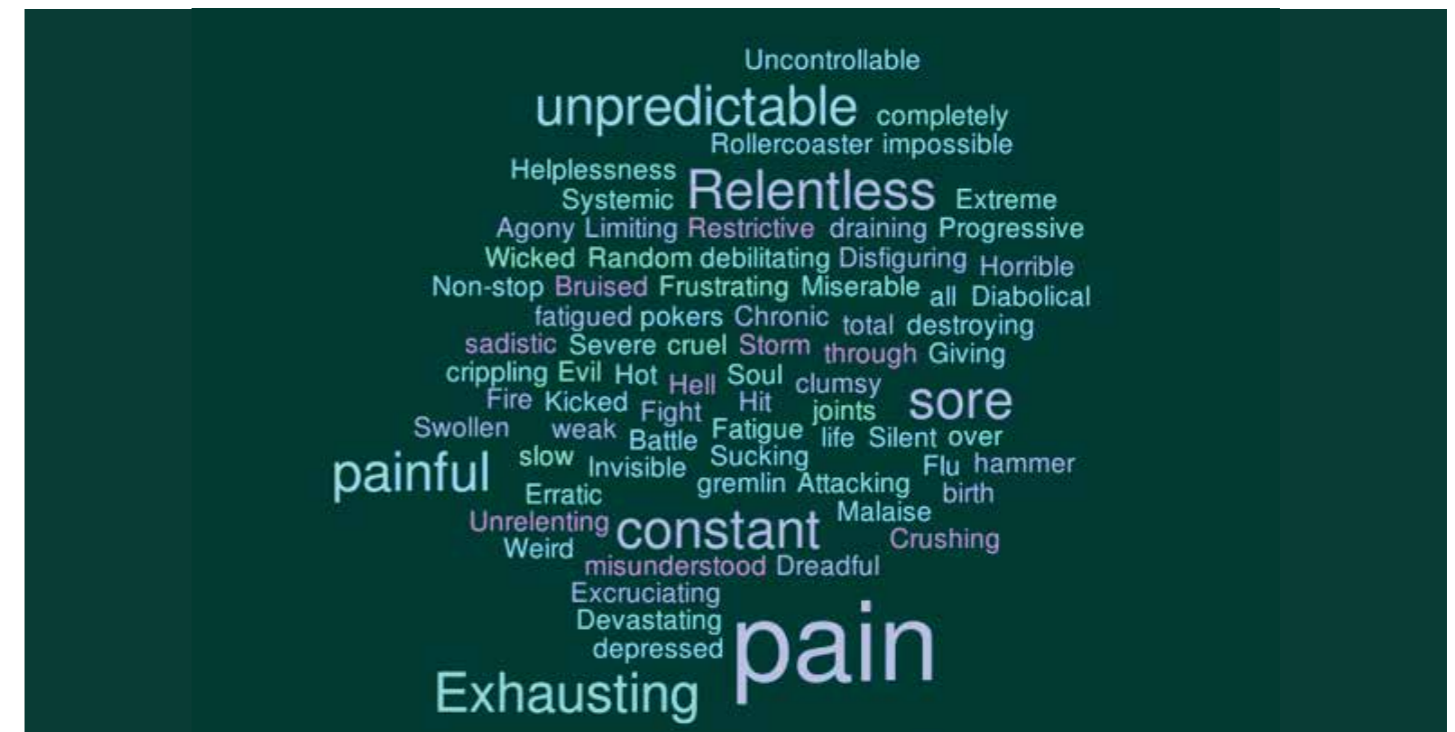
Was any of this information produced by NRAS?

331 people answered this question and again it was disappointing to note that 46% were not offered NRAS information when first diagnosed!

Action: Healthcare professionals order the NRAS Newly Diagnosed packs today - free - to hand out in clinic.



NRAS Newly Diagnosed Packs



If this is truly representative of the entire RA population of the UK i.e. 690,000 it could indicate that a lot of people might be living with uncontrolled disease! However, we appreciate that these opinions are entirely subjective.

People were also asked how they would describe their disease to someone who knew nothing about inflammatory arthritis, the responses were very emotive with very descriptive language being used.

Some people really painted a picture when describing their condition and we thought we would share some of the most literal descriptions:

- A wicked witch moves around my body hurting me and I never know where she is going to turn up next!*
- It's like a vampire sucking all your energy & replacing it with chronic pain. It sucks the life out of you literally & steals your old life away from you.*
- It's like someone has thrown you out of the boat of life during a storm on a journey in which you were already feeling very sick and left you to swim for shore grasping at any support you can get to whilst desperately trying to stay afloat.*
- It's as if your body is a pub and you never know where the fight will start, how long it will last and the severity of the fight on top of this there could be several fights going on at the same time.*

It like living with an unpredictable lodger, you never know when and if they will cause hassle

So what now?

It is clear there is need for better integration and shared care between primary and secondary care. NRAS will use your responses to work with all stakeholders to prioritise integration of services. **Action:** Could you be the patient voice in your locality by taking part in Clinical Commissioning Group meetings, Patient participation groups, Healthwatch, rheumatology service redesign meetings etc?

The right information at the right time is incredibly important- NRAS relies on rheumatology units to signpost patients, especially those newly diagnosed, to the free information and support available from your Society. **Action:** Could you be the NRAS patient link for your rheumatology team to keep NRAS booklets and information up to date in your unit? If you are a health professional let NRAS help you to help your patients in a variety of ways....just ask. As a health professional, don't forget that when you give your patient an NRAS booklet you are not only opening the door to high quality information but a whole range of support services that could change your patient's life for the better.

Peer support can be a life line **Action:** Could you offer support to others by being a telephone support volunteer? Can you offer support to others via the NRAS groups?

NRAS will continue to lobby for better and faster access to treatments and interventions so as to get more people's disease under control and more people into remission.

If you want to play your part in making the difference in any of these ways email enquiries@nras.org.uk or call 0845 458 3969. Together we can make the world of difference to those living with RA and JIA.

Your Society Needs You – NRAS are looking for new Trustees to join the Board of Trustee Directors

NRAS is looking for new trustees with diverse skills and backgrounds in line with the people we represent. We'd like to attract people of ALL ages, with a professional background, who have RA or JIA or who have a close family connection with the cause.

Due to the retirement of some of our trustees in the last 18 months, we now wish to recruit up to 5 new Trustee Directors. A full description of the particular skills and person we are looking for can be found on the website www.nras.org.uk/trustees.

We would like to attract some younger people (under 35) onto the Board, as well as those with more experience, so welcome anyone with skills and background to mirror those we represent. The role of our Board is to oversee and ensure good governance, approve annual financial statement and budget, protect the charity from liability, minimise risk, ensure legal compliance, and participate in fundraising.

In regard to our JIA@NRAS new childhood arthritis service, we have need of a trustee to take on a specific safe-guarding role in regard to our policies on this subject.

With a new children's service developing and a new trading arm set up to deal with directly commissioned NHS work relating to delivery of supported self-management

services, this is a great opportunity for the right people to help represent NRAS at Board level. We are keen to engage with anyone with the right credentials, interested in supporting the society going forward.

We are looking for people with any of the following skills and experience: Strategic development skills in digital, social media and IT as well as those who have worked perhaps in human resources, mentoring, marketing, fundraising, business development, commissioning and public services. We already have two Trustees with accountancy backgrounds and one with a legal background.

We are a 'doing' organisation, not a 'talking shop'. We achieve a lot and have an enviable international reputation. We require people who are passionate about what they do and are prepared to support a great cause with equal passion.

What's in it for you as a volunteer Trustee?

We believe this is a great opportunity to contribute in a key way to a vitally

important cause. If you want a future non-exec role anywhere, often time spent on a charity board can be a pre-requisite to achieving that.

Annual time commitment

- 4 Board meetings/year in Maidenhead
- 1 or 2 day-long events
- Attendance at key events (e.g. parliamentary launch of a report; prestigious fundraising events)
- 2 or 3 conference calls during the year.

To apply or for more information:

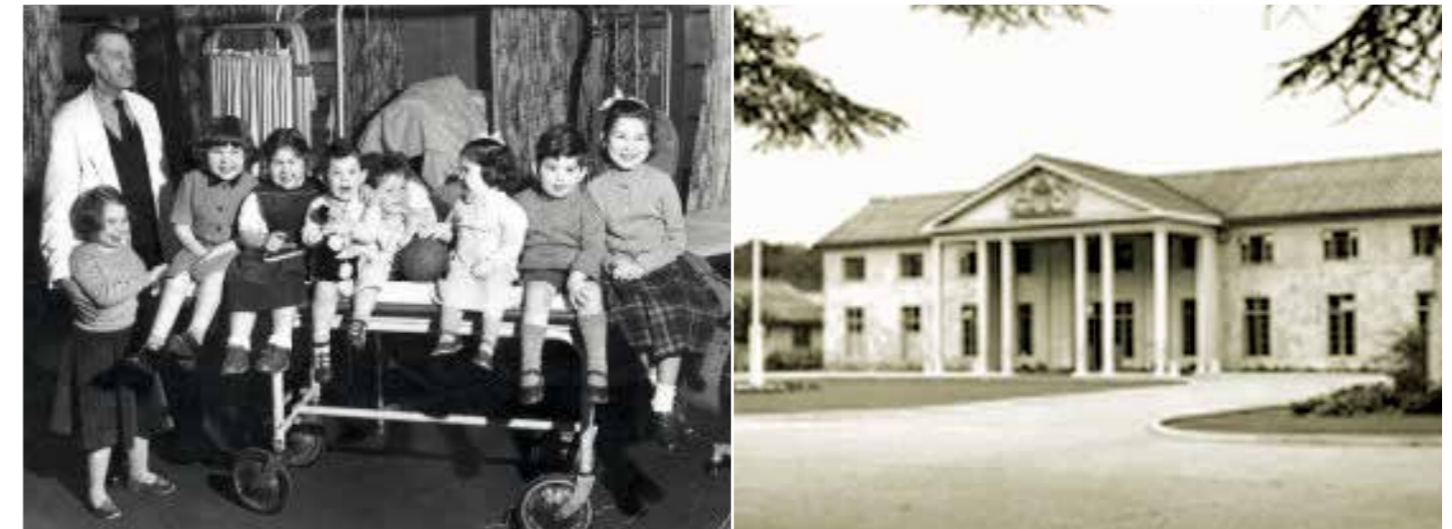
Please apply to the Chief Executive, Ailsa Bosworth

Email: ailsa@nras.org.uk Tel: work no. 01628 823524 Mobile: 07703 276791

Please provide an up to date CV and explain why you are interested. Please also indicate if you have RA or JIA or a close relation with either.

Canadian Red Cross Hospital for Children in Taplow remembered

This year is the 30th anniversary of the closure in 1985 of the famous Taplow unit which treated children with Juvenile Arthritis. In 1914, during World War I, the Astor family invited the Canadian Red Cross to build a military hospital on part of the Cliveden estate in Taplow, Berkshire, not far from the NRAS office.



The Red Cross built a small hospital on the site of the HRH Duchess of Connaught Hospital with equipment from Canada. During the Second World War, the Canadian Red Cross demolished many of the then existing buildings to make way for a new, larger hospital with more equipment which was named the Canadian Red Cross Memorial Hospital.

After the war the hospital was donated to the UK for use as a general hospital and research centre into rheumatism in children. After the completion of its transformation, it opened to the public in 1947 and soon afterwards came under the supervision of the newly formed National Health Service. In the following years, the hospital gained a large maternity unit and was also a training school for nursing and midwifery.

The Special Unit for Juvenile Rheumatism (now referred to as Juvenile Idiopathic Arthritis) served as a centre for the treatment of arthritis in children

and became world-famous due to the work and reputation of its foremost specialist, Dr Barbara Ansell.

In the early 1980s the hospital was becoming increasingly redundant due to health authority budget cuts and certain functions being superseded by the nearby Wexham Park Hospital in Slough. The closure of the hospital was announced in 1985 and it closed later that year.

We have Members of NRAS, now adults living with JIA, who remember Barbara Ansell and staying in the hospital. It's difficult to imagine this now, such has been the transformational improvement in the treatment and care of children and young people with JIA, but children from all over the UK came to live in the hospital (a bit like a boarding school) where they had their daily treatment

including hydrotherapy and exercise alongside attending school lessons!

If anyone reading this has memories of being an in-patient at Taplow as a child with JIA, please do write to us and let us know. We have already heard from one gentleman who was there and would like to connect with others who were there also.

Please email Nicola@nras.org.uk if you would like to be part of a Taplow virtual reunion!



Get involved...

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



Membership

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



Fundraising

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



External Affairs

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

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

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

More reasons why exercise is SO important for people with RA!

By Andrew Lemmey, Professor of Clinical Exercise Physiology, School of Sport, Health and Exercise Sciences, Bangor University, Wales.

There are a number of conditions (co-morbidities) associated with rheumatoid arthritis that your rheumatologist/GP may have told you about. These include increased risk of: cardiovascular disease (CVD), obesity, muscle loss, fatigue and disability. The good news is that all of these can be substantially improved by appropriate exercise.

The adverse changes in body composition (loss of muscle mass and increase in fat mass) are termed rheumatoid cachexia (cachexia means weakness and wasting of the body due to chronic illness) and are usually undiagnosed as physicians rarely assess body composition. However, rheumatoid cachexia is common, even in individuals with well controlled RA. For example, we regularly find that 2/3rds of our stable RA patients are significantly muscle wasted and 80% are obese. In turn, these changes in body composition promote weakness, disability, fatigue and CVD. The key driver of rheumatoid cachexia is inflammation. Consequently, it is vital to control inflammation, not only to preserve your joints, but to reduce these adverse effects on body composition. Unfortunately, however, even when inflammation is very well controlled (i.e. clinical remission is when DAS28 score is less than 2.6), body composition is not restored (i.e. muscle put on and fat shed). In fact, we have just completed a study looking at the effects of the widely used and very effective "treat-to-target" (T2T) therapy on body composition and physical function [T2T involves earlier and more aggressive drug treatment and has been shown to have considerable benefit versus previous treatments, including much better preservation of joints]. And despite the success of T2T (approximately 50% of our patients had achieved remission), it had not improved body composition nor, as a consequence, performance of function tests (our patients performed 25-35% worse than healthy sedentary individuals of the same sex and age in a variety of tasks e.g. walking speed, standing from a chair, grip strength, leg strength). We believe that the lack of effect in improving body composition of (even

successful) DMARD treatment is because i) rheumatoid cachexia primarily occurs in the pre-clinical phase of RA (before the initiation of DMARD treatment), and ii) DMARDs do not increase muscle; in fact, anti-TNFs and high-dose corticosteroids both increase fatness.



Prof. Andrew Lemmey with RA patient Christine Jones and Dr Sally Wilson clinical exercise physiologist.

These findings underline the importance of exercise as an additional part of your treatment, together with your anti-RA medications, as exercise builds muscle and burns fat and, as a consequence, restores function. We demonstrated this in a study (Lemmey et al., *Arthritis Care & Research* 2009, 61:1726-1734) which involved individuals with RA performing resistance training (RT; weight training). After 24 weeks' training (twice a week), patients had gained muscle, and lost a lot of fat (particularly fat around the trunk; which is of major benefit as this fat increases CVD and type II diabetes risk). In addition to improving body composition, RT more than doubled strength, and, as a consequence, physical function was restored to a level which was as good, even better, than that typical of healthy individuals of the same age and gender. Similarly, a combination of aerobic training (e.g. walking, cycling) with RT has also been shown to substantially reduce CVD risk (Stavropoulos-Kalinoglou et al., *Annals of Rheumatic Diseases* 2013, 72(11):1819-1825).

Whilst RA is characterised by muscle loss, there is no change in the quality of the muscle. As a consequence, individuals with RA respond to exercise, in terms of the benefits on aerobic capacity (endurance), strength, body composition, function, co-morbidity risk, quality of life, psychological

health etc., in the same way as non-RA individuals. Thus, exercise recommendations for individuals with RA are more dependent on current fitness level and co-morbidities than RA. In other words, training programmes for individuals with RA are usually no different than programmes for the general population, other than that some specific exercises might be modified to accommodate joint damage and pain. When commencing training, some muscle soreness is inevitable – this is normal and experienced by everyone who performs unfamiliar activities, but the soreness gets less and less the more often you do the activity. Provided you don't overdo things at the outset, your body will rapidly adapt to the demands of exercise. To avoid soreness when you start make sure you start at a relatively comfortable level and progress gradually. As you adapt and get fitter, it is vital that you progressively increase the distance you are walking, the speed you are walking, the weight you are lifting etc, as your body only gets fitter if you are doing more than it is accustomed to doing.



Christine Jones

It is important to emphasise that exercising, even at high-intensity, is safe for those with RA. Research studies have repeatedly shown that training DOES NOT increase joint damage, pain, disease activity, inflammation, or fatigue. In fact, studies regularly show that these improve with regular physical activity.

In summary, exercising is not only safe for arthritis patients, but the ONLY treatment that can fully restore your body composition (increase your muscle mass, reduce your fat mass) and physical function. Additionally, as with the general population, it is likely to substantially reduce your risk of CVD, diabetes and osteoporosis plus contribute to improved quality of life, vitality, confidence and mental health.

Policy & Public Affairs update

By Conn O'Neill, NRAS Policy & Public Affairs Officer

As a patient organisation, NRAS seeks to be the voice for people with RA and JIA. One of the most effective ways we make your voice heard is by engaging with key decision makers within the government and the health service, sometimes we do this in partnership with other charities but we always manage to punch above our weight.

We look at both policy and practice before making a judgement on the role we can play in driving up standards of care for everyone. Many people think of campaigning as marching down the street with a placard, sometimes it is, but it can be much more subtle. Our very existence as a charity is a statement of our belief and a reminder to anyone who finds us that we think there is still room for improvement.

In the run up to the UK General Election, NRAS produced a manifesto detailing the key issues affecting people with RA and JIA. Some of NRAS Members were able to meet with election candidates in their area and make them aware of the issues your society, NRAS was campaigning on, it was really important to capitalise on a politically fluid moment. The polls did not predict a majority government for either side and so everyone (including David Cameron) was a bit surprised by the albeit slim, Conservative majority on the morning of May 8th.

As proposed in their manifesto, the Conservatives are implementing a further round of spending cuts. Whilst the NHS is excluded from these cuts (in

fact all parties went into the election promising as much as £8bn extra funding for the NHS – over a five year period), Department of Health spending overall could still be subject to cuts of up to 40% and the huge Welfare budget at the Department for Work and Pensions (DWP) is a prime target for 'efficiency savings'. NRAS understands that we are living in a challenging economic environment, but we are doing our best to ensure that reduction in spending does not have a detrimental impact on the service provision for, or the day to day lives of, people with RA and childhood arthritis (JIA).

One of the biggest issues we are working with the DWP on at present is the roll-out of the Personal Independence Payment (PIP), a new benefit for which many claimants of Disability Living Allowance (DLA) will be eligible when that benefit is phased out. After early horror stories about the assessment for PIP, we are pleased that the DWP is working with NRAS and other patient organisations to improve the understanding assessors have of fluctuating long term conditions. Our information services team and one of

our medical advisors have reviewed the training material on RA provided to the assessors and I have recently attended meetings with the new service provider, Maximus (who replaced ATOS) and with the DWP's own engagement forum.

Politics is local, both geographically and on a personal level. We have already seen the devolution of health care to the Scottish Parliament and Welsh Assembly and by 2020 some regions of England are likely to have increased control of their own healthcare arrangements. Equally, decision makers are becoming more aware of the small number of people who make up the majority of spending in the NHS (the vast majority of spending is on patients with Long Term Conditions which include RA and JIA). It is important that politicians at every level understand the impact on real people of the decisions they make and so we encourage all NRAS Members to help raise awareness by speaking or writing to their representatives – you can use the e-action facility on our website to do this at www.nras.org.uk/campaign.

Scotland campaigns update

Update from the Chair of Scottish Campaigns Network, Sheila MacLeod

On 21 and 22 May Mavis Graham, John Paton and I attended the Scottish Society for Rheumatology (SSR) Conference and a celebration of 50 years of the Centre for Rheumatic Diseases in Glasgow. We were made most welcome as we ran the NRAS stand through the two days, which attracted widespread interest, and we took part in fascinating sessions on every aspect of rheumatological disease - background science, cutting edge research, treatment strategies and the evidence which supports them as well as surrounding issues such as pain and oral medicine. We all had good and productive conversations with conference participants from a wide range of disciplines.

Our main impressions were: the pace of change is rapid and there is real vigour and optimism; Scotland - particularly Glasgow - plays and will play a key part; the rheumatology community is

very highly committed to upholding and improving standards of treatment and care - we appreciate and support this; NRAS has a real place as a recognised and respected contributor; our relationship with healthcare professionals is increasingly a warm and productive one.

Ambassador visits to all the rheumatology teams across Scotland are nearing completion. It has been a big undertaking - involving exploring the road and the miles to various remoter spots - but we have found the opportunity enormously valuable. NRAS looks forward to growing collaboration for the benefit of people with RA across the whole UK and we as Scottish NRAS Ambassadors are playing our part in fostering that spirit of collaboration here in Scotland.

We continue to contribute the patient perspective to SSR Quality Improvement



Sheila MacLeod

Projects - in particular the Flare Clinic in Glasgow and Scottish Metrics for Assessment of Rheumatoid Arthritis Treatment (SMART), [which is fully described on page 7]. This project demonstrates the commitment of the profession to explore new ways to provide the best possible service and to build on these examples of good practice. We are more than happy to participate and look forward with optimism to further creative developments.

In an addition to the hard work being carried out in Scotland by the NRAS Ambassadors, the team in Maidenhead have also been involved in a number of Scotland centric projects.

We have worked in partnership with the Scottish Society for Rheumatology to make the case for increased funding of Rheumatology Nurse Specialists in light of additional funding being made available for Specialist Nurses at each Scottish Health Board. To make the case for Rheumatology Services to be funded with this additional money, we conducted a survey of Rheumatology Nurse Specialists in Scotland. The findings showed that alarmingly, whilst the majority of Specialist Nurses are over the age of 55 and approaching retirement, no health board has a structured succession plan in place. Already, our survey has shown that community based care from the Specialist Nurse is not a possibility for patients in most areas of Scotland with the majority only having resource to provide core services. This situation will only get worse without rapid investment in new Rheumatology Nurse Specialists and so we will continue

to urge health boards to allocate some of the funds provided to them by the Scottish Government for additional spending on specialist nursing in rheumatology. The full report is available on our website.

At the time of publication, we are in the middle of a large scale research project into the care needs of people with RA in Scotland. Working in partnership with Dr Kathryn Martin, an Epidemiologist at

the University of Aberdeen, we will be producing a report for publication in spring 2016 before the Scottish Parliamentary elections. With the political interest in the integration of health and social care, it is important that the needs of people with RA in both contexts are fully understood; if you are resident in Scotland, over 16 and have RA, please visit www.nras.org.uk/ScottishSocialCare to complete the survey.



Wales campaigns update

Our team of Welsh Ambassadors has been busy campaigning on your behalf and representing NRAS across the country. It has been a significant boost to our profile in Wales to have this dedicated team of volunteers on the ground. The Welsh Campaigns Network has not been up and running as long as the Scottish Network but both are now well established and share ideas with one another.

The Meet the Patients event held in the Welsh Assembly earlier this year is still paying dividends; we are very pleased to have developed strong relationships with some Assembly Members. Huw Roberts, Chair of the Welsh Campaigns Network, was able to work with Simon Thomas, AM, who tabled several questions about Rheumatology Services/RA in the Assembly before the summer recess. Following the return of new Assembly Members in the elections next May, we hope to establish a Cross Party Group on Musculoskeletal Conditions (MSK) in collaboration with other organisations, as this is likely to help us raise the profile of musculoskeletal and rheumatological conditions.

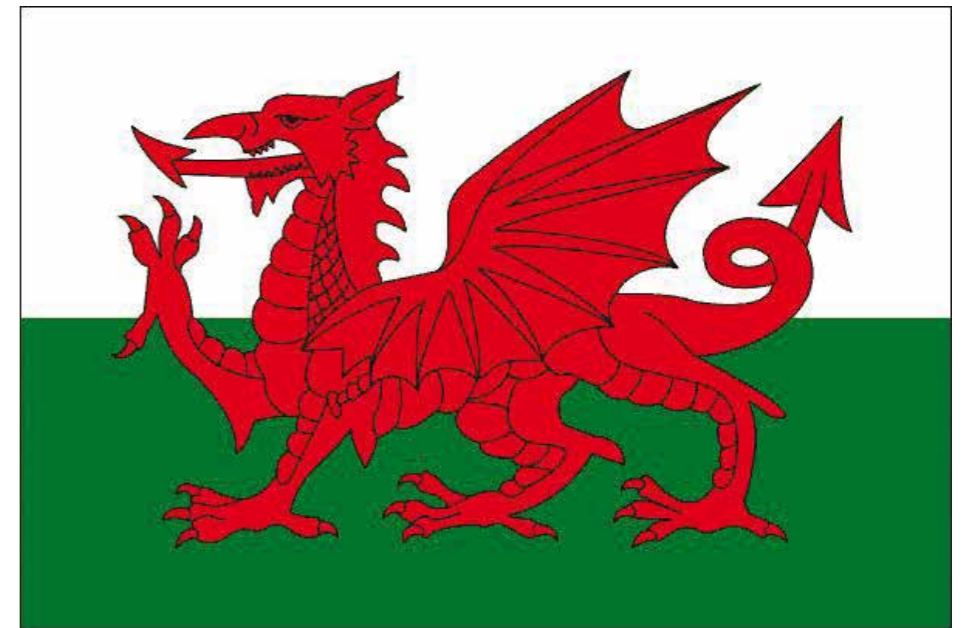


Richie Presenting to the Gwent NRAS group

We are putting together a wide ranging survey on patient needs, the results of which will be used to inform a brief manifesto ahead of the Assembly elections outlining the priorities for NRAS Members and people living with RA in Wales. The Ambassadors have begun a series of meetings with Health Boards to further their understanding of NRAS's work and establish a strong working relationship - when available we will share the findings of the survey with them.



Dr Sharon Jones & Dr Anurag Negi meet with chair of the Welsh Ambassadors Huw Roberts



Great North Run revisited!

This year's Great North Run saw a 21 strong team of NRAS runners taking to the streets of Newcastle for one of the most popular of all half marathons.

This year Ailsa, NRAS CEO, took to the streets in her wheelchair for the final time. Ailsa's team of fantastic 'pushers' – Dr. Chris Deighton, Professor David Scott, Dr Catherine Swales, Donna and Dean were joined en-route by NRAS Member Gemma Campbell. They all really stepped up to the mark and pushed Ailsa over the finish line in style. Ailsa said, "I am so glad I have been able to complete the Great North Run this year for this is definitely my last time to do it. It certainly was touch and go as to whether I would be able to do it at all this year as 2015 has been incredibly difficult for me; the last 8 months. have been the most challenging period I have had to face in my many years of living with RA. I have been battling with high levels of pain. My team of pushers have been incredible as have all those who have supported us by donating to on the Justgiving page, thank you each and everyone one of you.



Chris, David, Donna, Cathy, Gemma and Dean my valiant pushers

Our team this year raised over £13,000 in sponsorship, simply fantastic! A huge thank you to all our runners who took part, you are simply the best! If you would like to join our 2016 team now is the time to reserve your place in the team. Visit our website at <http://www.nras.org.uk/runs> to book your place today.

Hair Today and Gone Tomorrow

Whether our fundraisers are cutting their hair or growing their hair, 2015 seems to be the year to take on a Hairy Challenge! Two ladies who went for the chop were the lovely Pam Martin and Jo Osborn. Pamela who is from Aberdeen decided one way she could raise funds for NRAS and people like herself who live with RA was to be very bold and crop off her lovely locks! Friends and family showed their support and Pam raised £685.00.

Jo Osborn decided to support a friend who was going through treatment for cancer as well as showing her support for her mum who has RA, by braving the shears and shaving off her long flowing locks. Jo had her head shaved by her hairdresser on 25th September and asked people to 'Shave the Date' and come down and watch the proceedings at The Old Mill in Berkshampstead. Jo raised £3,500.

Carl Nero decided he would grow his hair for a whole year and ask people to sponsor his challenge. Carl will finish his challenge on the 31st December and so far is sticking to it. Carl's reason for choosing to support NRAS was that his mum has RA and he felt that he wanted to do something to help raise awareness about this disease. So far Carl has raised £310 and it's not too late to sponsor him: www.justgiving.com/carlnero/



Pam before and after the chop



Bubble blowing Jo before the chop



Carl Nero Hair Growing Fundraiser

Worcester RAmble Wows again

The NRAS RA Awareness Week RAmble was once again held in the lovely grounds of Spetchley Park, with the Worcester NRAS group firmly in the driving seat to make sure it turned out to be a real family event, particularly as it was held on Father's Day! With over 100 people walking together in their NRAS t-shirts, they certainly raised awareness of the disease and our awareness week.

Donna Saunders, Worcester Group Co-ordinator, decided to make this year's RAmble a memorable one with side

stalls and activities to suit everyone. The highlight for some of the children was when the local fire brigade turned up with their fire engine and flashing blue lights!

Thank you to everyone who turned up on the day and took part in one of the 3 NRAS walks and to all those who gave their time on the day to make sure everyone had a great time. A huge thanks also goes to Spetchley Park for allowing us the use of their grounds for our event. Almost £1500 was raised by the RAmble, well done everyone!



A "RAmbling RAbble went a RoAming!"

Marvellous Money from Morrison's

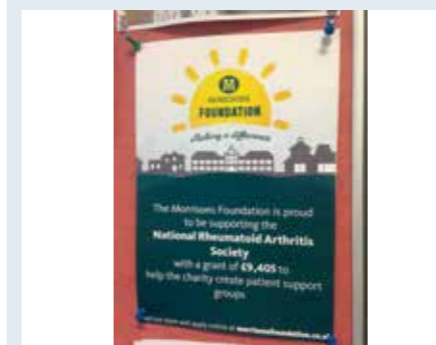
NRAS were elated to be given a donation for £9,405 on 24th August from the Morrison's Foundation to help us make a positive difference to those living with RA across the UK.

The cheque, presented by Morrison's High Wycombe Manager, Lee King, will be used towards the costs of launching and running new patient NRAS groups over the course of 2016.



Morrison's Cheque presentation

We are delighted to receive such a generous donation towards the society's work and this will help us to improve the lives of even more people with RA across the UK.



Morrison's Foundation poster

Turning their Skill to Cycling

A Team of 6 colleagues from the Derbyshire recruitment based company, Skillbase Ltd, decided to turn their own skills to cycling 82 miles from Nottingham to Skegness at the beginning of July. One of the reasons they chose to support NRAS is that their MD Jason Bates knows all about how this condition can affect day to day life as his wife Julie was diagnosed with RA a few years ago. At the time Julie was unable to walk due to chronic pain and fatigue. Fast forward now a few years and Julie is an active fundraiser and Group Co-ordinator for one of our local NRAS Groups, helping to support and inform others about the disease. The cyclists were all novices at distance cycling and got themselves kitted out for the challenge with new road bikes and all the top gear. They set themselves a fundraising target of £1,000 which, thanks to their supporters ticking Gift Aid with their donations, they have achieved. Well done to the team which also included Sean White, Northern Director. The photo shows them sporting various US president masks as the day they did their cycle was American Independence day!



Turning their Skill to Cycling

JOIN TEAM NRAS RIDE LONDON 30 & 31 JULY 2016

The vision for this race was to be one of the world's leading cycling events and a lasting legacy of the 2012 London Olympic and Paralympic Games – this has become a reality.

Registration fee: £50
 Minimum pledge: £500 (excluding your registration fee)
 Visit our website at www.nras.org.uk/cycle to book your place today. For more information email fundraising@nras.org.uk or call Val on 01628 501547.

DON'T DELAY, JOIN OUR TEAM TODAY!



Going the extra mile for Ruby and Molly

Emma Viola and her mum Jackie wanted to do something out of the ordinary to remember Emma's lovely Granny Ruby McGhee. At the beginning of July they took on a huge challenge to walk the El Camino de Santiago way which is approximately an 800km walk from France to Spain. Also known as The Way of St James. El Camino de Santiago is one of UNESCO's world heritage sites. Emma and Jackie, along with their friend Alison, set off on the 1st of July and trekked for 5 weeks. They started from St Jean Pied de Port, the French side of the Pyrenees. The days were long and hot but 32 days later they reached their final destination in Spain and had raised a fantastic £1068.88. They had a fabulous time, making new friends along the route and sharing some great mother/daughter time.



Emma and Jackie Writing in the sand

Ruby had lived most of her adult life with Rheumatoid Arthritis and as Emma said on her Just Giving page "We saw how hard it was for her and she was such an inspiration living with the symptoms - no complaints - such a sweetheart. Love you wee Ruby xx." Emma and Jackie were not the only people this year to complete this amazing walk for NRAS, back in June another fundraiser, Valerie Watson, also completed the long trek to Santiago.



Valerie Watson El Camino De Santiago

Again Valerie was doing this to remember her mum, Molly McIntosh. The cathedral at Santiago had been on her bucket list to visit, so Valerie was determined to live her mum's dream. However to complete the walk for Valerie was a real challenge as she lives herself every day with RA. This was not going to stop her though. Thanks to the support and companionship of her husband, Pepe, and her friend, Barb, she reached the cathedral where she admits to shedding a tear! Valerie said, "As a long time sufferer of rheumatoid arthritis, I feel it is only right for me to support NRAS." Valerie and her fellow walkers raised a fabulous £533.18.

All we would like to say to these lovely fundraisers is 'Gracias y bien hecho'.

A Challenge with a difference – Snowdon by Night!

Mother and daughter team, Hayley and Tara wanted to do something positive to remember their mum/nanny – Patsy who had lived with severe RA for many years and was an inspiration to so many. They came up with the crazy idea of climbing Mount Snowdon by night (yes by night!). As the big day arrived Hayley and Tara went from being incredibly excited about the challenge to thinking it would be awful and they wouldn't be able to complete it. Yes it was hard work and a massive commitment to train most weekends in advance of the trek but to reach the top of Mount Snowdon at 2am in the pouring rain and pitch black was absolutely amazing, it was also a huge relief that it was over! Tara found going down the toughest whilst Hayley found going up the hardest, with the ascent becoming very steep and the wind whipping up the higher they went.

The commitment both ladies gave to this challenge was amazing. There were moments when Hayley really didn't want to train, and said, "there were a few times when I really didn't want to go walking again, but then I thought that there would be an end to it soon, mum could not see an end to her pain so in comparison I had nothing to moan about."

The support they received from everyone was fantastic - from donations to their Justgiving page, to encouraging messages and lots of offers to keep them company on their training hikes. Family and friends overwhelmed them with their generosity and kindness. Hayley and Tara were able to surpass their target for NRAS by raising a fantastic £1651.25 which made it all worthwhile.

Well done ladies and a massive thank you for raising so much money.



Snowdon by Night

The Berkshire Golf Club; sitting atop of the scorecard

NRAS must extend heartfelt thanks to the fantastic Lynne Proctor and her fellow Ladies of the Berkshire Golf Club, for raising a monumental £7,791 for NRAS as her chosen charity of the year as Lady Captain.

Lynne, who wanted to support NRAS due to the personal experiences of a number of her friends with RA, had the following to say:

"I'm delighted to have been able to support such a fantastic charity that does such great work, locally and UK wide, for everyone affected by rheumatoid arthritis. I'd just like to thank all the Ladies as well as the fabulous team at the Berkshire for their unwavering support over my year as Lady Captain, together we have achieved something special for NRAS."

Lynne supported NRAS with a number of activities including a silent auction,



her Captain's day, as well as a bridge tournament. We are delighted at what she and the club have raised for NRAS and it has helped to support our vital work.

If you or a family member or friend are inspired by Lynne and want to support NRAS also, please get in touch with Oliver Hoare, our Fundraising Manager, on 01628 823 524 or email oliver@nras.org.uk.

The Sun Shines for the Royal Parks Half

On a beautifully crisp sunny October morning 14 NRAS runners took part in this year's Royal Parks Half Marathon. Between them they raised over £8000 for NRAS, a fantastic amount from a simply amazing team! Well done to everyone who took part and a huge thanks to all those who came along to support the team.



Joe's Junior York Run

Young Joe Ingram is following in his Dad's footsteps. In August Joe, who is just 9, took part in the York Junior 2.5K. Joe has obviously caught the running bug from his dad Tom, who back in 2013 ran a 10K, 5 half marathons and the Yorkshire marathon! Joe like his dad chose to support NRAS as his grandma has Rheumatoid Arthritis. Well done Joe who completed his run in a record time and raised an amazing £210.



Joe Ingram at the York Junior 2.5k run

2015 miles for 2015!

When we were contacted by Ruth Archer at the beginning of 2015 she told us that her plan was to run 2015 miles during the year, 2015 and raise £2,015! She was doing this to support her lovely brother Ben who was diagnosed with RA in 2009, aged just 27. Ruth has certainly kept to her word and took part in an amazing 12 events over the course of the year. She took part in three of the largest iconic marathons over the year which included London, Paris and Berlin. She also ran a number of half marathons culminating with her last event in October - the Royal Parks Half Marathon. We were fortunate enough to finally meet the lovely Ruth with the rest of our Royal Parks NRAS team runners. Ruth has been a true inspiration and complete running machine!!! She has amazed us all with every event, achieving personal bests and also finishing with a smile and encouraging other runners along the way. Ruth wanted to support NRAS as she said she wanted to give something back to 'a wonderful charity who helps people who suffer everyday just like my amazing brother Ben.' We think Ruth too is a wonderful person and she deserves a well earned rest in 2016.

As if this wasn't enough, Ruth's son Georgie got in on the act and took part in a half marathon cycle ride and raised a fantastic £100 to go towards Ruth's overall total for the year, well done to you and thank you.



Ruth Archer

Caring Carillion's tempting teatime treats and much more

Carillion Communications, a local company based in Maidenhead who are one of the UK's leading audio visual specialists, made the decision earlier in the year to support NRAS by organising some fundraising events during 2015.

The first event they held was an NRAS Tea Party, with lots of lovely cakes baked by staff and friends (our favourite was the flake cake, very tasty indeed!), then in August, Jerome, Sam, Gary and James each braved a tandem skydive! Weather conditions were perfect on the day and all 4 made it safely back down to the ground. Caring Carillion staff have so far raised £2,000, however, with, as we go to print, an autumnal barbeque still to

happen, it won't be just the waistlines that will be increasing!



Nothing Flaky about Carillion's efforts- YUM!

Competition time! Planes, Trains and Automobiles- Top Tips for Trips Wanted.



Large nomad travel case internal

Do you find packing your RA meds for a trip a bit tricky? Want to win a super Travel Case, worth £40, specially designed for taking your meds away. All you have to do to be in with a chance to win this top of the range Nomad Travel Case, courtesy of The Cool Icebox Company, is share your best travel tips with us for the next Spring 2016 Magazine.

Found a nifty way of making yourself comfy in hotel beds?

Found the ideal way to cope with heavy luggage?

Got a gadget you go nowhere without?



Large nomad travel case external

Tell us and others and you could be taking your meds away in style on your next trip.

Send your top travel tips to Clare at clare@nras.org.uk or by post to NRAS, 4 The Switchback, Gardner Road, Maidenhead SL6 7RJ.

Can't wait to see if you win? Visit www.coolicebox.com/nomad-travel0case to buy yours today!

Join the



We launched the NRAS Lottery in September 2013 and a huge thank you to all those who have signed up already. We now have over 350 players, and are seeing a regular stream of winners each week.



But we need more

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

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



Dear Helpline...

Are there any non-medicinal ways to control pain?

Whilst medication plays an important role in treating pain, there is a large array of drug free pain relief therapies and techniques that can be used to help.

Some of these are: biofeedback, ice, heat, exercise, psychotherapy, acupuncture, hypnosis, massage, mind-body relaxation techniques, chiropractic, physical therapy, TENS and occupational therapy. These techniques can be used alone or in combination. In the same way that not every drug is right for everyone, so it is with these non-medicinal methods of pain relief. Relieving pain often requires a trial-and-error approach.

In studying pain and how to modify it, researchers and doctors often think in terms of the "gate control" theory. This concept holds that pain impulses can be dampened down before they reach the brain in a part of the spinal cord called the dorsal horn. When an injury or other painful stimulus activates tiny nerve fibres, it opens the "gate" so a pain signal is sent to the brain. But if other sensory signals are coming in from other parts of the body at the same time, neurons in the spinal cord effectively disconnect the pain message and close the "gate". For example, doctors often try to reduce the pain of inoculations in children by

rubbing the child's skin immediately after giving the injection, so interrupting the original pain signal.

Most of these non-medicinal therapies do not carry the risk of side effects as most drugs do. To find out more about living with long term pain go to:

<http://www.arthritisresearchuk.org/arthritis-information/arthritis-and-daily-life/pain-and-arthritis/pain-report.aspx>

I have a number of gadgets to help me around the home, but I sometimes struggle when I'm out and about, and squeezing the trigger on the petrol pump can be a real struggle when I'm on my own. Is there anything I can use to help with this?

You are not alone in having this problem, and thankfully there are some products available to help hold the trigger in place for you. Here are a couple of examples:

Pump Pal

Cost: £9.99

Website: www.pumppal.co.uk

How it works:

Clips over the handle and is then turned to lock the trigger into place.



Pump Pal available in pink, blue, black or green

Fuel Mate

Cost: £5.00

Website: <http://fuelmateuk.wix.com/home>

How it works:

A pin which can be held on a keychain and inserted into the handle of the petrol nozzle, to hold the trigger in place.



Fuel Mate available in red, blue, gold or silver

ServiceCall is a system designed to make it easier for a person with limited mobility to use petrol stations, banks, supermarkets, shops and many other services. You simply aim a small infrared transmitter to activate the ServiceCall receiver fitted in thousands of service providers' windows.

The following companies have already installed ServiceCall:



These are just a small selection of the many companies who have invested in ServiceCall to provide attended service. If you are looking for ServiceCall in your area or for when you are travelling you can search their database on the website (you can search by town, motorway, post code etc) <http://www.service-call.net>

I am prescribed a number of different medications each month for my RA and am worried about the cost. Could I be entitled to free prescriptions or get any help with prescription costs?

Unfortunately at the moment rheumatoid arthritis is not listed as a condition for which patients are entitled to free prescriptions, though you may be entitled if you meet certain other criteria. However, if you are not entitled to free prescriptions, there are still schemes that could help you to reduce the overall cost, especially if you regularly pay for multiple prescriptions.

NRAS are part of the 'Prescription Charges Coalition' which is made up of 40 organisations campaigning for free prescriptions to people with long-term conditions. You can read more about this in the Campaigning section of the NRAS website, www.nras.org.uk/free-prescriptions

The charge for a single prescription item is currently £8.20, which soon adds up if you need two or three items each time and this is especially the case if you have more than just one condition. There are a number of different NHS schemes to help with the cost of medications.

Free NHS prescriptions are available to you if you are:

- Over 60, or
- Under 16
- Between 16-18 and in full-time education
- Have a medical exemption certificate (MatEx), which can be awarded if you:
 - Are pregnant or have had a baby in the previous 12 months
 - Have a specified medical condition (unfortunately this does not currently include RA)
 - Have a continuing physical disability that prevents you from going out without help from another person



- Hold a valid war pension exemption certificate and the prescription is for your accepted disability

- Are an NHS inpatient

You should also be entitled to free prescriptions if you or your partner (including civil partners) are named on, or are entitled to, an NHS tax credit exemption certificate or a valid HC2 certificate (full help with health costs), or you receive either:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance, or
- Pension Credit Guarantee Credit
- Universal Credit

NHS Low Income Scheme

If you are on a low income you may be entitled to help with NHS prescriptions on the NHS Low Income Scheme. You can apply to this scheme if your savings, investments or property (not including the home you live in) do not exceed £16,000.

To apply, you will need to complete an HC1 form, which is available from Jobcentre Plus offices, most NHS hospitals or by calling 0845 610 1112. Under this scheme, you may be granted help with all or some prescription costs.

Prescription Pre-payment certificates (PPC)

Another option to help with prescription costs is the NHS prescription pre-payment certificates. If you know you are consistently going to be paying for multiple prescriptions each month it may be cheaper to buy a PPC.

If you pay for at least four prescription items every three months (ie pay a total of £32.80 or more) or at least 13 items in 12 months

(a total of £106.60), you could save money with a PPC. A three month PPC will cost you £29.10 and a 12 month PPC costs £104.00. There is also the option to pay by direct debit, allowing you to spread the cost over 10 monthly instalments so you do not have to pay one lump sum.

How much can I save?

- If you need two items each month you can save around £90 with a 12 month PPC
- If you need three items each month you can save around £190 with a 12 month PPC
- If you need four items each month you can save around £290 with a 12 month PPC

You can buy your PPC online at <https://apps.nhsbsa.nhs.uk/ppcwebsales/patient.do>

Or call the PPC order line on: **0300 330 1341** (Monday to Friday, 8am-6pm, and Saturday, 9am-3pm)

For more information on help with prescription costs, visit the NHS Choices website: www.nhs.uk/NHSEngland/Healthcosts/Pages/help-with-health-costs.aspx



Activity of genes and immune system “affected” by seasonal changes

A new study in the UK has shown that there are changes in genetic and immune system activity depending on the season. This could explain why the symptoms of diseases such as rheumatoid arthritis vary depending on the time of year.

Study co-author, Chris Wallace, a genetic statistician at the University of Cambridge says:

“Our results indicate that, in the modern environment, the increase in the pro-inflammatory status of the immune system in winter helps explain the peak of incidences of diseases that are caused by inflammation, by making people more susceptible to inflammation’s effects.”

In the study, blood from more than 16,000 people from both the northern and southern hemispheres was looked at. The results, published in the medical journal “Nature Communications”, indicated that the activity of almost a quarter of the genes tested (5,136 from 22,822 tested) varied according to the time of year. Some were shown to be more active in the winter and others more active in the summer.

Immune cells and fat tissue and the composition of the blood were also changed.

During the winter, the immune systems of people had pro-inflammatory profiles and raised levels of proteins linked to cardiovascular and autoimmune diseases compared to the summer. One inflammation-suppressing gene, ARNTL was found to be more active in the summer and less active in winter. Previous studies on mice have shown that this gene suppresses inflammation and so this may help to explain why people’s levels of inflammation tend to be higher in the winter.

This seasonal variation may have evolutionary roots says Wallace.

“Evolutionarily, humans have been primed to promote a pro-inflammatory environment in our bodies in seasons when infectious disease agents are circulating. This environment helps people fight infections.”

“It makes sense that our immune systems adapt to cope with variation in infections as these are thought to be the main cause of mortality for most of our evolutionary history.”



Plant extract inhibits rheumatoid arthritis activity in mouse model

An extract from a plant found in a species of flowering tree in SE Asia (*C. sappan* L.) has been found to exhibit great therapeutic potential. It has both analgesic and anti-inflammatory properties. A study aimed at understanding the anti-rheumatic activity of brazilin (the compound isolated from the tree) was undertaken recently. Evaluations were carried out on mice with type-II collagen induced arthritis (CIA). The mice were divided into four groups. Three groups received initial injections of type-II collagen followed by another at 21 days. On day 22, brazilin or methotrexate was given daily or every three days respectively to two groups of mice. On the 42nd day, mice sera (an amber-coloured, protein-rich liquid which separates out when blood coagulates) were collected and the levels of pro-inflammatory cytokines (proteins) and stress enzyme markers were measured. Brazilin reduced the arthritis index score and the extent of acute inflammatory fluid build up in the paw in the CIA mice. It also prevented joint destruction, surface erosion, and enhanced bone formation. It also reduced the serum levels of inflammatory cytokines including TNF- α , IL-1 β and IL-6.

The conclusions of the study were then that brazilin purified from *C. sappan* L. shows protective efficacy in CIA mice and may be useful in treating inflammatory disorders including rheumatoid arthritis.



Recent studies suggest link with high salt intake and auto-immune diseases such as rheumatoid arthritis

We all know that too much salt in the diet is bad for us, causing problems such as high blood pressure, heart disease and an increased risk of stroke. Despite this risk, many people are still consuming a daily average that is over the recommended 6g of salt a day. According to the NHS, people in the UK consume an average of 2g per day over this recommended level. However, for people with autoimmune conditions, such as rheumatoid arthritis, there may now be another reason to cut down on salt.

Researchers from Yale, Harvard and other leading institutions have discovered a potential link between salt intake and the induction of ‘TH17’ cells, a subset of T-cells, which are known to play an important role in the inflammatory

process. It is thought that these cells and the effect that salt intake has on them could hold the key to explaining why there has been an increase in the number of people with autoimmune conditions in the last half-century.

There have been a number of theories as to why the number of autoimmune conditions has increased, particularly in Western and developing countries. It is thought to be unlikely that genetic factors would alter significantly over a relatively short period of time, which points towards environmental factors, which could include high salt intake. Three recent studies have suggested that higher salt intake could be a risk factor not only in developing rheumatoid arthritis, but also for making the

symptoms worse. Cutting down on salt intake can be tricky, as relatively high levels of salt can appear in some foods which you might not consider salty, for example sweet products like biscuits. To give you a rough guide, the NHS suggest that a product with 1.5g for 100g (0.6g sodium) is a high level of salt and 0.3g for 100g (0.1g sodium) is a low level of salt.



New personalised therapy for treating rheumatoid arthritis

Researchers at the University of Queensland, Australia have successfully targeted the underlying cause of rheumatoid arthritis (RA) with a therapy that modifies the immune system for each individual.

This new immunotherapy has been designed specifically for individuals carrying high risk arthritis genes and anti-CCP anti-bodies. Anti-CCP, which stands for anti-cyclic citrullinated peptide antibody, is a blood test which helps your doctor confirm a diagnosis of rheumatoid arthritis. Anti-CCP is a very useful test to order during the diagnostic evaluation of a person who may have rheumatoid arthritis. If present in such a patient at a moderate to high level, it not only confirms the diagnosis but also may indicate that the patient is at increased risk for damage to the joints.

The patient’s immune system is taught to ignore a naturally occurring peptide that is mistakenly identified as a foreign body thus preventing the production of CCP antibodies that cause inflammation.

A sample of the patient’s blood was taken and a particular type of immune cell called dendritic cells were extracted and modified. These were then injected back into the patient creating a personalized form of immunotherapy.

Findings published in the medical journal “Science Translational Medicine” indicated that this technique was safe, helped to suppress the immune system and thus delivered a reduction in inflammation.

A spokeswoman for Arthritis Research UK said that

“This treatment acts to re-educate the immune system so that it recognises healthy tissue, stopping the vicious cycle of joint inflammation and damage.

“This is particularly exciting as it is not simply a way to treat symptoms but to actually stop RA in its tracks. However, more research is needed before this treatment is proven to be effective and safe.”



JIA Family Day 2015

Following the success of the JIA@NRAS launch family fun day in 2014 we had this year's family fun day at the same location on July 18th, however unlike last year the rain clouds stayed away and the sun shone down on us all day – a great day was had by all!

The children were totally spoilt for choice and couldn't make their minds up whether to ride on the quod pods (buggies pulled by a quad bike) first or sail a pirate ship on the lake. And then, when they had exhausted their need for speed and shanty adventure it was back to the giant jenga, football and face painting! In between all of this they could sit quietly and explore their creative talents on the arts and craft table.

Meanwhile, parents and grandparents, aunts and uncles were spending time with a team of paediatric rheumatology experts. These health care professionals shared their expert knowledge on specific subjects including transition (moving from paediatric to adult care), medicines management and eye care (Uveitis). The presentations were repeated twice during the afternoon which gave every adult family member an opportunity to participate. They proved very popular, but were somewhat warmer than outside as the air conditioning let us down but everyone stuck with it as they wanted to hear from our experts!

Question and answer sessions followed the expert presentations and this gave the audience a rare opportunity to ask specific questions of the rheumatology panel. Everyone on the panel was very generous with their time and consideration. Many had travelled some distance and given up their Saturdays with their own families to support the day.

Afternoon Tea was a welcome break in between the health professional sessions, and what a feast! The main tent was overflowing with little white and brown triangles of soft bread bursting with fresh ingredients, large quantities of very lemony lemon drizzle cake, baskets of melt in the mouth shortbread and tier upon



Ahoy me hearties we're off to the Pirate Ship!

tier of cupcakes covered in chocolate and sprinkles, smarties and marzipan miniature flowers; and all the children and young people got a tub of vanilla ice cream too! The afternoon tea was just too tempting and I think we all were seduced into having seconds and thirds!

It was lovely for the families to meet and share with other families and I am sure that a few swapped telephone numbers and have kept in touch with each other. The family day is a great opportunity to meet others with JIA and many of the older children commented that it was much better than they thought it was going to be! (High praise indeed from youngsters.) Needless to say we are looking forward to next year and already looking for a venue. We asked everyone who attended to give some feedback and the results were unanimously very positive.

Next year we would love to hold a family fun day in two locations, this will allow many more families to attend and help us to reach a greater audience. So keep a look out for next year's dates and locations; we will be posting the information on our website, Twitter and Facebook and if you came this year, we will be emailing you the information.

In the meantime if anyone has any great venue suggestions for next year, please get in touch with me anne@nras.org.uk

To see more photos, please visit our website <http://www.jia.org.uk/jia-nras-family-day>

Quotes from the day

"I just wanted to let you know how much we enjoyed and appreciated today. It was our 1st year attending, and we were amazed at how much was put on for all the children (and adults)."
Janina O'Brien and family

"I should thank you too. My children had a wonderful day out with highlights being the pirate ship and the soft play bus. They were very happy and exhausted when we left! I had a great day too, learning a lot from both the professionals and the patients' families. It seemed to be a great success all round. Congratulations!"
Sally Painter

"It was good to meet you at the family fun day near Coventry the other week. The girls really appreciate the family fun days and meeting other kids with JIA."
Daniel Madge and family

"JIA & Me"

Following a year of in depth research and asking patients, parents and health care professionals what the new JIA@NRAS service could do for children and young people, one of the recurring recommendations was to develop a programme of confidence building activities. To address this need and to tackle isolation and self esteem issues in a fun and engaging way, we are rolling out a series of art competitions across the UK over the next 2-3 years.

Children and young people will have the opportunity to produce a piece of art expressing their feelings about living with JIA. The young artists and their families will be invited to celebrate their submission with NRAS and members of their rheumatology team at a Saturday prize giving event (sorry kids no time off school required!). All the dates and venue details will be updated on the JIA website.

We couldn't do this without the generous support of the specialist nurses and consultants in the rheumatology units; we are very much looking forward to making this a sustainable project to enable and encourage the children and young people to continue to express themselves and their feelings through art.



JIA@NRAS website continues to develop

As promised the content on our JIA web pages continues to develop; by the end of the year we hope to have several useful and practical facts sheets on school and the learning environment; some key information and tips on how to deal with bullying and various information sheets on moving from paediatric care to adult care (transition).

In addition, Ailsa and Anne recently visited Bristol Children's Hospital to film a joint clinic in action and to interview the health professionals and young people concerned. We'd like to thank Professor A V Ramanan FRCPCH, FRCP, Andrew D Dick FSB FMedSci Professor of Ophthalmology, and special thanks to Specialist Nurse Helen Strike.

The videos, including some clips of young people talking about life with JIA and Uveitis, are now on the website.



My Story... *Edgar Stene Prize 2015 By Charlotte Secher Jensen*

Every year the European League Against Rheumatism (EULAR) and the Standing Committee of Patients Against Rheumatism in Europe (PARE) offer the Edgar Stene Prize for the best essay on a previously determined topic.

The national organisations of people with rheumatic and musculoskeletal diseases from across Europe invite people in their countries to participate in the competition by writing and submitting an essay on the topic of the year. The 2015 winner came from Denmark and we thought we'd share an excerpt from the winning essay. The full essay can be read on the website www.nras.org.uk.

41 year old Charlotte is married and lives in Gjern, a village close to Silkeborgin. She has two children: a daughter aged 16 and a son aged 13.

Over the last few years Charlotte had read about the Edgar Stene Prize in the Danish patient association's magazine but the topic hadn't been quite right for her to participate. This year, however, the topic really caught her interest.

"I immediately felt that I had something to share" says Charlotte, "I chose to write to write because I wanted the health professionals at the hospital to learn how much a doctor or nurse's way of acting can change not only a patient's experience of the consultation, but also how the patient feels when he or she leaves the hospital."

Living in the moment

I still remember that day. The day I was diagnosed with rheumatoid arthritis. My thoughts were all over the place. They whizzed round and round in circles, in utter confusion... Why? What was it all about? And what now? That night – the night after that day – is what I remember the best. How I wept silently into my pillow until you could have wrung it out. How I crept into the kitchen in the dark so as not to wake the family, and turned the thermostat on the radiator up full. I remember the reassuring, monotone clicking of the radiator and the warmth, the meditative shushing noise it made, like the sea, calming, giving me a kind of artificial comfort.

I sat myself down awkwardly on the hard kitchen floor and rested into the radiator's unfeeling arms, which gave me a warm, weak hug. I sat there in the dark heavy hearted. I felt the burn on my back where, I hoped, I would one day have my angel's wings in my fantasy world. The burning pain gave me a few seconds' peace from the sharp stabbing I felt in all my limbs.

My tears dried up. Something happened. My thoughts folded their wings together; I took a deep breath and got determinedly to my feet. A battle was raging in my mind between light and dark. And the light won! I intended to live in the moment and in the future. This was my life. My decisions. But I quickly realised that I needed something to lean on. I had a long journey ahead of me.

I soon learnt, the hard way, that there are three different types of hospital visit. Those where I leave the place no wiser than before. A waste of time, waste of money and waste of the present moment. Then there are the visits where I leave in tears – either because I have not been seen or listened to, or because I have had to behave too much like a chronically ill patient.

Perhaps it was one of those visits where I had to have examinations and blood tests that I simply did not have the strength to endure. That felt like a violation of my exhausted body and frayed mind. With a doctor or a harassed nurse who, I felt, held my future life in their hands. He or she would barely look at me, looking down instead at the notes that they should have read – or at least skimmed through – before I walked in the door. Tired eyes and non-committal comments, "Your blood tests look fine. So you should be alright." I feel as if I am just a number. They leave – I leave – with hopes dashed.

And then there is the last kind. The best kind. Those where the doctor or the nurse

asks, "How are you?" and I answer, "I am very well." They nod, lean back attentively and say, "And how are you really?" I am aware of the person beneath the white coat, the warmth of their eyes, that they want me to be well, to have a good life, in spite of the excruciating pain and powerlessness. They have read – or at least looked through – my notes. They remember my name. I am not a number!

Those visits are the light at the end of the tunnel... When you are way down in the dumps and the nurse smiles warmly at you and says that everything will be alright. That although she doesn't have a rheumatic disease herself, she recognises – because she has seen it all before – the powerlessness, the fear, the helplessness about medication and side effects and all the rest of it that I end up spilling out because it has taken hold so deep within me, and at long last there is someone who knows how to press the right buttons.

I feel the weight lift from my shoulders. Everything loosens up. It's going to be alright. My shoulders relax and I can breathe freely again. She is careful inserting the needle, comforting me all the while. She gives me hope and belief that the present moment is OK, the future will be better, that it is possible to learn to live with a rheumatic disease. [continue to read the rest of Charlottes essay at www.nras.org.uk/stories/]

I am ready to live in the moment and to meet the future. It is possible to travel with a rheumatic disease in life's rucksack, provided you have help to pack it properly. I embrace the present moment and I embrace life!

"Taking control of my life – working together with health professionals to achieving my personal goals"



Group news... 2015

It has been an exciting few months in the External Affairs department, with the launch of the 50th NRAS Group and the planning of two groups in previously unchartered territory!

In May, Gill and Kim made the westerly trip to sunny Yeovil for an information evening hosted by Group Co-ordinators Elaine and Tina and supported by the Yeovil District Hospital rheumatology team. The group launched way back in early 2009 and have been running successfully since then. To show their continued support for the group the rheumatology team came together for the evening where Dr Sally Knights, Consultant Rheumatologist, gave a fascinating insight into the future of RA medication followed by a lively Q&A session. We wish Yeovil NRAS many more successful years.



Group, HCP's & Gill in Yeovil

At the Pembury and Tunbridge Wells meeting in May a presentation and huge thanks were made to Tony Carter, NRAS Group Co-ordinator, who is moving to the south coast after many years helping coordinate the group meetings. Tony's wife Maureen was also a big supporter of the group and could always be found helping to make tea and coffee, greeting new arrivals and generally helping out. Tony and Maureen will be greatly missed by all the group and we wish them every happiness in their new abode.



Farewell to Tony Carter from the Pembury TW Group left to right: Maggie Cash, Tony, his wife Maureen and Daphne Harris (Co-ordinator)

June was an exciting month that saw the launch of the NRAS Group in Bury St Edmunds. Gill, Kim and Anne (NRAS Youth and Family Services Manager) travelled to West Suffolk on 10th June to warmly welcome over 100 people to the evening event. NRAS was very lucky to have the enthusiastic support from the whole rheumatology team at West Suffolk Hospital and a special thanks to Dr Catherine Bevington, Consultant Rheumatologist, who helped plan much of the event. Dr David O'Reilly, Consultant Rheumatologist, gave the key note speech of the evening, followed by the Q&A session with his team that stimulated many interesting questions from the audience. We received lots of positive feedback from the attendees with many keen to see a group in the area and we subsequently have four super Volunteers to co-ordinate ongoing meetings. Two meetings have already been planned to take place before the end of the year, for full details please visit the website.



Some of the West Suffolk HCPs with Gill at the end of a fantastic evening!

We thought we would share with you some of the fun things the NRAS Chesterfield Group have been getting up to in the last few months. Since its launch in October 2014 the group has gone from strength to strength and now has many activities outside the group meetings that many attend and enjoy! Food workshops are held once a month, the topic in August was 'Do you find nuts and seeds boring?' Some delicious foods were made and tasted, guided by Rachel Honman, a Nutritional Therapist from DerbyNutrition4Life, who has been working with the group to encourage them to eat foods for a healthier lifestyle. September's topic was 'Healthy sweet treats!' If you are interested in the Food Workshops please see one of the co-ordinators at the next NRAS Chesterfield meeting to find out dates and topics.



Food workshop

What a treat! Just a few of the supporters from NRAS Chesterfield enjoying Mamma Mia at Hardwick Hall for a Summer Nights experience. The weather couldn't have been better; lots of singing and dancing was witnessed. What a brilliant night! The group will be making it an annual event.



Chesterfield group event

Finally, congratulations to one of the Group Co-ordinators from Chesterfield who was nominated by the group attendees and won a Local Hero award, for all the hard work she has put in to supporting people in the area with RA. A worthy recipient and we offer warm congratulations.

By the time you are reading this we will have also launched the very first NRAS group in Northern Ireland. NRAS has never had a group in Northern Ireland before, so are thrilled at the opportunity to work with the team from Altnagelvin Area Hospital, part of the Western Health and Social Care Trust, to achieve this milestone. The event took place at the hospital on Wednesday 21st October. See the full story of the launch in the next NRAS magazine in 2016.

No doubt it will continue to be a busy time for the External Affairs team helping to get these new groups up and running and looking to next year for the launch of many more NRAS groups! For more information about groups please visit www.nras.org.uk/groups or call the office and ask for Gill or Kim.

NRAS Greater Glasgow and Clyde

It was way back in November 2014 when discussions first started about a group potentially launching in the Greater Glasgow area. The RA Self Management Programme has been running very successfully in this area of Scotland and there was keen interest as a result, about the ongoing support available, which sparked discussions about setting up an NRAS group to provide information and peer to peer support. NRAS is very lucky to have the support of Scottish Ambassadors on the ground who were willing to help support this venture. There hasn't been an active NRAS group in Scotland since 2012 so we were delighted with the support of the healthcare professionals from the Greater Glasgow and Clyde MCN and planning got underway in January this year. A very special thank you goes to Fay Campbell, GGC Rheumatology MCN Manager, who has helped with many aspects of getting us to the point of the group launch.

Scottish Ambassadors Mavis Graham and Liz Mackay-Saville have been driving this project forward from the very beginning and they now have a team of 11 keen volunteers ready to take the group into 2016.

Here are some of the co-ordinating group with a cheque for £500 that



Glasgow group organisers

they secured through a local business who wanted to support the launch of this new group. This money was used to finance the launch event and the following meetings. Thanks to the enterprise and hard work of the co-ordinators this group is off to a fantastic flying start!

The group launched on a sunny, warm evening in central Glasgow on Wednesday 16th September at the Renfield Centre in St Stephen's Church on Bath Street. Gill, Kim and Conn (Government Affairs Officer) flew up to Scotland to co-host the event with the Glasgow rheumatology health professionals and local volunteers. Almost 100 people turned out on the evening to hear about the help and support available from NRAS, the exciting plans for the new group and guest talks from rheumatology health professionals from the Glasgow area. Dr Anne McEntegart, Consultant Rheumatologist and Clinical Lead of the Greater Glasgow & Clyde NHS Rheumatology Managed Clinical Network, gave the keynote speech of the evening and then went on to take part in the Q&A panel with fellow colleagues Liz Mclvor (Rheumatology Nurse Specialist and NRAS Nurse Advisor for Scotland),



Glasgow planning group with donated cheque

Kirsty Bell (Specialist Rheumatology Physiotherapist), Katy McAlarey (Specialist Occupational Therapist) and Violet Butters (Specialist Podiatrist). NRAS would like to extend a special thank you to all the healthcare professionals that attended and took part in the event, without them this would not have been possible. Having over 15 healthcare professionals giving up their evening to be at this event is an excellent achievement and shows how dedicated they are in supporting a patient group in the Glasgow area, which is integral to the success of the group going forward. There was most definitely a feeling in the room of interest and excitement and so many are grateful to have the opportunity to meet others with the disease and offer each other support. NRAS Scottish Ambassadors and Group Co-ordinators Mavis and Liz also both spoke about why they were motivated to get the group started, how RA had impacted on their lives and how finding NRAS and accessing NRAS services gave them hope in a difficult time.

For Gill and Kim (NRAS) it was great to meet all the people they had been working with on this project for the last year and put faces to names! There is no doubt everyone involved has worked hard to make this new group successful and all are looking forward to the first two meetings later in the year. We wish the Greater Glasgow and Clyde NRAS group every success and we hope this will be the first of many thriving groups in Scotland.

An NRAS Glasgow Group

By Mavis Graham, Scottish Ambassador & Glasgow Group Coordinator

It's over seven years since I heard those fateful words, "you have rheumatoid arthritis".

I went home clutching a leaflet, and several appointment letters, feeling devastated by the diagnosis, but also with a strange sense of relief, that at last there was a name to explain how ill and fatigued I had been feeling for so long.

My rheumatology department is great, and I have received fantastic support on the long journey through medication, side effects, depression, hope, despair and acceptance.

When I discovered NRAS, it meant access to information and the support of others. I volunteered to be a Scottish Ambassador, and through this have had the opportunity to learn so much about the disease, to meet a multitude of healthcare professionals, to participate in lobbying politicians and to help to disseminate information and contribute to the improvement of services for all.

However, it has always been my desire to help form a group, for mutual support, sharing information and tips, learning

more about our condition and proactively influencing the provision of services in the future while having some fun along the way. I can always remember how alone I felt when I was diagnosed and how difficult it was for my family and friends to understand.

Together with my fellow ambassador, Liz, we met with the Greater Glasgow and Clyde Health board, specifically under the remit of the Managed Clinical Network of rheumatology services. With their support, and NRAS, we decided to go ahead and launch an NRAS group as a joint venture.

With a group of like-minded volunteers the coordinating group was formed. There is no doubt that this small group of eleven have worked tirelessly, including securing funding for the launch, but we have had a lot of laughs, and I think we have already benefited from the mutual support that we expect from the new group.

We launched on Wednesday, 16th September and we could not have achieved this without ongoing support from our local rheumatology

departments, and NRAS, and would like to thank everyone involved.

Hopefully, this was the first meeting of many and the group plan to meet monthly going forward. The first two meetings were already organised for the 21st October and the 17th November with speakers talking about occupational therapy and stratified medicine. Watch out for more interesting topics in 2016.

For further information about future meetings, please call Kim and Gill on 01628 823 524 or email groups@nras.org.uk or visit www.nras.org.uk/groups. All are welcome, you don't need to be an NRAS Member and meetings are free to attend.

Do come and join us!!



Chesterfield group event

A Tribute to Julie Corneill by her fellow Group Co-ordinators

Julie Corneill, Chair of the Mid Somerset Rheumatoid Group (MSRG), sadly passed away, aged 67, on 25th May 2015.

Julie and her husband Tom raised four children and once they had flown the nest, Julie, who was born in Manchester, became a keen charity worker. She co-ordinated volunteers at her local hospital, Musgrove Park in Taunton Somerset, worked for the Samaritans and helped many other groups in numerous ways.

In June 2010 patients with RA in the Taunton area were invited to a meeting organised by the Rheumatology Nurses at the hospital, where Clare Jacklin spoke about the work of NRAS and canvassed opinion as to whether there would be an interest in starting up a local patient group. Volunteers would be needed to help set up this new venture and naturally Julie, who had been known to the Rheumatology team as a patient for many years, immediately stepped forward to offer her services and experience. Julie became Chair of the newly formed group and helped to steer it to a very successful launch in March 2011.

Julie was passionate about helping people with RA, attending the NRAS

co-ordinators' conferences and working tirelessly to publicise and raise the profile of the disease. She spoke on local and national radio, ran information stands during RA awareness week each year and was always at the forefront of fundraising efforts. When members of MSRG complained that a new appointment system at the Taunton hospital was not working for them, Julie led a delegation to meet the Directorate Manager and succeeded in getting changes made. Thanks to Julie's leadership, the MSRG is thriving with an average attendance of 48 people at most meetings

Outside the group, Julie also counselled many patients newly diagnosed with RA who were struggling with their diagnosis. Her warm, wise and kind manner helped to dispel their fears, and her first-hand knowledge of the disease provided answers to their questions. Julie also welcomed first year student nurses on placement days into her home to learn about the day-to-day difficulties of living with RA.

Towards the end of her life, Julie, true to her indomitable spirit, continued to attend the MSRG meetings using her portable oxygen machine and even hosted a meeting when she was experiencing great difficulty in breathing.

Julie and her family asked for donations in her memory to be given to the Mid Somerset Rheumatoid Group to support it in the years ahead and £588.00 has recently been received from her husband Tom.

Julie was a wonderful woman, generous, fun, and with a great, irreverent sense of humour. She was adored by her family and loved and respected by all who knew her. She was a true unsung heroine, who quietly went about giving of herself without expecting any reward. She is already greatly missed by everyone connected with MSRG and many others in the community at large.

APPy to help you! The RA Coach with you whenever you need

RA Coach is a new, online support programme specifically designed for people living with rheumatoid arthritis (RA) and their relatives.

Developed by GAIA in Germany, RA Coach provides personally tailored information and guided exercises to empower and improve the quality of life for people with RA by:

- Showing effective techniques to help reduce pain
- Teaching methods for managing stress, anxiety and depression
- Giving advice about RA and its treatment
- Helping develop healthy self management habits

RA Coach can be accessed via any device connected to the internet and users can register for free by visiting www.ra-coach.com

Users of RA Coach will be introduced to evidence based pain reduction techniques which have been designed to complement conventional drug treatments. These include meditation, breathing and relaxation exercises which are presented in an interactive, structured format including audio recordings.

As a healthy lifestyle can play an important part in influencing the severity of RA symptoms and the potential success of treatment, the programme also guides and supports people in their efforts to exercise regularly, maintain a healthy diet and to stop smoking.

To help users monitor their progress over the weeks and months, the programme contains simple tracking tools that specifically checks how their health changes over time. Specific self monitoring items cover RA symptom severity, general health and wellbeing, activity and exercise, nutrition and medication taking.



The picture is of most of the MSRG committee, and shows from left to right, Maggie Johnston, Julie Corneill, Kui-leng Marrow (RA nurse), Teresa Jewell (RA nurse), Sue Pargeter, Lorraine Cook, Janet Wagstaff and Lynne Waknell. Lizzie Spence and Jenny Chamberlain, the other two committee members were not present when the photo was taken.

Zoë Ide shares her story of putting her experience of living with RA to good use

Zoë has been volunteering for NRAS since 2012. In her regular job she is a City Recruiter specialising in research analysts for fund managers and banks.



Zoë Ide

One, unusually quiet, lunchtime an email pinged its way asking for volunteers to edit and review articles for the NRAS website. Not feeling on top of my abseiling capability at the time, nor blessed with industrial cake baking skills, this seemed a perfect way to make a contribution. My hand went up.

This was just the beginning... Articles about joint replacements (elbows difficult!), the benefits and dangers of exercise (good idea in general – push it if you can, but not if your joints are in bad shape) and RA related monozygotic genetics (identical twins to you and me) morphed into a final reading of the NRAS Sexuality, Emotions and Relationships guide. This one stopped me in my tracks. I was bowled over by the in-depth personal revelations, caring practical advice and shared experience. Suddenly realising how much these booklets and articles can make such a difference, especially when we don't always have somewhere obvious to turn to for help - I decided to get more involved in the work NRAS does.

More varied projects followed: a constructive and enjoyable morning spent with 8 lively patients pondering "remission - and what this really means" was followed by a weekend scratching my head over which entry really had the "patient in focus" for the NRAS annual competition; then a trip up to the Department of Health to question the rather elusive/our current Health Minister as the RA representative within a musculoskeletal round table event these were some of the highlights of this era...

Three years on and I am now officially 'a veteran', working as a volunteer patient representative on two very exciting heavy weight projects.

The First National Audit of Rheumatoid and Inflammatory Arthritis is a hugely ambitious project that measures how new patients are cared for over the crucial first three months of their first presentation in a Rheumatology unit. It covers 3 different perspectives of care including the patient view point. It's the first ever audit in an outpatient setting and will be presenting its early findings this year. You can find more information on the British Society of Rheumatology website and follow the links on the National Clinical Audit button.

**National
clinical
audit**

I am also involved in a fascinating research initiative called MATURA.



As we all sadly know, currently our treatment is very much a 'trial and error' process. Rheumatology scientists hope that by analysing our blood and joint tissue, that they can make significant breakthroughs in identifying which drugs (particularly biologics) will have the best chance of working for us quickly based on our particular body makeup. This is known as Stratified Medicine and you can find out about this on their website: www.matura.whri.qmul.ac.uk

Through volunteering in these many different ways I have been given an amazing perspective on this disease of ours. I have also been educated and stretched – you definitely discover new skills! The best part however has been the meeting of some really inspiring professionals involved in our care - and the resilience and humour of people with RA. Maybe there is a "humour" gene that needs to be studied?

Reads like an advert to recruit volunteers? I hope so! There's an NRAS opportunity waiting just for you I'm sure! To register your interest email volunteers@nras.org.uk

Christmas Gift NRAS Membership

If you're struggling to find the perfect gift for a loved one then why not give the gift that lasts all year?



Christmas Gift Membership Card

If you have a family member or friend who lives with rheumatoid arthritis, why not consider buying them a gift of 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 give it to them yourself.

If you have RA yourself and are being pestered by family and friends to give them some ideas what you'd like for Christmas why not put them out of their misery and suggest they buy you the gift of NRAS Membership. NRAS Membership is a thoughtful and unique gift that will not only benefit you but

thousands of others like you as well. There are only so many scarves and bath oil one needs in one's life after all!

Membership of NRAS is the best way to hear the latest RA news and enables us to better support you, your family, your health professionals and others living with this disease. If you are interested in Gift Membership then please call Emma in Membership on 01628 823524 or visit our website <http://www.nras.org.uk/gift-membership> to print off the Gift Membership form and send it back by post.

Christmas – a time for family so why not join the NRAS family today?

How we spend what you raise for NRAS

We recently published the NRAS Annual Review for 2014, which showcased many of our successes and achievements of last year. In our reporting we aim to be as transparent as possible and analysed our activity in greater depth than ever before. We looked at how we spend our funding and of every pound that we raise, 70p is directly spent on providing NRAS services. This includes our invaluable helpline and Information Standard accredited publications, activities in campaigning for change to improve the lives of those living with RA and the network of NRAS groups and telephone support provided by NRAS Volunteers. Of the remaining 30p, 18p is spent on raising the next £1 and 12p on the office essentials we cannot function without.



To read the full 2014 Annual Review visit the NRAS website www.nras.org.uk/annual-reviews. Remember if you pay UK tax on your salary or pension you can make every donation worth 25% more just by ticking the Gift Aid box!

NEWS & EVENTS

Employment & Support Allowance fact sheet now available

An easy to read and clear explanation of ESA benefit, what is it, how to claim and much more can now be found at www.disabilityrightsuk.org.uk

When Should You Get the Flu Shot?

October and November are the optimal time for vaccination but it still may be beneficial in later months. The CDC (Center for Disease Control and Prevention) recommends patients at high risk for flu complications get the flu shot. Some of these groups include but are not limited to:

- people over 65
- adults and children 6 months and older who need regular medical care due to a weakened immune system – so Rheumatoid and Juvenile Idiopathic Arthritis falls into this category.

For more information please visit the CDC website: www.cdc.gov/flu

It's not too late:
Get your flu shot today!!

Help raise vital funds for NRAS by recycling your unwanted bits of jewellery!

In this magazine you will have received a freepost jewellery recycling envelope. Simply fill with any unwanted items of jewellery – plastic or metal, we can even recycle broken or damaged jewellery. Pop it back in the post and funds raised will go towards our work to improve the lives of those living with RA.

The weather outside may be frightful, but our Christmas cards are so delightful!

NRAS has another beautiful range of Christmas cards for you to choose from this year. Cards are still only £4 a pack and we offer free postage and packaging on all orders! All proceeds from the sale of the cards go directly to helping people living with RA and JIA. Order today to avoid disappointment!

Additionally we have a few remaining cards from last year's stock which we are selling at the bargain price of just £2.50 a pack.

To purchase your NRAS Christmas cards please visit www.nras.org.uk/shop or call the fundraising team on 01628 823524. Thank you and Merry Christmas!

New groups Springing up in 2016

South Cumbria and Warwickshire are just two areas that in the first quarter of 2016 will see the green shoots of budding NRAS groups. Keep an eye on your enews bulletins or the website to get full details in due course.

Poorly PCs need to retire!

Like any forward thinking, ground breaking, efficient organisation NRAS relies on the wonderful world of technology to "get the job done". However some of our "technology" is on its last legs, i.e. 60% of our computers are over 5 years old and therefore need to be replaced as a matter of some urgency. Being able to reach as many people with RA in a more efficient and effective way is vitally important and for this we need to be able to keep our systems and technology as up to date as possible. However, as you will all know computers don't come cheap so we thought we'd put a request out to our Membership to ask if anyone out there can help by either funding or signposting us to a business or source that can supply us with new computer towers. If you can help please email clare@nras.org.uk or call 0845 4583969.

Berlin calling...

NEW for 2016 - NRAS has guaranteed places in the Berlin Marathon! This is a marathon not to be missed whether you are a seasoned runner looking for a personal best, or an excited beginner about to take on your first marathon, Berlin is the one for you.

Registration fee: £75

Minimum pledge: £800 (excluding your registration fee)

Visit our website www.nras.org.uk/events to book your place today. For more information email fundraising@nras.org.uk or call Val on 01628 501547.

Do something amazing, sign up today!



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If you are a UK tax payer on your salary or pension, you can gift aid any donation made to NRAS (including your membership subscription) by simply ticking the box on the form or by completing a separate form if you are already donating. You only need to sign the declaration once and then all donations made are eligible for gift aid.

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

giftaid it

Tweets

TWEETS 4,985 FOLLOWING 1,715 FOLLOWERS 3,796 FAVORITES 556



NRAS @NRAS_UK · Oct 12

Thanks to the staff at Eli Lilly for inviting us to talk to them about #RA today & joining the #WADHigh5



11 7



NRAS @NRAS_UK · Oct 12

Massive thank you to our amazing team who ran @royalparkshalf yesterday to support people living with #RA. #RPHM



7 4

Please Remember NRAS in your Will

A gift to NRAS in your Will is a way of continuing to support a cause which mattered to you during your lifetime. A legacy can be anything from a small amount of cash to a house; a piece of jewellery to a masterpiece! Leave it to NRAS to make a difference to the lives of those living with RA.

Leave it to Us to make a Difference



nras

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