"Being diagnosed with **Rheumatoid Arthritis** aged just 22 completely changed my life. Luckily, NRAS were there to support me through the process, and provide all the information and guidance I needed. Being able to speak to people who understood the disease better than I did was invaluable."

Philip Aherne



## Annual Review 2016

Changing Minds, Changing Services, Changing Lives





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We will: Support everyone living with the impact of RA and JIA

Supporting all with RA or JIA to live life to the full

#### **OUR MISSION**

**OUR VISION** 

at the start and at every stage of their journey

**Inform** – be their first choice for reliable information

**Empower** all to have a voice and take control of their RA or JIA

patient-led specialist organisation providing support and advocacy specifically for the >400,000 people in the UK living with rheumatoid arthritis and the >12,000 children and families living with the impact of Juvenile Idiopathic Arthritis in the UK, their carers and the health

We take pride in the fact that everything we do and stand for is patient-led. Our team works closely with Members, Volunteers and the wider populations of people with RA and JIA, our Board and our team of Medical and Allied Health Advisors to fund, design, co-ordinate and deliver a wide range of high quality services for all affected by RA and JIA.

The National Rheumatoid Arthritis Society is the only professionals who treat them.



We also work hard to influence and shape the policy

and service environment to ensure equitable access

to the best treatment and care for all with RA and JIA.

We know that access to best care and treatment is not.

the reality for many and there are a number of reports,

research papers and audit data to evidence this. Our

Policy and Public Affairs work is vital in ensuring that

those who take decisions about health and social care

are informed of the impact that RA and JIA have on lives

and wider society, and understand the value that access

to the best care and treatment brings to individuals, the

NHS, the Exchequer and whole communities. Seeing

the right person, with the right skills at the right time,

improves outcomes and saves money in the long term.

# Why we exist





"I'm very happy with our performance this year. We can be justifiably proud of our achievements. We've reached many of the aims and targets set out in our strategic plan for 2016 – 2019 and are on track as we move into year 2 of the plan. The good year-end result puts the charity in a strong position financially for the start of the new financial year in January, 2017 and maintains our reserves."

Ailsa Bosworth, MBE, Founder and CEO

### From the CEO

In 2016, the Charity recorded a substantial surplus. Our aim at the beginning of the year, was to ensure that we came in on budget and with a minimum breakeven result and I'm delighted to say that we did considerably better than that. I wish to thank the wonderful NRAS team for their hard work, passion and commitment in achieving such an outstanding year-end result. I would also like to pay tribute to our Board of Trustees, for whom most of them 2016 was their first full year of service. They are all incredibly committed and 'hands-on' which we welcome, and have a wide range of skills which we are very pleased to make regular use of!

We delivered a number of key projects in 2016 which included launching 'Who Cares?' a major Health and Social Care report on people living with RA in Scotland, launched in the Scottish parliament. Our over-arching goal is to be there at the start of everyone's journey with RA or JIA and this year, our Rheumatoid Arthritis Awareness Week in June, led to our reaching many more people with our key messages than ever before.

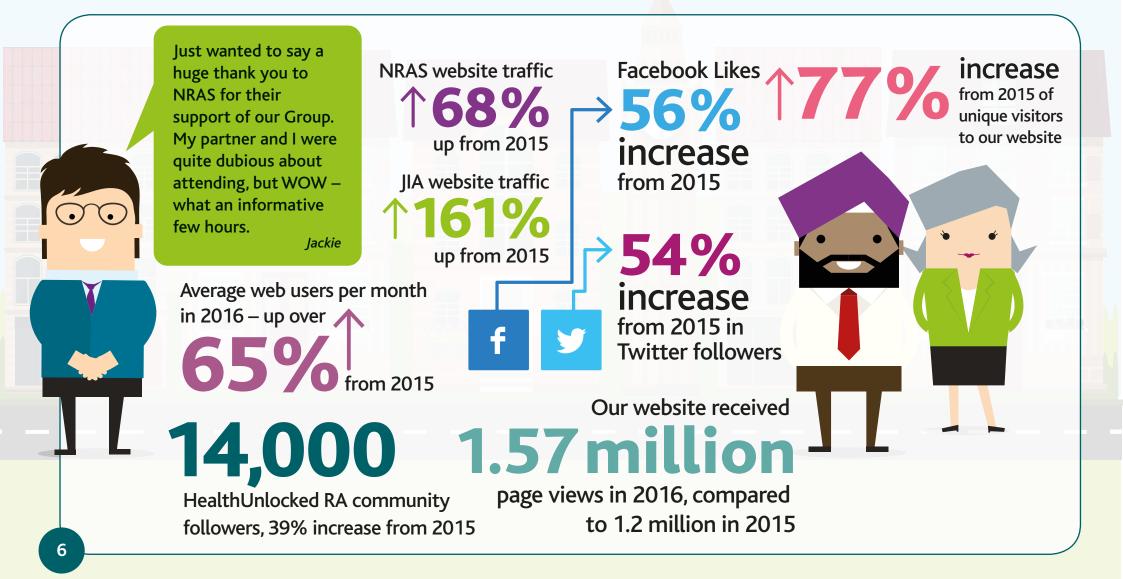
Additionally, in June, we had a stand at the European League Against Rheumatology Congress (EULAR) which took place in London with approximately 14,000 delegates. We were pleased to engage with many other patient groups from across Europe as well as clinicians and allied health professionals from all over the UK and the rest of the world. We made excellent progress on a major new project 'Love your Heart'. Heart disease accounts for almost half of all deaths in RA, with death from cardiovascular disease (CVD) occurring in RA patients approximately 10 years earlier on average than in the general population. Love your Heart is an interactive, on-line programme to educate people with RA about their increased risk of cardiovascular disease (CVD) and provide them with the means to change health behaviours to reduce their risk of developing cardiovascular disease. Reducing cardiovascular risk is likely to improve their long-term health outcomes. This will be launched in late summer, 2017, following a pilot. Our 5th Healthcare Champions event, hosted by the Prime Minister, took place in early November and 13 individuals/teams came to parliament to receive their awards accompanied by the patients who had nominated them. This event gives patients the opportunity to nominate health professionals who go above and beyond for their patients and it was a most successful and enjoyable evening, also attended by MPs, peers and some of our key funders.

2016 has seen the start of a 12-month process to improve our administrative infrastructure by investing in further software development of our Salesforce platform and staff training. By making these changes we increase our efficiency and free up valuable staff time by streamlining essential reporting functions as well as administrative and back office work.

We do substantial work in the field of supported self-management and providing the tools, resources and giving people the confidence to self-manage well is one of our key aims. You can find out more about this important work on page 23.

### Changing Minds...

**2016 was an exciting journey** for us, supporting thousands of people affected by Rheumatoid Arthritis (RA) and Juvenile Idiopathic Arthritis (JIA) to be able to live their lives the way they want to.



### **Changing Services...**

I think you are doing a great job and have been of massive benefit to large numbers of our patients as they come to terms with this lifelong condition – thanks!

I always promote NRAS to my patients, hugely impressed with the quality of work that you are doing and recommend you to all patients with RA.

Over 1,200 Healthcare Professional Members Campaigning for a **tertiary service** for paediatric rheumatology in Wales

> Thank you for all that you and your charity NRAS do for our patients, you really try and fill the gaps. Life would be harder without NRAS for many people.

Working with NICE National Institute for Health and Care Excellence to review and revise national guidelines in RA

Working NES with

on the National England Biosimilar Programme Board



Working with the Scottish Society for Rheumatology on national metrics for early RA

NRAS is an amazing resource for both patients and practitioners... keep up the good work and fantastic progress.

## Changing Lives...

Trained telephone

8

peer to peer support

**Volunteers** providing

Thousands

of contacts to

our helpline by

phone and email

We know from interacting with thousands of people with and affected by RA and JIA over the course of each year, just how important and life changing our work is.

Volunteers

doing a wide range of fantastic work

Nearly

**NRAS** groups

across the UK

**Successful** 

national

regional

days held

and

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

My daughter was only diagnosed at the start of this year so this is all still quite new to us. I attended the parents' session in the morning which was really interesting and informative. My husband joined in with the water play and bear hunt activities with my daughter and they both thoroughly enjoyed their time. My daughter is just four so we explained that lots of the children there had the same 'childrens' arthritis' that she has. This has been a cause of much interest and conversation ever since. If we're lucky enough to attend in the coming years I'm sure spending time with others with the same challenges in life will be invaluable.

I also got a chance to speak with a couple of other parents and exchange our numbers. It was great to talk to people who understand. In the nicest possible way, a lot of my friends don't really know what to say, so they end up changing the subject or making a 'positive' sort of comment that doesn't always match the circumstances. Once again, thank you so much to you and the team. It was a lovely day and I'm so happy we had the opportunity to attend.

# Many, many thousands

5.6

of publications sent out to individuals, health professionals and hospital units

'When an Employee has Rheumatoid Arthritis', 'How to claim Personal Independence Payment' and 'I Want to Work' booklets were amongst the most popular



POST





### Case Study: Philip Aherne

It is difficult to know precisely when I first started suffering from Rheumatoid Arthritis. The first time I remember significant symptoms was during the third year of university when I woke up and my wrists were so inflamed that I couldn't move my hands. I rushed to the college nurse, she just said I had been doing too much sport and that I should take ibuprofen and eat bananas. Things would have been very different for me if I had been referred to a rheumatology consultant then.

As it happens, I kept on suffering but I gradually got used to the pain, and although it was debilitating and intense, when it passed after a few days I generally forgot all about it and just got on with my life. Two years later, however, the disease accelerated considerably and I found it difficult to move my body, it took time to get out of bed and I had to take stairs one at a time. I finally went to the doctor when I couldn't put any deodorant on, because I couldn't press down on the spray with my finger.

The diagnosis came pretty quickly, but once I was on medication the disease worsened considerably. Some days I would be effectively paralysed, and I would need help to get in and out of chairs, to get dressed, to open doors. I couldn't even hold a book open. I was 22 years old and at the start of a PhD and my parents had to care for me as if I was a toddler again.

It is difficult to describe the pain, you cannot sleep, you cannot rest, and you cannot escape how you feel. There were days when I would lie awake in a delirious state of pain and just hope it would end. I was exhausted all the time, and some days even trying to do the most basic things like go to the toilet were beyond me.

It is very difficult to be so utterly dispossessed of the ability to control your body. You have to be versatile as every decision you make requires you to think about the pain you'll be in to do it. Chairs, plates, cups, cutlery, shoe-laces, belts - all these things seem to mock you because you can't use them normally. I hate having to think of myself as an 'ill person' and it took me a long time to come to terms with the idea of being 'disabled'. I make sure I exercise and keep my weight down, I build in time for rest, and prioritise things I like doing. This way I have not let RA stop me doing what I want where possible and reasonable.

Whilst I think I've handled it relatively well, it's difficult not to feel some concern about how it may impact upon the rest of my adulthood. It's a very difficult subject to bring up with girls I'm dating, for example, and, when and if things get serious, it will have consequences as, should I want to father children, I may have to come off all my medication for six months before I can start to even try and conceive.

Despite everything, having RA has taught me humility, patience and compassion. It has focused my mind on achieving what I want in life.

I want to raise awareness about RA. If the nurse had caught it when it was just beginning, my story would have been dramatically different. If I can help just one person get diagnosed within the first two months of their disease, then that is enough for me.

### **Rheumatoid Arthritis** Facts & Figures

RA is incurable and the most common form of inflammatory arthritis within the field of autoimmune disease.



NRAS provides tailored packages of support and information on all aspects of living with the disease and we are the 'go to' organisation for everyone affected by RA.

The disease affects over 400,000 people in the UK, predominantly women in the mid years although you can get the disease at any age from 16. It presents as a chronic, aggressive, immune mediated attack on articular cartilage which can happen in the hands, wrists, elbows, shoulders, hips, knees, ankles or feet. Joints and other connective tissues become swollen, red, stiff and painful, limiting even simple daily living activities and, unchecked, can result in irreversible bone and joint destruction as early as 3-6 months after disease onset. RA is accompanied by an increased risk of cardiovascular disease and can result in premature death. Fortunately, today, the complications which were common 15-30 years ago are much rarer now, and when the disease is caught early and brought under control, people can expect to live life to the full.

RA is different for everyone living with the disease, although pain and fatigue, to varying degrees, are symptoms affecting all. Some struggle with fatigue more than others where as some may struggle more with joint stiffness or chronic pain. NRAS provides tailored packages of support and information on all aspects of living with the disease and we are the 'go to' organisation for everyone affected by RA.



# What you need to know about RA

- It's a lifelong condition
- It's a type of disease called an 'auto-immune disease'
- People can develop it at any age, even as young as 16 years of age
- Everybody's disease is different
- It not only affects joints, it can also affect other organs such as heart, lungs, kidneys and even the eyes
- If inadequately treated, it is a destructive disease and can shorten life
- It is a progressive disease
- With the right treatment, most people diagnosed today can expect to lead full lives with their symptoms under control

Aran has thrown himself wholeheartedly into raising awareness and funds for JIA and hopes to do more for NRAS in the future.

### Aran's Story (aged 11)

I don't really remember a time when I didn't have arthritis. It's always been a part of my life.

My very first childhood memory was waking up in a hospital bed, confused about where I was and what was happening to me. I now know that I had just had my first procedure on my knees. I had just turned three. Most of my early memories are of hospital visits, blood tests and injections. I was being examined by a doctor every other week, or at least that's how it felt. But most of all I remember the pain in my knees. Not wanting to walk because it just hurt too much and taking ages to get up in the mornings because my knees were so stiff and cranky. I used to get tired a lot. Not your 'no sleep' kind of tired, but the kind of tired that leaves you completely wiped out and unable to do anything. I didn't really understand what was wrong with me at the time. All I knew was that my knees were poorly.

There were lots of ups and downs along the way trying to find the right medication that worked for me, but once we did, things improved quickly. Nowadays, my arthritis is very well controlled. Most afternoons you will find me tearing up the rugby pitch or playing football. I love sport and understand that being active is a really important part of keeping my joints healthy. I have never let my JIA stop me from doing the things I enjoy. Of course, some days are harder than others, but I refuse to let it get the better of me.

The more I have learnt about the disease, the more I realise that I am lucky. I know that there are other children whose arthritis is not as well controlled as mine. Having JIA has taught me that strength comes from the inside and learning to cope with this disease has given me a determination and drive to help others that I might not have otherwise had.

My wish is that one day there will be a cure for arthritis. Until then, I will keep doing what I can to continue raising awareness for the disease that affects so many of us.

Aran's dad, Anil, raised over £400 running the London Marathon.

Most large secondary schools in the UK will have at least 1 or 2 children with JIA

### Juvenile Idiopathic Arthritis Facts & Figures

Juvenile idiopathic arthritis (JIA), is the most common form of arthritis in children and adolescents. ("Juvenile" in this context refers to an onset before age 16, "idiopathic" refers to a condition with no defined cause, and "arthritis" is the inflammation of the synovium of a joint.)

JIA is an autoimmune, non-infective, inflammatory joint disease of more than 6 weeks duration in children less than 16 years of age. The disease commonly occurs in children from the ages of 1 to 6, but it may develop at any age up to 16 including as late as 15 years of age. It is a subset of arthritis seen in childhood, which may be transient and self-limited or chronic. It differs significantly from inflammatory arthritis commonly seen in adults such as rheumatoid arthritis. It is also important to correct a common misbelief that after the age of 16 JIA turns into RA. It doesn't and remains JIA into adulthood.

There are 7 different sub-types of of JIA and it affects about one in 1,000 children in any given year, with about one in 10,000 having a more severe form.

- There are 12,000 to 15,000 children and young people in the UK living with JIA
- Up to 30% of children and young people with some form of JIA may develop uveitis which if untreated can lead to blindness
- Up to 50% of children and young people continue to live with JIA in adulthood
- JIA-at-NRAS has seen a 70% increase in the amount of families seeking information and support

# 'Kids just wanna have fun'

Family Day, Ilkley, West Yorkshire, July 2016'

### **2016 sees significant growth** in families seeking support from JIA-at-NRAS

2016 saw the successful launch of our major annual Family Fun Day, held in Ilkley, West Yorkshire.

Many families, children and young people joined us and subsequently a parents' support group has been established in the Bradford area. We also held regional fun days in Newmarket and Cardiff to support future service development and delivery. 'JIA and Me' Art Competitions took place in Southampton, London, and Sheffield.



These important events have enabled over 200 families and children to come together, share experiences and contacts, learn, reassure and engage in fun and educational activities which is vital in supporting these families' feelings of isolation and anxiety.

JIA-at-NRAS developed and delivered two key new publications, produced in collaboration with healthcare professionals and parents – 'JIA Explained' and 'Managing JIA in School'. These booklets have been exceptionally well received and are proving to be invaluable to parents, health professionals, teachers and school staff in supporting families, children and young people living with JIA and its impact. Well over 5,000 copies were distributed following their launch in autumn 2016.

We continue to shape the policy and service environment to ensure best care for all and in this regard, have continued to provide patient support to the East of England Paediatric Rheumatology Network and are making real progress in our aim to convince the Welsh Health Specialised Services Committee (WHSSC) of the need for a tertiary service for paediatric rheumatology to be established at Cardiff Childrens' Hospital.



### **Our Fabulous Volunteers**

Our trained telephone support Volunteers offer an empathetic listening ear as well as practical real-life tips on living with RA through their own experience. They are matched carefully to the caller requesting support depending on their topic of concern, their age, geographical region but most of all their experience.

Quotes from two people who benefitted from a call from a telephone support volunteer:

"I just wanted to thank you for organising a chat with Tracey for me. I really appreciated her experience and it's been a help. I hope to be able to return the kind gestures in the future"

"Speaking with Francesca was a very positive experience for me... I was very apprehensive to receive a phone call but I felt very reassured that it was ok to open up. Personally I think she provided a balance of opening up to give context to the conversations we were having and to encourage me to talk about what I needed to. Sharing experiences was very positive and I think the call definitely helped me".

The NRAS Group meetings across the UK are run by small teams of dedicated Volunteers who coordinate the speakers and all the logistics despite living with RA themselves. Here's what an attendee at the Colchester group said:

"I had a lovely time at the meeting, really nice Group. Great work you all do to help so many. Many, many thanks for all the work you do to help us who suffer with RA. People like you, help people like me, come to terms with RA, and just to know someone cares, makes life worth living. Looking forward to the next meeting"

"I always say as frustrating as my diagnosis has been, the silver lining has been being involved in this charity - you are all amazing and I feel like a better person for being involved. As a younger person in London this experience has really humbled me and brought me back to reality through the amazing people I have met. I am really grateful for the charity and in a really strange way for getting this disease because I can safely say the benefits so far out way the possible negatives" Katy Pieris, Group Coordinator

Many Volunteers do a wonderful job of representing the charity and those who live with RA by participating in a wide range of projects and events, such as being on the steering groups of academic research projects; telling their personal patient story for the media to raise awareness, providing the patient view to educate health professionals, speaking at industry and parliamentary events and many other ways of raising the profile of RA and NRAS. Thank you to all our wonderful Volunteers who do so much for so many.



# Our Ambassador Networks in Scotland and Wales

Our trained Volunteer Ambassadors in Scotland and Wales have continued to fly the NRAS flag in the devolved nations in 2016 and do great work on behalf of NRAS to support people with RA and JIA in these nations.

In Scotland the Chair of our Scottish Network was instrumental in working with the Scottish Society for Rheumatology (also in collaboration with Arthritis Care Scotland) to provide the patient view in developing metrics for audit of early RA. In Wales we launched a major patient survey and joined forces with the British Society for Rheumatology who also did a survey of clinicians in Wales, to write a joint report published at the end of the year entitled 'State of Play of Rheumatology in Wales' and are grateful for the support



of our Welsh Ambassadors on this survey. We launched an NRAS Group in Northern Ireland in 2016 and hope to build on our contacts there in 2017/18. We also plan to launch a new Ambassador Network in Manchester next year in view of the devolved status of this area to ensure that we maximise opportunities for patients to improve care pathways and health and social care integration.

### **Changing Minds...**

#### **EDUCATING**

Our Rheum2talk workshops for rheumatology healthcare professionals on the topic of the impact that RA has on patients' emotional and intimate relationships, continues to be a huge success. 1-day workshops were run in Leeds, London, and Derby during 2016 with four more planned for 2017. NRAS is the only organisation providing this kind of training, helping health professionals to understand how and when to open the door to sensitive discussions on intimate subjects which are difficult for patients to raise, yet are central to emotional wellbeing. Lack of emotional wellbeing impacts lives in a major way and can affect physical wellbeing.

Additionally, in 2016 we provided educational support for health professionals at several events which included

- Presenting at the British Society for Rheumatology (BSR) Best Practice Award event on the benefits of our 6-week self-management programme
- Presenting at both the annual BSR rheumatology conference and the EULAR Congress
- Being a guest lecturer for medical students at Keele University
- Homecare health providers' staff training
- An invitation for Clare Jacklin, Director of External Affairs to visit Qatar to address the Arab Arthritis Awareness network

#### **RAISING AWARENESS**

The focus of 2016's RA Awareness Week was 'Spotlight on RA' to highlight some of the key difficulties of life with RA, whilst also taking the opportunity to share with people, who don't know, the early symptoms of RA. The campaign started by sharing three posters depicting different aspects of the effects of living with RA that are generally unknown or misunderstood: depression, cardiovascular risk, and impact of smoking. In addition, a series of special videos were filmed in which people with RA were asked to 'shine a spotlight' on their experiences of living with RA and the impacts of the disease that they would most like people to know about. A range of social media activity was planned during the week based around the videos, posters, infographics, and events that took place between 13 and 19 June.

#### **INFORMATION AND SUPPORT**

A key service NRAS offers those living with RA and JIA is the provision of evidence based quality information and support.

The team handled thousands of telephone calls and email enquiries and provided social media responses to people via HealthUnlocked, Facebook and Twitter. The NRAS Helpline team moderate the discussions on social media on a daily basis to ensure that our peer support platforms can exist in a safe and supportive space. This also enables the team to offer additional information and support where needed in a timely way.

The Information and Support team update health information on the NRAS website on a regular basis, working with various rheumatology health professional contributors and ensure that all medical information is peer and reader reviewed. We have a notice board at work that we use to promote and raise awareness of charities/causes/ illnesses, to date NRAS have been the best source of information and posters, particularly with the invisible symptoms campaign.

Ps: your publications are really useful, I recently used the Employers Guide to explain things better to a new manager at work!

NRAS Member, Richard Aged 27

The team have contributed articles for the NRAS magazine, issued three times per year, providing lay summaries of the latest research and drug information. The 'Ask the Helpline' section of the magazine is very popular and offers a way of sharing some of the most topical questions being asked on the helpline.

We supply free information sheets and booklets on a wide variety of topics. Rheumatology healthcare professionals across the UK rely on NRAS publications for sharing vital information with their patients about all aspects of living with rheumatoid arthritis or juvenile idiopathic arthritis. Amongst the most popular booklets are those for the newly diagnosed and the 'I want to work' booklet covering issues in the work place. In 2017, we will be publishing four new booklets which we know are eagerly awaited by people with RA and healthcare professionals alike.





### **Changing Services...**

#### OUR POLICY AND PUBLIC AFFAIRS WORK

During the 2016 RA Awareness week, we launched Spotlight on RA at a parliamentary reception, attended by a large number of MPs from across the political spectrum. In the Autumn, we launched *Who Cares?: a report on the health and perceived social care needs of people with RA living in Scotland in the Scottish Parliament. Who Cares?* was written in partnership with the University of Aberdeen and therefore brings academic rigour to a person-centred report. We will be repeating this innovative approach to research collaboration in 2017 by working with the University of Manchester to produce a follow-up to our 2007 report: *Working with RA.* In December, we partnered with the British Society for Rheumatology, to produce *The State of Play: Rheumatology in Wales.* 

Events in the Westminster and Scottish Parliaments and the Welsh Assembly highlight the work and findings of NRAS and raise awareness of RA and JIA. Our fifth Healthcare Champion Awards in November 2016, held in Westminster, paid tribute to the many dedicated healthcare professionals who support people living with RA and JIA across the country. We were delighted that the Prime Minister, in her capacity as founding patron of NRAS, sponsored the event and presented the awards.

In June, Theresa May, who was then Home Secretary, facilitated a meeting for NRAS with the then Secretary of State for Work and Pensions to discuss the serious challenges people with RA and JIA have in securing the welfare support they need. This meeting led to our CEO and Founder, Ailsa Bosworth MBE, being appointed as a member of the Government's Expert Advisory Group to the Work and Health Unit, which continues to provide us with an unprecedented opportunity and level of access to influence policy at the highest level. Details on our relationship with the Prime Minister relationship can be found at www.nras.org.uk/patrons.

In 2016, we met with politicians from every major political party and secured their support for key campaigns, particularly around welfare and work/ employment. Welfare reform was a recurring item on the political agenda in 2016; we have responded to government consultations and through coalitions made clear our objections when appropriate, but we have also supported incremental reforms that make the system more robust at times.

Often, by running a wide variety of campaigns, we have successfully influenced change by making a quiet but forceful case for people with RA and JIA. Our very existence as a charity is a statement of our belief and a reminder to everyone that we believe much needs to be improved to ensure equity of access to the best health and social care, and we will continue to campaign for it.

#### COLLABORATIVE WORKING WITH OTHER ORGANISATIONS

We're working in partnership with other organisations to bring about improved access to better care. The daily challenges of living with rheumatoid arthritis (RA) or juvenile idiopathic arthritis (JIA) can often be similar to those of people living with other long-term health conditions. Indeed, a large proportion of the >400,000 people living with RA and JIA in the UK will also have another existing long-term health condition.

Working collaboratively with partners in the charity sector and with relevant professional bodies forms an important part of our work. It is prudent to pool resources but more importantly, to deliver a consistent message to government, health authorities, commissioning bodies and other decision makers. On longer-term projects, our joint working often sees us joining forces with coalitions and alliances in order to over-achieve as a smaller charity. These include:

#### Arthritis and Musculoskeletal Alliance (ARMA)

ARMA brings together patient and professional organisations, big and small, working in the musculoskeletal (MSK) arena. NRAS champions the specific needs of those living with inflammatory arthritis and welcomes the opportunity to link in with wider MSK priorities.

#### British Society for Rheumatology (incorporating: British Society for Paediatric and Adolescent Rheumatology, British Health Professionals in Rheumatology, Primary Care Rheumatology Society, Scottish Society for Rheumatology)

Professional organisations we regularly work with enable us to ensure that health professionals understand the key issues that concern people about their care. A regular partner is the British Society for Rheumatology, which is the umbrella organisation representing the entire multi-disciplinary team in rheumatology. A recent example of our joint working with the BSR was our report on services in Wales which can be accessed via our website.

#### Disability Benefits Consortium (DBC)

The welfare system in this country is a safety net that we can be rightfully proud of. As a group of over 50 disability charities, we consistently stand up for the rights of disabled people, including people with RA, when challenged by government reforms.

#### **Fit for Work Coalition**

Being meaningfully occupied, through paid employment or achieving other personal goals, is one of the top priorities for most people with RA or JIA. Through the Fit for Work Coalition, which includes experts and patient representatives, we explore the challenges for people with MSK conditions with regard to staying in or returning to work. This collaborative work complements the work we carry out in this area focussing exclusively on RA and JIA.

#### **National Voices**

This collective of patient organisations and other health charities is the authoritative voice for the health and social care sector and challenges the government on the development of a sustainable NHS and broader health and care system.

#### Prescription Charges Coalition (PCC)

NRAS is delighted to co-chair this Coalition alongside Parkinson's UK and Crohn's & Colitis UK. Together, 40 organisations are calling for everyone with a long-term condition to be exempt from the prescription charge of £8.40 per item. The current medical exemption list, written in 1968, is woefully outdated and applies a regressive charge to millions of people already at a financial disadvantage.

#### Specialised Healthcare Alliance (SHCA)

The care for children with JIA is a specialised service, currently commissioned at a national level by NHS England and equivalent bodies. Devolution plans seek to upturn this and through this alliance we gain an understanding of and share our views on the consequences of changes to an already delicate funding system.

### **Changing Lives...**

#### **SUPPORTING RESEARCH IN 2016**

We collaborated with the University of Chester on the creation of a major European survey to look at the economic burden of RA. We felt this was an important piece of work as up to date data on this subject is lacking. 10 European countries participated in the patient and physician survey and the analysis of the data collected will be the subject of a report entitled *BRASS (Burden of RA Socio-Economic Study)* to be published in 2017.

University of Manchester – We work with UoM on a regular basis. Our CEO sits on the Steering Group of the British Society for Rheumatology Biologics Registers (BSRBR) and the RA Register is run by UoM in partnership with the BSR. The BSRBR-RA tracks the progress of people with rheumatoid arthritis who have been prescribed biologic (including biosimilar) drugs in the UK to monitor the long-term safety of these drugs. The BSRBR-RA is one of the largest prospective studies of patients receiving these drugs in the world with over 20,000 patients registered in the study since it started in 2001. We have also supported a recent study by UoM entitled 'Cloudy With a Chance of Pain'; the world's first smartphone-based study to investigate the association between pain and the weather and a further study on the use of steroids in those with long term conditions.

Other academic institutes that we have worked with to support research studies during the year include;

- Oxford Academic Health Science Network
- King's College
- University of Sheffield
- University of Salford
- University of Birmingham
- Loughborough University
- University of Derby
- University of West England
- University College London
- University of Aberdeen

"I'm writing to express my sincere thanks to you for your letter of support for the extension [to the research study] .....I am sure that your letter being from a patient group carried significant weight. I know that NRAS continues to provide support to MATURA in many ways. I'm most for grateful for your help. Thanks again"

Professor Costantino Pitzalis MD, PhD, FRCP, Professor of Experimental Medicine and Rheumatology, Head of Centre for Experimental Medicine & Rheumatology, Queen Mary University of London



MANCHESTER

Oxford

Academic Health

Science Network

**University** of

MANCHESTER

The University

Sheffield.

Of

1824 The University of Manchester











#### MAKING OUR SERVICES MORE ACCESSIBLE

A diagnosis of Rheumatoid Arthritis can be devastating. RA causes physical damage and social, economic, psychological and cultural problems that impact on all aspects of life. People cope as well as they can but are often overwhelmed with the amount of information on the disease, medications they have to take and are confused by worrying statistics. When they come from a different cultural background, where language can be an issue as well as underlying cultural differences and beliefs, this feeling of being overwhelmed can be even greater and more distressing.

The internet is a good source of information when you know where to look, but can be misleading or inaccurate, even for native Brits with no language or different cultural problems, leaving people bewildered, frightened, and unsure as to what to do next. This is worsened by a lack of contact time between patients and their healthcare team, an issue noted in Sir Simon Stevens 2014 Five Year Forward Review on the future of the NHS, which states that most patients with long term conditions spend less than 1% of their time in contact with healthcare professionals (HCPs).

One of the Society's goals is to improve access to health information. We have a responsibility to ensure that our evidence-based information is accessible in different ways to suit individual preferences, whether in print from one of our 80 plus information publications, by phone to our dedicated free-phone helpline or electronically via our website, social media platforms and fast growing community forum.

As part of our three-year strategic plan 2016-2019, this year we initiated the 'Accessible Information Project' to

provide those with RA with equally tailored, but more easily accessible information. A key part of this project is to provide resources and develop innovative solutions which are accessible to the South Asian population across the UK.

We launched our Apni Jung project at the British Society for Rheumatology annual congress and presented a new area on our website entirely dedicated to the S Asian population.

The purpose of this web area is to build up a body of information and resources in Hindi and, where possible, Urdu and Punjabi, which are the most common languages used across India, Pakistan and Bangladesh. We are making our information available in video and downloadable audio podcast formats as not everyone from this population can read their mother tongue, especially the older members of these communities. This is a beginning and we look forward to taking this project further in 2017.

#### **MEMBERSHIP**

Our Members are essential to the work that we do and we were delighted to break through the 5,000 Member barrier in 2016. We have in excess of 1,200 healthcare professional Members. We offer Membership to healthcare professionals at no charge currently as we feel it is a real and valuable investment in supporting people with RA.

Through our Membership scheme we reach many people: our magazine is sent to over 7,000 people, three times a year. Our monthly e-newsletters (to Members, healthcare professionals and supporters) are sent to over 12,400 people and enable us to keep them informed of our new publications, research opportunities, Group launches and events. A survey we held in 2015 showed our Members wanted more regional events so we decided to change our annual Members' Day to three regional open 'Rheum for You' conferences which would enable more people to attend. Members were able to attend free and a small charge was made for non-members. In 2016, these were held in Gloucestershire, Derby/Nottingham area and a third was organised by the NRAS Scottish Ambassadors and took place in Stirling, our first open conference in this format in Scotland.

"Many thanks for my Membership Welcome Pack it arrived today. I have had RA for 16 years and reading some of the articles in the magazine and publications online has been surprising! Things I can relate to and things I can relate to and things I never understood. After so long you think you have seen/heard all there is to know about it. It's certainly an eye opener. Thank you so much."

New NRAS Member



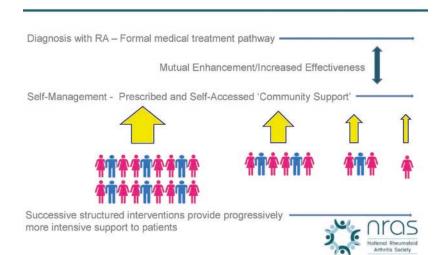
'Absolutely fantastic course, it has helped me enormously. I feel much more positive and informed and am looking forward to the future'

### **Commissioned Services**

NRAS Community Services Limited

After a successful pilot, 2016 saw the first addition to the NRAS self-management training resource since the introduction of the 6-week RASMP course in July 2011. `*New2RA*', a short, easy to follow workshop, was designed to help people newly diagnosed with RA to better understand the physical and emotional changes they experience, and enable them to gain reassurance and support from sharing with a small peer group. `*New2RA*' formed the first stage in a proposed `pathway' approach to self-management support from NRAS, which would see development of at least one more short workshop for people with existing disease who did not need the more intense 6-week support provided by the RASMP course.

#### **SSM** Pathway for RA



NRAS Community Services signed formal 2-year contracts to provide a range of patient support services in two areas of Sussex, which enabled the recruitment of two excellent and committed staff to the role of Local Services Supervisor for the respective East and central Sussex contract areas. As part of the development phase of work in Sussex, we facilitated an `away day' discussion with management from the Sussex MSK Partnership East and staff from the Rheumatology Unit at East Sussex Hospital Trust, looking at critical issues of staffing and the care pathway. In central Sussex, we ran two workshops for primary care practitioners on how to better meet NICE Standards of diagnosis, referral and care of Rheumatoid Arthritis. We also contributed to two meetings of the newly-formed Patient & Carer Forum.

> NRAS also reached agreement to provide New2RA workshops for patients in Croydon, Newcastle and Oldham, with delivery underway in Croydon and Oldham by the end of the year; while 6-week RASMP courses were delivered in partnership with Rheumatology Units in Bath, Brighton, Glasgow and Fife.

With the growing interest in, and recognition of the importance of, digital and on-line services, NRAS entered into an initial partnership with *`Patients Know Best'* to develop a dedicated NRAS patient-controlled portal for use in Rheumatology Clinics. *`Patients Know Best'*  is the only system of its kind that stores information behind the secure NHS N3 network, but provides access via any web-enabled device. Each patient's record is uniquely encrypted, and only the people to whom the patient gives consent can decrypt and access the record. We also had preliminary discussions with the Danish developers of the *`RheumaBuddy'* App, which is targeted at young people aged 12-35 and in which we see potential to support parents and young people in our JIA-at-NRAS programme.

NRAS Director of Commissioned Services was also:

- An active board member of the Health Quality Improvement Partnership (HQIP), the body responsible for clinical audit in the NHS in England and Wales
- The Chair of the Quality Institute for Self-Management Education & Training (QISMET), an organisation that publishes quality standards and audits and certificates providers of self-management support to patients with long-term conditions
- A consultant to Camden CCG as part of a team advising on a new MSK service specification and tender
- A member of the Steering Group for the National Voices `Wellbeing Our Way' programme
- A contributor to the DWP Expert Advisory Group on the government Green Paper on work and disability – acting for the CEO in her absence

### Working with the pharmaceutical industry

NRAS has an excellent reputation in the UK for high achievement and committed representation of the patient voice in RA and JIA. A large part of this reputation is based on our integrity, openness and transparent working practices, and determination to always do the right thing for those we represent, however difficult that may be, and this ethos runs throughout the organisation in everything we do.

This is also reflected in our work with the pharmaceutical industry, which we believe has brought significant benefits to people with RA and JIA. Particular highlights for working with industry this year have been the launch of the improved NRAS Know Your DAS app with the support of Roche/Chugai which is being used by thousands of people with RA and the 'Behind the Smile' series of videos sponsored by Lilly which have been hugely influential in encouraging people to tell their team when they are 'not OK'. The video has had thousands of views, not only in the UK, but worldwide.

The introduction of biosimilars to the UK market as originator biologic drugs come off patent is a hot topic and NRAS has been strategically involved in working with NHS England, NHS Scotland and other stakeholder organisations (listed below) to ensure that the patient voice is represented in how these new treatments are implemented to the benefit of patients, patient outcomes and rheumatology services.

- ABPI (Alliance of British Pharmaceutical Industry)
- NHS England
- Generics and Biosimilar Initiative (GABI)
- British Biosimilars Association (BBA)

• Our Chief Executive is a member of the NHS England Biosimilar Programme Board

It is important that we clarify our position for working with industry.

- We have a policy for working with industry which is published on our website, and is reviewed annually
- Any project which we undertake jointly with industry must align with our vision, mission and aims as an organisation
- We will never promote, advertise or endorse an individual drug
- We will always declare pharmaceutical funding or sponsorship on any publication or published material
- In any project we undertake with industry support, which involves the publication of a survey or report of any kind, editorial control will always rest with NRAS and we will not allow this policy to be modified under any circumstances
- It should be noted that where pharmaceutical companies report 'in kind' support on their websites, it is clear that under this kind of working arrangement NRAS receives no direct funding at all, neither do the amounts shown necessarily correlate to an 'equivalent value' as far as NRAS is concerned. These amounts should actually be offset by the 'in kind' resource which has been contributed by NRAS and NRAS resources, but this is not something which we account for, nor do the pharmaceutical companies show or take account of the in kind support we, in turn, provide to them

- No member of NRAS staff or Trustees will ever accept any personal payment or honorarium for presenting at an event of any kind organised/sponsored by industry
- We have never, nor would we ever, ask a pharmaceutical company or their representatives (public relations or public affairs agencies) to lobby government in regard to drugs or access to individual drugs
- It is our policy to ensure that industry funding will not exceed a maximum of 15% of our total income in any year

You can view our full policy on working with industry on our website.

### **Pharmaceutical Funding 2016**

Funding for:	To support NRAS projects and services	Reimbursement for use of NRAS resource and expertise	TOTALS
AbbVie Ltd			
Scottish Survey	£2,000		
Core funding	£20,000		
Magazine distribution	£20,000		
Clare to Ad board panel on Biosimilars		£300	
Total	£42,000	£300	£42,300

Eli Lilly & Company Limite	be		
Spotlight on RA project		£3,100	
Patient input		£1,000	
Behind the Smile project	£2,500		
Corporate Membership	£5,000		
Medicines booklet	£6,000		
Fatigue booklet	£12,000		
RHEUM2talk	£27,000		
Total	£52,500	£4,100	£56,600

NAPP		
Honourarium	£437.50	
Total	£437.50	£437.50

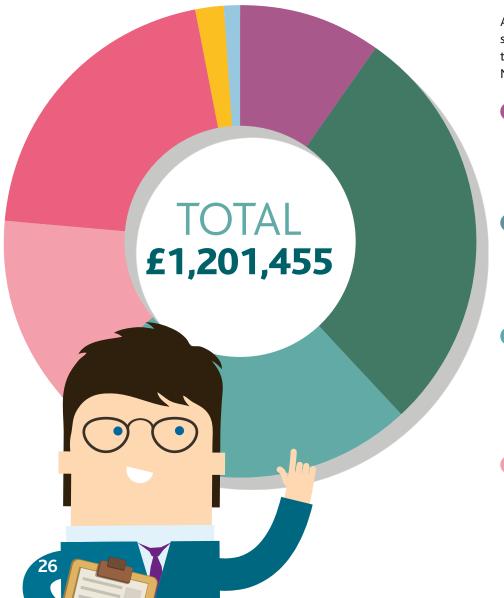
Pfizer Ltd			
Ad board meeting Oct 2016		£800	
Havant site visit		£1,000	
Use of video clips		£500	
Honorarium		£500	
Booklet rewrites	£12,600		
World Arthritis Day Radio coverage	£3,000		
Total	£15,600	£2,800	£18,400

Funding for:	To support NRAS projects and services	for use of NRAS	TOTALS
Roche/Chugai			
DAS app development and promotion	£70,000 <b>IN K</b>	IND	
Total	£70,000 IN K	IND	
Sandoz		·	
NRAS attendance at Biosphere meeting		£466.42	
Corporate Membership	£5,000		
NRAS speaker expenses		£205.48	
Total	£5,000	£671.90	£5,671.90
UCB			
Media advisory board London		£500	
In Tune Project	£15,000		
NRAS resource utilisation		£250	
Match funding		£500	
Total	£15,000	£1,250	£16,250
Grand total			£139,659.40

Total Pharmaceutical Companies funding to support NRAS projects and services	Pharmaceutical Companies reimbursement for use of NRAS resources and expertise
£130,100	£9559.40

### Where our money comes from...

NRAS receives no statutory funding at all and is entirely funded by voluntary donations, grants, events, sponsorships, memberships and a range of other income streams.



A maximum of 15% (of total income in any one year) comes from industry joint working and support. We are extremely grateful for the generosity of our donors, fundraisers and members for their ongoing support and for helping us to raise an amazing £1,070,530 for NRAS (including JIA-at-NRAS) in 2016, exceeding our 2015 income by nearly £36,000.

### Corporate (including pharmaceutical income) | 10%

For more information about our industry income and how we work with industry, see pages 24 and 25

#### Trusts, Grants & Contracts | 29%

This includes the generous grants from Trusts and Foundations towards our work, including our JIA-at-NRAS service, as well as our commissioned services

#### Gifts in Wills | 26%

Gifts in a will are one of the most personal commitments a person can make. We are extremely grateful to those who made a lasting gift to NRAS to help our vital work continue

#### Donations | 11%

Donations are made from our generous donors, members and regular givers including the NRAS lottery and our e-fundraising initiatives

#### Events & Community | 21%

Income from our fabulous fundraisers who did incredible things to raise money for us, which included cycling, running, walking, trekking, baking and many other activities

#### Income 2%

A small percentage of our income is derived from investments and interest

#### Research & Studies | 1%

Income received from research projects and academic studies we participate in



### Where we spend our money...

In 2016, we continued to help those living with, and impacted by RA and JIA to be able to live the life they want and deserve. Our goal is to be there for anyone diagnosed with RA or JIA right at the start of their journey and whenever they need us along the way.

We want to help people living with RA and JIA live as full a life as possible through a better understanding of their disease and learning how to self-manage effectively so that they can focus on the other aspects of their life. The following figures include **3.5%** of our total income covering costs of governance.

#### Changing Minds | 33%

We provide education and support in many different ways for people living with RA and JIA. We also help to change the minds and behaviours of health professionals by educating them about the real impact of living with RA and JIA and providing specialist educational workshops such as Rheum2Talk. We raise awareness of the seriousness and invisibility of RA and JIA in every way possible and particularly through our marketing and communications during RA Awareness Week, World Arthritis Day and at our events. Our many publications and sources of evidencebased information are available in different formats and through different platforms and channels to suit individual preference and need.

#### Changing Services | 32%

One of our key strategic aims is to influence and shape the policy and service environment to ensure equitable access to the best treatment and care for all with RA and JIA. We are a patient-led charity, and this means that we actively engage with people living with RA and JIA to help us set the direction of our campaigns every day. This also ensures that our campaigns are always evidence-based. We know that access to best care and treatment for all is not a reality and there is much evidence to demonstrate this. Our Policy and Public Affairs work and collaborative working with other coalitions and alliances is vital in ensuring that those who take decisions about health and social care are informed of the impact that RA and JIA have on lives and wider society, and understand the value that access to the best care and treatment brings to individuals, the NHS, the Exchequer and whole communities. Our work to support the development of national standards and guidelines as well as our collaborations with NICE and other government bodies and stakeholders evidences our commitment to the goal of access to best care.

#### Changing Lives | 35%

We are committed to providing support, information, services, education and patient advocacy of the highest quality to and on behalf of all those affected by RA and JIA. We also provide a range of services including our valued magazine (three times annually) to our Members. We support our growing network of patient Groups, delivering valuable face to face services across the UK. Our Helpline is freely available to anyone struggling with their disease and needing support and our range of self-management programmes and resources help people with RA to learn selfmanagement skills and gain more control over their lives. Additionally, our Members say that being part of NRAS gives them a sense of belonging, making them feel part of a friendly group and not alone in facing the daily challenges of living with RA.

Our supported self-management services help people to understand issues such as the importance of taking prescribed medication to help control their disease (adherence) so that health outcomes are improved as well as the need to make lifestyle choices to promote good general health such as exercising, stopping smoking and maintaining a good, balanced diet.



### **Our wonderful NRAS Fundraisers**



Some brave fundraisers took part in various Community Challenges around the UK – such as Skydives, Tough Mudders, Climbing Ben Nevis, Snowdon or 3 Peaks, Zip Wire Challenge, Coastal Path walks, Triathlons, Swims and Half marathons. They raised nearly **£52,000** 





We had places in a number of **serious** and *fun runs* which are always popular events







Intrepid people took part in UK and overseas treks Cyclists who cycled various distances, alone or as teams in organised rides (or not) and even a Unicyclist. Our cyclist who raised the most was **Dr Vineet Joshi** who did Land's End to John O'Groats for JIA and raised just under £6,000!

The overall total raised by the cyclists was an impressive **£17,000+** 













Lots of folk held tea parties for NRAS and raised nearly

£4.000



A **huge** thank you to all our fundraisers...

### The Team behind NRAS...

Ailsa Bosworth MBE	Founder & CEO
Alison Cini	Information & Support Coordinator
Anne Gilbert	JIA Service Manager
Beverley Briggs	Senior Information and Support Coordinator
Brianna Gumb	Fundraising Coordinator
Bronwen Cranfield	Community Fundraiser
Clare Jacklin	Director of External Affairs
Conn O'Neill	Policy & Public Affairs Manager
Dawn Bamforth	Local Services Supervisor - East
Denise Pointon	Director of Finance (left Nov)
Emma Sanders	Individual Giving and Membership Officer
Gill Weedon	External Affairs Coordinator
Ian Hayward	Director of Finance (started November 2016)
Karen Keech	Local Services Supervisor - Central



Kim Fitchett	External Affairs Coordinator
Lorraine Price	EA to CEO
Mark Arnold	Trusts & Grants Officer
Michele Gagie	Finance Administrator (started in Nov)
Michelle Vickers	Head of Fundraising (started in Nov)
Oliver Hoare	Head of Fundraising (left Nov)
Phil Baker	Director of Commissioned Services
Sally Wright	Head of Marketing and Communications (started in Nov)
Sarah Venables	Projects and Events Administrator
Shivam Arora	Web and Digital Media Officer
Tammy Mallowan	Office Administrator
Val Eyre	Events Fundraiser
Victoria Butler	Senior Information and Support Coordinator

### Our Corporate Partners and donors...

We have been generously supported by several corporates, trusts and foundations throughout 2016. It's impossible to list them all, but we would like to thank everyone for their generous support. Here are just a few organisations we have worked with;

Allchurches Trust Limited CHK Charities Limited William Leech Charity Monument Trust **Garfield Weston Foundation** The Grocers Charity Mars Tesco The Joicey Trust Bill and May Hodgson Charitable Trust The Joseph Strong Frazer Trust BGS Cayzer Charitable Trust

# Message from our Chair **Steve Crowther**

It gives me huge pleasure to write my first (and only) Chairman's annual review, as Interim Chair. I would first like to start by paying tribute to my predecessor, Graeme Johnston, who was a trustee of NRAS for 7 years, for 6 of which he was Chairman. He provided great service to the Charity and will be missed.

I am delighted to have taken over as Chair from Graeme, albeit on an interim basis, and to continue to act as Treasurer on the Board of Trustees. A new Chair will be appointed in 2017 from within the seven new Trustees appointed from the end of 2015 and through 2016, following several retirements by long-standing Trustees who had served the charity loyally for many years.

In our new Board, we have a wide range of skills and diverse talent to support the Charity's development and future growth in what is a challenging market place for third sector organisations. New regulatory frameworks for charities regarding fundraising, data gathering and data protection as well as new and more onerous accounting regulations mean that good governance and risk management is even more essential and I'm pleased to say that NRAS has always had strong controls in this area.

2016 has seen a robust performance from the team and produced excellent financial results. Total income increased by more than 20% to  $\pm$ 1.3m in the year, with strong performances across several income streams including Donations and Gifts, Legacies and Grants. The Charity continues to be run on a prudent basis with strong budgetary and financial controls, and easily met its target of retaining 6 months of operating costs as cash and investments. The projects and work-streams delivered by the charity in 2016 in addition to maintaining and increasing its front-line services were both innovative and substantial and many are mentioned in the Chief Executive's report in this review. It's also great to see my colleagues on the Board getting involved in several of these.

In particular, the exciting potential from our partnership with Patients Know Best and the NRAS/PKB patient portal is something we can build on in coming years as digital patient platforms and e-records progress towards becoming the norm. More and more people with RA, their families and health professionals are engaging with us in a wide variety of ways and this increased engagement can be measured in web and social media analytics as well as growth in Membership and supporters of NRAS. More innovative ways to measure the impact of what we do is something we are conscious we need to invest in and the Board and Senior Management Team will be working on this well into 2017.

The Board are also delighted to see the great progress in the provision of our JIA services, an important and growing part of the charity's work and the uptake of the new booklets, 'JIA Explained' and 'JIA in Schools' launched at this year's British Society for Paediatric and Adolescent Rheumatology Conference, has been fantastic. All credit to the JIA team.

NRAS has always punched well above its weight and I am delighted to say continues to do so. NRAS celebrated its 15th birthday in October, the Management Team and all the staff, Volunteers and Members should be immensely proud of their achievements.

### Our Trustees...





Steve Crowther

Kirsten Fox





Ellie Andrews

Gordon Taylor





Zoe Ide

Richard Boucher





Simon Collins

### Patrons, Trustees and Advisors...

#### **TRUSTEES**

#### **MEDICAL ADVISORS**

Steve Crowther **Kirsten Fox** Ellie Andrews Gordon Taylor Zoe Ide **Richard Boucher** lennie lones Simon Collins

Dr Alaa Hassan Dr Asad Zoma Dr Christopher Deighton Dr Gulam Patel Dr James Galloway Dr Lesley J Kay Dr Lorraine Croot Dr Martin Lee Dr Marwan Bukhari Dr Patrick D W Kiely Dr Richard A Watts Dr Richard Haigh Dr Richard Reece Dr Ruth Williams Dr Stefan Siebert Dr Yasmeen Ahmad **Prof Ernest Choy** Professor David G I Scott Professor lain McInnes Professor Kuntal Chakravarty **Chief Medical Advisor** Professor Peter Taylor

#### PAEDIATRIC MEDICAL **ADVISORS**

Dr Athimalaipet Ramanan Dr Clarissa Pilkington Dr Gavin Cleary Dr Janet McDonagh Dr Jeremy Camilleri Dr Jonathan Packham Dr Madeline Rooney Dr Nick Wilkinson Dr Rachel Tattersall Dr Kristina May Prof Tauny Southwood Sarah Hartfree (Nurse Specialist, Paediatric Rheumatology) Jane Willock (Clinical Nurse Specialist, Paediatric Rheumatology, Wales)

#### **NURSE ADVISORS**

Anne Quinn **Diane Home** 

Dr. Kanta Kumar (representing ethnicity issues in rheumatology in clinical practice)

Liz McIvor

#### Suzanne Davies

#### **ALLIED HEALTHCARE ADVISORS**

Robert Field (Podiatry)

Sandi Derham (Occupational Therapy)

William Gregory (Physiotherapy)

#### PATRONS

The Rt Hon Theresa May MP, Prime Minister and Member of Parliament for Maidenhead

Professor Gabriel Panayi, **Emeritus Professor of** Rheumatology, Kings College, London

Professor David G.I. Scott. Honorary Professor University of East Anglia

Mr Mark Liddell





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healthunlocked.com/NRAS healthunlocked.com/IIA

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