## Annual Review 2015

For everyone with RA and JIA to be able to live the life they want to



## **In 2015 NRAS**

Raised £1,034,544, spent £944,672 delivering our patient support services, launched 6 new NRAS Groups, answered 2,706 helpline contacts, sent out 40,064 free NRAS publications

National Rheumatoid Arthritis Society

and did so much more...

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Every year
1,000-1,500 children & young
people are diagnosed with juvenile idiopathic arthritis
idiopathic arthritis

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## Why we exist

The National Rheumatoid Arthritis Society (NRAS) is 'the voice' of people affected by Rheumatoid Arthritis (RA) across the whole of the UK and in due course, we hope to be so for Juvenile Idiopathic Arthritis (JIA). Founded in 2001, we are the only UK charity devoted specifically to RA and JIA.

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

## **Our Vision**

For everyone with RA and JIA to be able to live the life they want to.

### **Our Mission**

#### We

Ensure that people affected by RA or JIA have the information, tools and support to be able to access high quality care and services best suited to their individual needs and preferences.

Do everything we can to raise standards of care and ensure equitable access to high quality care and treatment for all with RA and IIA.

Pioneer innovative and effective ways to support all those living with RA and JIA to lead full and active lives with maximum well being, able to pursue their individual goals.

## Our Goals 2015-2017

To have delivered and embedded our innovative supported self-management pathway in at least one region

To become the 'go-to' organisation for everyone affected by and working in the field of JIA

To improve our capabilities, competencies and efficiencies in the areas of fundraising, data management, information and communication

To improve the benefits system to better represent those with fluctuating conditions

To provide new training programmes for healthcare professionals addressing areas they feel in need of

To evolve our frontline services to reach many thousands more who continue to need our help. Also, we will develop new resources for South Asian communities

To raise awareness of RA and NRAS as well as developing new self-management tools

To improve the mechanisms by which best practice can be shared across the UK

## Life with RA and JIA

Rheumatoid Arthritis and Juvenile Idiopathic Arthritis are both diseases (syndromes) of the autoimmune system and contrary to common misperception, are not caused by wear and tear. Simply put, this means that your body's immune system, which is designed to defend your body against infection and 'foreign' invaders, goes wrong and becomes activated to attack your body, causing inflammation. Autoimmunity can be the cause of a broad spectrum of human illnesses, known as autoimmune diseases.

When you have RA, your immune system attacks the lining of your joints (the synovial lining). This causes inflammation, which leads to symptoms such as pain and stiffness, accompanied by severe fatigue, often affecting one's ability to carry out even the simplest day to day tasks. It is a progressive, lifelong condition, for which there is currently no cure. An estimated 31,000 cases are diagnosed each year in the UK. JIA affects children and young people under 16, and also causes inflammation in the joints and the severity of JIA can vary from mild to extremely disabling. Symptoms include stiff, painful and swollen joints. Approximately 1,000 - 1,500 new cases are diagnosed each year. In both RA and JIA other organs can also be involved and complications can arise, although, thankfully due to modern medicines and approaches to treatment these are much less common than they used to be.





When you have RA, your immune system attacks the lining of your joints (the synovial lining). This causes inflammation, which leads to symptoms such as pain and stiffness, accompanied by severe fatigue, often affecting one's ability to carry out even the simplest day to day tasks.



Approximately

## 690,000

people live with RA in the UK



Everybody's disease is different and there are a number of sub-types, it's not one disease Typically develops between

40-60 years of age

Although you can get it at any age

20%

of patients
with juvenile
arthritis develop
depression in
late adolescence

Up to

of patients continue to live with their juvenile arthritis in adulthood and have a higher risk of developing heart disease

children and young people live with JIA in the UK, that's one in every

that's one in eve 1.000

**Approximately** 

12.000

Up to

of children with oligoarticular juvenile arthritis may develop eye

inflammation that

can cause blindness

The majority of GPs have no training in paediatric musculoskeletal medicine and lack confidence in prescribing standard treatments for JIA

Approximately

31,000

people are diagnosed with RA each year, that's more than one in every 20 minutes

RA



It doesn't only affect the joints. It can sometimes affect other parts of the body, like the eyes, lungs and heart

For those who do stay in work on average they have

40 days

of sickness absence per year, compared to **6.5 days** 

for those without the disease

40%

of those newly diagnosed stop work within the first

YEARS

5

 The overall cost of RA to the UK economy is approximately

E4.75 billion per year



E

NHS spending on RA is estimated to be

4560 million per year JIA

## **RA&JIA**



There is no cure



With early diagnosis and the right treatment, most people diagnosed today with either RA or JIA can expect to lead full and active lives with their symptoms under control

# Chief Executive's Report



We started 2015, for the first time in our 15 year history, with a deficit which meant that we had a major challenge to come in on budget in the year. I am delighted to say that not only did we succeed in meeting our targeted income, but we exceeded it and generated a surplus which represents an extraordinary effort by the whole team. I therefore want to start my report for 2015 by paying tribute to the NRAS team who worked extremely hard to keep costs down throughout the year and to maximise every opportunity to bring in additional income. I'd also like to thank our board of trustees for their support and guidance throughout the year.

In spite of the challenging start to the year, we set ourselves an ambitious number of key projects to deliver in 2015 including:

- The launch of a major annual event with the Livery Companies of the City of London to build contacts and relationships with the Junior Wardens
- ✓ Launch of the first phase of the new JIA-at-NRAS website in February www.jia.org.uk and development work started for Phase II
- Annual JIA Family event

- Progressing towards delivery of supported selfmanagement services as sub-contractors against two commissioned service contracts in the South of England
- ✓ Starting to roll out our health professional workshop Rheum2Talk, teaching health professionals in rheumatology how to open the door to conversations about sensitive issues that matter greatly to people with RA, on self-confidence, self-esteem, emotions, relationships and sexuality
- Development of a new three-year fundraising strategy
- Development of a new three-year organisational strategy
- Launch of a three year programme of art competitions in specialist paediatric rheumatology centres across the UK for children and young people with JIA
- ✓ Our third RA Awareness Week in June
- A major survey on health and social care to be launched in Scotland in collaboration with Aberdeen University in 2016

- Culmination of a two year programme of visits by our Scottish Ambassadors to rheumatology units across Scotland to raise awareness of the help, support and services NRAS can provide to their RA patients
- V Expansion of our Welsh Campaigns Network and start of a programme of visits to Health Boards across Wales
- ✓ Partnering Chester University on a major pan European Burdon of RA survey and report (delivery of report scheduled for autumn 2016)

All of the above projects have been successfully delivered (or will be, as some completing in 2016), alongside consistent delivery of our front line services such as our helpline, our peer to peer support programme, support of and launch of new groups, and production and review of our publications.

The development of a new three-year organisational strategy and fundraising strategy was a major work-stream and focus for the staff and trustees over the summer and autumn period and involved a lot team sessions, including three key staff workshops led by our Director of Commissioned Services, Phil Baker, on Theory of Change. All charities should be able to demonstrate their impact to funders and stakeholders and five year plans are frequently expected and yet are sometimes not worth the paper they are written on. Much of what we do is responsive to the health and social care environment we find ourselves in and as a national charity, we are also dealing with four different health economies and parliaments. General elections, government white papers, budget announcements, changes in how services are commissioned etc. are all outside of our control and yet a key intention was to put a three year plan together which we were confident we would be able to deliver on. These team sessions helped the staff to focus on the end goal – where we wanted to be by 2019 – and revise our 'vision', mission, and develop five key strategic aims which we can be measured against. In due course, we will be able to demonstrate our impact and value to the constituents we serve in delivering this new strategy.

We are confident that the draft strategy effective 1st Jan., 2016, is 'owned' by our committed team and once published in the first quarter, 2016, will be the blue-print to take the charity forward over the next three years.

The new fundraising strategy is embedded within the overall organisational strategy and will enable us to grow our sustainable income streams over this period so that we can deliver on all our strategic aims.

Finally, I was thrilled and completely delighted to end the year with the announcement of my MBE for services to people with rheumatoid arthritis in the New Year's Honours published on 31st December. I share this award with my brilliant team and those past employees and trustees who have all helped to make NRAS the successful organisations it is today.





Ailsa singing at the NRAS Christmas Carol Concert



Ailsa meeting MSPs at our Scottish Meet the Patient event



Ailsa nominated as a Patient Leader by Health Service Journal

# NRAS is the "go-to" organisation for people with RA

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. We ensure that we provide tailored packages of support and information on all aspects of living with the disease so that NRAS is the 'one-stop-shop' for everyone affected by RA.

During 2015, the Information and Support team responded to over 2,700 contacts, 36% of which were digital contacts via email, our HealthUnlocked NRAS forum and our social media platforms. Queries about medication, benefits, general support and support for people currently going through diagnosis of RA were among the most common topics. Our HealthUnlocked peer led forum, moderated daily by our in-house team, now has over 10,000 regular users, a 59% increase in users since 2014.

During the year, some of our existing publications were updated and plans put in place to undertake major re-writes in respect of some of our most popular booklets in 2016 as well as getting funding in place to create some completely new publications next year. NRAS currently have over 80 information products, all freely available in print and online. We mailed over 40,000 copies to individuals and to resource hospital units.

Our reach via our Facebook and Twitter continues to expand significantly. Over the year we have seen a 32% increase in Facebook likes and a 26% increase in Twitter followers. We have worked to ensure that our materials and support packages feature and cross over to our social platforms as more and more people choose to engage with us in this way.

Our website Twitter followers

The Newly Diagnosed, I Want to Work and our Benefits publications were the most popular

## Helping those in need



## "

Thank you to Ailsa for all the hard work and dedication to helping us all with RA. NRAS have provided brilliant information and support and I am very grateful to all of you. \*\*J\*\*

Carol Gibbins

## "

Just wanted to say a huge thank you to the NRAS for their input at the Minerva [for the Preston Group launch]. My partner and I were quite dubious about attending, I am relatively newly diagnosed, and have never been one for going to seminars etc. other than work related. But, wow – what an informative few hours.

Alongside people from NRAS there were nearly the "full team" from the centre; consultants, nurses, pharmacists, occupational therapists, physiotherapists and administration staff. Nearly every one of them had a few words to say — answering questions and the like — but what really came across was that these dedicated people really care about the patients who suffer from this horrid condition. We left feeling much better about things - knowing that help is just a phone call away and that I am not "just an NHS number". I also feel so lucky to have this facility as I know many people are not as fortunate in their treatment. HUGE THANKS again to all those who gave up their time to be there. I am sure that all those who attended will appreciate it.

Jacki Shorrock

## "

I have used the helpline, it really made a difference on a bad day. I'm sure I will be using it again at some point! I think NRAS is amazing, keep up the good work.

Claire Lewis

## How we have worked to change care and services for the better

In 2015, we continued our work to improve care and services for people with RA, and we have achieved a number of successes.

- On Disability Benefits, we have been active members of engagement forums organised by both the Department for Work and Pensions and the private companies contracted to carry out claimant assessments. We ensured the needs of people with RA were properly represented.
- We launched an e-action tool on our website: 35 members/supporters contacted their MP to congratulate them on their election and make them aware of RA. 75 contacted later in the year to talk about the Welfare & Work Reform Bill.
- We have collaborated with other organisations representing people with progressive and/or fluctuating conditions to contact government ministers.
- In Scotland we lobbied health boards to allocate additional funding for specialist nursing to Rheumatology in partnership with the Scottish Society for Rheumatology. There are no longer any mainland health board areas without a



## Coalitions and other Groups NRAS belongs & contributes to

NRAS is the only organisation representing people with musculoskeletal conditions who attend this engagement forum. The group looks at operational and strategic policy changes that may improve the process for anyone claiming or applying for PIP.

**Department for Work** and Pensions - Personal **Independence Payment** (PIP) Improvement Group

**Prescription Charges** Coalition (PCC)

This coalition of 40 organisations is calling for an extension of the Prescription charges exemption to all people with long term conditions. The Prescription Charge increased earlier this year to £8.20 per item. The list of exempted conditions was introduced in the 60s and has not be updated since.

## Fit for Work Coalition

This coalition focuses on issues facing those with musculoskeletal conditions in getting into and remaining in the work place. They have given a generous amount of time to looking at RA lately, especially reviewing the 2009 National Audit Office report on RA.

National Voices is a collective of healthcare charities and patient organisations. It represents our collective interests to government and is well respected across the political spectrum. NRAS representatives attend their Long Term Conditions Group and their Public Affairs Network.

National Voices Care and Support Alliance (CSA)

The CSA can be very helpful as social care policy is very difficult to engage with and understand in its entirety. NRAS is currently working alongside some other progressive conditions charities (Multiple Sclerosis, Motor Neuron Disease) on a care act implementation briefing paper to go to social care leads across the country early in the New Year.

## **Disability Benefits** Consortium (DBC)

A coalition of over 50 disability charities campaigning to protect and reform vital disability benefits. We have played an active role in this forum, including helping produce the DBC 2015 Manifesto and supporting their annual survey.

## **Specialised Healthcare**

The SHCA covers issues relating to specialised commissioning, which includes paediatric rheumatology. They are currently leading on seeking assurances around the status of specialised services in areas such as Manchester where health and social care is set to be devolved.

## **Royal College** of Nursing (RCN) Alliance (SHCA) Policy Exchange

This is the forum through which the Royal College, a professional body, engages with patient organisations. As specialist nursing is very important for people with RA, it is important to maintain a good relationship with the RCN. This can be a valuable place for collaborative working and hearing about relevant initiatives from a specialist nurse perspective.

## Arthritis & Musculoskeletal Alliance (ARMA)

ARMA is the umbrella organisation representing the musculoskeletal sector, whose members represent patient organisations, health professional organisations and the research community. NRAS attends its chief executive meetings and our Policy and Public Affairs Officer attends their 'Policy and Comms' meetings.

# How we empower, educate and encourage people affected by RA to lead full lives

People living with RA have a wide variety of needs. During 2015 we ensured we were utilising our limited resources as effectively as possible to support everyone needing our services.

By making better use of social media and online communities we were able to increase the reach of the Society. During 2015 we trained an additional 20 volunteers with RA via our online training programme, enabling us to provide help to even more people on a one to one basis via our 'Telephone Peer Support Service'.

2015 saw the launch of six new patient groups around the UK: The Wirral, Preston, North London, West Suffolk, Glasgow and Londonderry. The launch of the Northern Ireland Group was the first for NRAS in the country and the Glasgow Group cemented our local presence in Scotland.

Currently we have **342** Network Volunteers of which **48** are trained to provide vital peer to peer Telephone Support. **65** peer to peer calls were matched in 2015.

Through our Membership scheme we reach many people: our magazine is sent to over **7,000 people**, three times a year. Our monthly e-newsletter is sent to over **9,600 people**.

Introductory membership offers were again promoted at group launches, recruiting **53** Members in this way.

Our Members are essential to the work that we do and we were delighted to break through the **5,000** Member barrier in 2015. We now have in excess of **1,000** healthcare professional members and we finished the year with a total of **5,041** Members.

@NRAS\_UK my membership pack arrived today, magazine looks great, magazine look forward to thank you, look forward in raising getting involved in #RA awareness #rheum #RA

"My membership is like gold dust to me and is worth every penny, superb!"

I look forward to the magazine as it keeps me up to date with current RA news as well as having some useful advice. I read this from cover to cover and then pass it on to my partner who does the same. It increases his knowledge of RA and helps increases his knowledge of RA and helps him appreciate the problems I have.

# Our Volunteers: Building one big community

48 NRAS Groups are providing invaluable community peer support across the UK, with more group launches planned for 2016.

## **NRAS** Groups

- 1) Ashford
- 2) Banbury
- 3) Blackpool
- 4) Bolton
- 5) Brighton
- 6) Bury St Edmunds (West Suffolk)
- 7) Cambridge
- 8) Chesterfield (Derbyshire)
- 9) Colchester
- 10) Cumbria
- 11) East Dorset (Bournemouth)
- 12) East London (Mile End)
- 13) Gateshead
- 14) Glasgow
- 15) Gloucester
- 16) Great Yarmouth
- 17) Gwent (Caerphilly)
- 18) Heart of England (Solihull)
- 19) Isle of Wight
- 20) Lincoln
- 21) Londonderry
- 22) Medway
- 23) Mid Cornwall
- 24) Mid Somerset (Taunton)
- 25) North Durham
- 26) North East (Newcastle)
- 27) North Hampshire (Basingstoke)
- 28) Plymouth
- 29) Oxford
- 30) Pembury & Tunbridge Wells
- 31) Plymouth
- 32) Preston
- 33) Salisbury
- 34) Salford
- 35) Sheffield
- 36) Southend-on-Sea
- 37) St. Helens
- 38) Surrey
- 39) Swansea
- 40) Thanet
- 41) West Dorset (Dorchester)
- 42) West London
- 43) West Middlesex

- 44) Weston-super-Mare
- 45) Worcester
- 46) Wrexham (Wales)
- 47) Wirral
- 48) Yeovil

- 49) Croydon\*
- 50) Pembrokeshire\*
- 51) South Cumbria\*
- 52) Warwickshire\*

\* Planned to launch in 2016



# How we pioneer information, education, training and support for health professionals

NRAS Healthcare professional membership continued to grow during 2015 with many healthcare professionals finding the support the society offers invaluable, especially the free information booklets that NRAS supplies to all units and the visits from NRAS staff and Ambassadors to the rheumatology teams to inform them of the wide range of resources and support we can provide for their patients.

NRAS contributes to medical student training in a variety of ways and in 2015 included support to the University of Manchester MSc Programme in Clinical Rheumatology. Ensuring that we share the patient's perspective widely with stakeholder leads to improved understanding of the real impact of living with RA by rheumatology health professionals leading to more patient centred care.

The Rheum2Talk nurse and allied healthcare professionals' training workshops have also proved highly successful and the NRAS workshop was a finalist in the BSR (British Society of Rheumatology) Best Practice Awards 2015.

As a practitioner keeping up to date with 'what's new' within the speciality can be difficult. The magazine always has at least one article on an aspect of care that is of interest to the practitioner team. The research update section is also much appreciated.

Personally I find the patient stories inspirational and often signpost new patients to them to illustrate that there is life beyond a diagnosis of RA. I find the magazine very informative and professionally produced with a wide range of interesting topics discussed. Keep up the good work.

Hugely impressed with the quality of the work that you are doing and recommend you [NRAS] to all patients with RA.

I would encourage all health professionals to make use of the outstanding patient support material, services and networks provided by NRAS. No-one understands the subjective burden of rheumatoid better than those who have lived with this condition and experienced both the problems and benefits of management regimens that problems and benefits of management regimens and really make a difference and the type of support and really make a difference best opportunity for optimum encouragement that offers best opportunity for optimum outcomes. NRAS excels in all these areas and can ably help your patients.

Peter C. Taylor MA, PhD, FRCP, FRCPE –
Norman Collisson Professor of Musculoskeletal Sciences,
Kennedy Institute of Rheumatology, Nuffield Department of
Orthopaedics, Rheumatology and Musculoskeletal Sciences,
Orthopaedics, Rheumatology and Musculoskeletal Sciences,
University of Oxford and Chief Medical Advisor to NRAS.

you so much for informative training courses. I treat people with rheumatoid arthritis as a podiatrist almost every day, I feel that offering advice and sharing information regarding RA with them is equivalent to physical treatment, or maybe more. In order to do so, I educated myself further with NRAS. Many thanks again for your assistance.

## Rheum2Talk Workshops

One of the key roles of the charity is to provide health professional training specifically to support the complex needs of those with RA.



Our Rheum2Talk
Workshop addresses the
lack of training given
to nurses and allied
healthcare professionals to
help them open the door
to discussions about the
sensitive and emotional
issues which are so
important to patients.

Successfully piloted in 2014. Two facilitated workshops ran in Manchester and Oxford in the last quarter 2015 and 26 attendees completed the training. The feedback was excellent and many said they would hold a session with other allied health professionals in their unit to tell them about the training and make some of the materials available. Funding is being sought to be able to continue to provide these workshops in 2016.

Thank you all for providing such a useful interactive day. I found it raised many emotional issues for all of those who attended and found the facilitators were skilled in exploring there issues to positive effect.

Such a great day, informative for making a difference to RA patient.

compulsory training for all those treating chronic disease.

for an excellent day of learning, I feel empowered to discuss the 'tough' issues with my patients.



## What our fantastic Volunteers are achieving



4-VOLUNTEERS

48NRAS GROUPS

342 NETWORK



NRAS Staff, Members and Volunteers were represented at or involved in:

Stakeholder and patient events including

European

patient representation events including EUPATI, EULAR 8

Academic/ student/market research projects

3 Clinical Research **Projects** 



Pharmaceutical companies

requested interaction with NRAS on a variety



Meetings

with RA and JIA

Global networking

events with patient groups from across the world

Health professional and industry education

events including 2 Rheum2Talk NRAS

Projects/ discussions/ representations

on the introduction o Biosimilars including at the EMA European **Medicine Agency** 

## 2015 Timeline



Staff Celebrating World Arthritis Day







Launch of the JIA Parents HealthUnlocked Community





Ramblers Celebrating RA Awareness Week



Noteworthy performs at the Carol Concert

## How we help to shape the national environment and policy direction

As a patient organisation, NRAS is 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 is 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 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 IIA. Some of our members were able to meet with election candidates in their area and make them aware of the issues we were campaigning on, it was really important to capitalise on a politically fluid moment.

The UK wide General Election in May 2015 saw a new Conservative government returned to power, they promptly began work on the Welfare & Work Reform Bill. We joined other members of the Disability Benefits Consortium in hosting a briefing session for MPs and influencing work on this Bill was a cornerstone of parliamentary work in the latter half of the year.

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 many regions of England are likely to have increased control of their own healthcare arrangements. Equally, decision makers are becoming more aware of the people who make up the majority of spending in the NHS (over 70% of spend on

make and so we encourage all our members to help raise awareness by speaking or writing to their representatives – you can

treatment and care in the NHS is on people long-term conditions, of which RA and JIA both are). It is important that politicians at every level understand the impact on real people of the decisions they use the e-action facility on our website to do this.



In Wales and Scotland, we have teams of ambassadors who make up our Campaigns Networks. The more established network in Scotland completed their programme of visits to Rheumatology units across the country whilst the Welsh network have begun a similar process.

## Meet the Patients event

In January 2015, NRAS built on previous success by hosting a highly successful 'Meet the Patients' event in the Scottish Parliament. This created an opportunity for people with RA from across Scotland to meet with politicians - and one another - to raise awareness and understanding of the condition. Duncan McNeil, MSP, Convener of the Health and Sport Committee kindly sponsored the occasion in support of NRAS and highlighted the key priorities of early recognition, diagnosis and treatment and provision of ongoing, good quality multi-disciplinary care.



Ailsa, several of our Scottish Ambassadors and a number of clinicians; were encouraged by the keen interest taken by Parliamentarians, 17 MSPs attended, with promising offers of support for the future. Clear, too, was the enthusiastic nature of the RA community in Scotland; NRAS has a terrific resource in its membership and, in turn, we are supported by excellent and highly committed healthcare professionals.



## Fundraising and growing sustainable ncome

2015 saw significant pressures on charities and fundraising teams from intense media scrutiny on the sector. In light of this NRAS took the opportunity to review its fundraising strategy and plans for future growth. The review included analysis of each of our fundraising products to assess return on investment. This led to our withdrawing one or two products, the aim to develop a new community package for 2016 and led to our focus on developing more sustainable monthly giving. As a consequence a new fundraising strategy was developed to establish a stronger foundation for regular future income.



For 2015 the best performing income streams for the year were legacies, corporate income, events and community, general donations and trusts and foundations.

Legacies continued to perform well, providing significant support for the charity during the year.

NRAS receives support from a variety of organisations which during 2015 included industry corporates such as AbbVie, NAPP, Pfizer, Roche and UCB. Pharmaceutical Industry support is closely monitored to ensure it adheres to our policy for working with industry and total funding from industry will not exceed 15% of our income in any financial year. We also received charity of the year support from a number of organisations including The Berkshire Golf Club and Trigon Pensions Ltd.

312 fabulous fundraisers

ran, swam, trekked, walked, cycled, climbed, baked , 'car booted', partied, sang, raffled, quizzed, pampered and shaved hair to support us in 2015 raising an amazing

£145,486

Event and community fundraising support continued to grow with record team sizes in the RideLondon100 Cycle Ride and the Royal Parks Half Marathon. Community activities grew with a cultural shift of many people now choosing to do multiple activities during a month or year period. Overseas challenges remained popular, the Kilimanjaro Trek still being the most popular trek we offer. A new event for Junior and Renter Wardens of the City of London Livery Companies was developed and delivered, with the intention to make this an annual event, creating enduring relationships.

Towards the end the year the online donate process received investment to improve the donor journey and experience. This first stage launched in November and a sharp increase in donations and regular gifts was quickly realised. Also a campaign of regular cash appeals was developed with a view to these becoming a firm activity within the NRAS fundraising product portfolio.

Trust and Foundation grants are an invaluable contributor to our income enabling many of the projects, designed to support and help those living with RA and JIA, to be successfully delivered.

NRAS is extremely grateful to all individuals and organisations who supported the charity throughout the year.

# Celebrating our fabulous Fundraisers



Liam cycling the RideLondon100



Emma at the summit of Mount Kilimanjaro 2015



Matt having completed the Great North Run



Carillion Communications sell fantastic baked cakes



Tara and Hayley host a car boot fundraiser



Beverly conquers the Sahara Trek



Morrisons foundation supporting NRAS



Ailsa and team at the Great North Run

## Our service for children and young people with JIA and their families 10,510 Unique

Our JIA service provides support, information, education and advocacy services to help children and young people with JIA, their families and their healthcare professionals. JIA differs from RA greatly and so do the needs of those affected by it; NRAS has been providing tailored resources for those affected by the disease since 2014.

In February we launched our JIA parents website, which brings together a hub of information to support children and young people affected by the disease. During 2015 we had 10,510 unique visitors to the site. Website traffic from the UK accounts for approximately 45% of all visits (4,719). If we apply a rudimentary calculation to this we can estimate that we are reaching 39% of those living with JIA in the UK, that's over a third of the patient population, a sizeable proportion.

We also launched a series of video clips filmed at Bristol Eye Hospital which aim to educate about the hidden dangers of uveitis, an asymptomatic inflammation within the eyes. Professor Andrew Dick alerts parents to the need for eye screening.

Our first education resources were also developed and aimed at teachers and parents of children transitioning to secondary school. These resources have been developed to help parents understand what kind of information they need to provide to the school about their child's disease, and describes the support available from local government as well as details on the statutory guidance for schools on supporting pupils with long term medical conditions.



## In 2015:

both patients and experts for the NICE Multi Technology Appraisal for: 'Abatacept, Adalimumab, Etanercept and Tocilizumab for the treatment of Juvenile Idiopathic Arthritis'.

## 10,510 Unique **Visitors**

to our JIA website. Launched online community for parents of a child with JIA



Our resource pack includes information on:

- ✓ Signs & symptoms
- Medications & treatments
- How to manage the condition (& what is a flare)
- ✓ The student's role
- Emotions & mental health
- Bullying (inc. cyberbullying)

At our second Family Day in July we welcomed over 100 people to the day. Like last year lots of fun activities were available for the children and young people which included face painting, arts & crafts, giant Jenga, pedalos and trips on the lake in a pirate ship. Whilst these activities were going on, expert presentations were delivered on a number of subjects including life with JIA; the medications; and the possible complications of Uveitis. We had positive feedback from the day:

- Over 85% of attendees said that the day exceeded expectations.
- Over 88% of attendees said the day was quite or extremely useful.

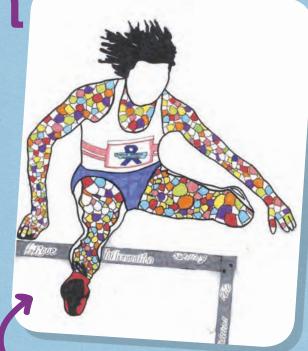
In late 2015 we also launch a parent's peer support hub through the blogging platform HealthUnlocked. Called JIA Parents HealthUnlocked, this is a safe area, monitored by our staff providing reliable peer-to-peer support for parents.

JIA&ME Art Competition

Art can be a significant way in which young people can express how they feel about the way disease impacts upon their lives. It can be difficult for youngsters to express how they are feeling, with too few outlets to express themselves. Our JIA&ME Art Competitions provide an artistic outlet helping to break down barriers to feelings and involves all members of the family and the paediatric rheumatology team. The children and young people with JIA can enter either a painting, drawing, collage or photograph to the competition. Launched in 2015, we ran the competition at the following centres:



Oxford University Hospital Bristol Royal Children's Hospital



This winning piece, entered by Becky at Bristol highlighted her struggles with medication. Becky has visualized her challenges with JIA; pain; fatigue; swelling; and isolation, but now her treatment is working for her she feels she can overcome them.

"

The session has been revolutionary for Holly, myself and our family. Prior to the day, we didn't talk about Holly's JIA. Now we are more open, talking about it, which is helping us to understand what Holly is dealing with instead of making assumptions.

Feedback from Mum of Holly, the winning entry for 12-16 year olds in Oxford.



# A focus on improved outcomes for people with RA

In 2015 we remained committed to our programme to deliver supported self-management (SSM) and further develop our unique SSM pathway. 2015 saw the first Annual General Meeting of NRAS Community Services Ltd (NCSL), which was set up as a trading arm for our commissioned services.

## Key elements of NCSL's work programme during the year were:

- ✓ A sequence of meetings leading to Service Level Agreements with prime contractors in east and central Sussex covering the next two years of commissioned self-management support.
- Development meetings with the new Patient Directors in east and central Sussex, and with voluntary sector agencies in central Sussex involved with wider MSK conditions and the local communities.
- ✓ Presentations on NRAS services to the new User & Carer Forum and the Brighton-based Rheumatology team.
- ✓ Two meetings with the Sussex MSK Partnership in East Sussex: one helping to identify patient experience and outcome measures to be used for the overall programme, and one with the NHS Trust Rheumatology team, preparing for a clinical pathway review and a move to a more community-based service. Acting as a consultant as well as provider of SSM, NRAS/NCSL was asked to facilitate a subsequent review meeting.
- ✓ Both MSK partnerships agreed with our recommendation to pilot use of the new `MSK HQ' patient-reported outcome measure, developed by Keele University/ Arthritis Research UK with substantial input from NRAS.
- ✓ In late spring the first two `New2RA' workshops were delivered in Haywards Heath for central Sussex MSK Partnership. (See opposite)
- On-going work, as part of the Musculoskeletal Solutions Alliance (MSA), included the provision of support to Wiltshire CCG and clinical teams who started a countywide clinical network. We also secured `in principle' funding from Wiltshire Prevention Board for a pilot programme supporting care plans and self-management in three localities.



## NRAS Director of Commissioned Services, Phil Baker also:

- ✓ Attended Oxford CCG MSK pathway redesign meetings and subsequently joined the Implementation Board to oversee the roll-out of Oxfordshire's new MSK service.
- ✓ Attended a number of meetings convened by Gloucester CCG as part of a full MSK/ Rheumatology service review, advising managers and healthcare professionals on the patient perspective and aspects of service improvement.
- ✓ Travelled to Stockholm as part of a British Society for Rheumatology delegation to the Karolinska Institute, reviewing and discussing the Swedish national rheumatology registry, reflecting the patient perspective in discussions about `importing' the Swedish model to the UK.

## Self-management Support Programmes for people with RA

As an integral part of the work that NRAS is being commissioned to deliver in central and east Sussex, NRAS has developed a unique supported self-management (SSM) pathway which is intended to be delivered in parallel with the clinical medical pathway and is equally important if, as we believe, the best outcomes for both the patient and the NHS are to be achieved.

The diagram indicates the flow of people with RA through an initial 2 hour workshop following diagnosis - New2RA – which aims to normalise feelings of anxiety, fear and isolation and introduce participants to the principles of self-management, the importance of medicines adherence and key lifestyle information, then through a slightly longer workshop months further down the line for those with existing disease who need further self-management training and then finally our 6 week RA Self-Management Programme for those who are finding it more difficult to manage their disease.

Future intention will be to develop a mechanism to enable us to deliver all or a combination of the above dependent upon local need and funding available.

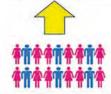
#### SSM Pathway for RA

Diagnosis with RA - Formal medical treatment pathway

Mutual Enhancement/Increased Effectiveness



Self-Management - Prescribed and Self-Accessed 'Community Support'







Successive structured interventions provide progressively more intensive support to patients



o In 2015 RASMP courses were delivered in Bath, Brighton and Scotland, and the first `New2RA' workshops were delivered in central Sussex.

As part of our commitment to quality assurance, the RASMP course will be reviewed formally during 2016 and learning from the delivery of `New2RA' will feed into the ongoing development of the above SSM pathway and resources.

#### RASMP lay tutor – bath 2015

When you hear someone say the feel inspired, or how the course has changed their life and that they know they're not alone, it is extremely rewarding.



It made me realise that I was not alone ... and the fact there was always someone at the end of a phone if I needed help or advice. It has definitely given me a more positive outlook and has made me stronger and more able to cope. Thank you soooooo much \$\$\frac{1}{2}\$



## 'New2RA' participant 2015

"

I thoroughly enjoyed the course and feel it has been very worthwhile. It has enabled me to take control of my health and given me many tools that will be very useful.

## Where our money comes from

NRAS is almost entirely funded by voluntary donations, grants, sponsorships and memberships, with 2% raised from our trading arm NCSL. We are extremely grateful for the generosity of our donors, fundraisers and members for their on ongoing support and for raising £1,034,544 for NRAS in 2015.

In 2014, for the first time in our 15 year history the Charity recorded a deficit. Our aim in 2015 was to ensure that we came in on budget and with a breakeven result. Not only did we succeed in meeting target income but we exceeded it and generated a surplus for the year.

### Corporate | 12%

11% of our annual income is from the pharmaceutical industry for both core and project funding.

#### Trusts, Grants & Contracts | 32%

This includes the generous grants from Trusts and Foundations towards our work, including our JIA-at-NRAS service launched from Appeal funding across 2014 and 2015, as well as our commissioned services.

### Gifts in Wills | 17%

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

## Events & Community | 14%

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

## Donations | 21%

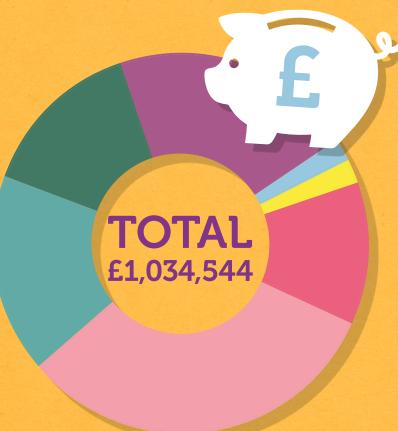
Donations are made from our generous donors, members and regular givers including the NRAS Lottery and our e-fundraising initiatives.

### Interest & Investment Income | 2%

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

## Research & Studies | 2%

Income received from research projects and academic studies we participate in.



We have been generously supported by a number of trusts and foundations throughout 2015, a selection are below:

- Big Lottery Fund Awards for All
- The Cutler Trust, the charitable arm of The Worshipful Company of Makers of Playing Cards
- The Eveson Charitable Trust
- The Mrs F B Laurence Charitable Trust
- The Monument Trust
- The Maud Van Norden's Charitable Foundation
- The Morrisons Foundation
- The James Tudor Foundation
- Garfield Weston Foundation

## How we spend our money

In 2015 we spent £944,672 on helping everyone living with RA and JIA be able to live the life they want to. Our goal is to be there for anyone diagnosed with RA or JIA right the start of their journey (and whenever they need us along the way) and to help them to live as normal a life as possible, through understanding their disease and learning how to self-manage effectively so that they are able to achieve the goals they want in life.

## Governance, Support& Administration | 12%

8% of our income is spent on the office essentials we cannot function without. The remainder is spent keeping the charity on target to continue to deliver excellent resources and to achieve our goals.

## Education θInformation | 22%

This includes our invaluable Helpline, on call for anyone struggling with their disease, and our award winning Information Standard Accredited Publications, all of which are provided free of charge.

## Community Engagement & Support | 35%

This includes our growing network of patient groups, delivering valuable face to face services across the UK, as well as our Telephone Support Calls.

## ■ Invested to raise the next £1 | 19%

For every £1 we invested in fundraising we raised £5.65. The fundraising team also completed a strategic review with a new three year strategy developed for launch in 2016 to increase reliable and sustainable income streams.

## Campaigning for Change | 12%

Raising the importance of RA and JIA with key policymakers and stakeholders, increasing their priority within the political spectrum.



# How we work with the Pharmaceutical Industry

NRAS has an excellent reputation in the UK for high achievement and committed representation of the patient voice in rheumatoid arthritis. 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 rheumatoid arthritis patients. However, it is appropriate 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: www.nras.org.uk/industry-support



## Pharmaceutical Funding 2015

Below is a breakdown of the project funding we have received from the pharmaceutical industry throughout 2015. Please note, the breakdown of funding does not show travel expenses or honorariums. Also the figures include carryover from 2014 and deductions for funds carried across into 2016. These inclusions and deductions account for multiyear projects.

£5,000

:	AbbVie Ltd	
· ;	Core Funding	£25,000
jec	Magazine Distribution	£20,250
Project	Documentary Filming	£2,500
	Scottish Welfare Project	£18,000
	TOTAL	668 886
	TOTAL	£65,750
	TOTAL STATE	£65,/50
	Medac	£65,/50
ct:		£500
oject …;	Medac	

Eli Lilly and Company Limited	
Patient Project – Workshop and Survey	£2,400
World Arthritis Day Meet the Patient Event	£500
TOTAL	£2,900
Merck Sharp & Dohme Ltd	
Rheum2Talk Training	£5,000
Contribution towards NRAS Welsh Ambassador	
Programme	£5,000
TOTAL	£10,000
	Patient Project – Workshop and Survey World Arthritis Day Meet the Patient Event TOTAL  Merck Sharp & Dohme Ltd  Rheum2Talk Training Contribution towards NRAS Welsh Ambassador Programme

:	Roche Ltd	
÷	Rheum2Talk Training	£5,000
Project	Contribution towards NRAS Welsh and Scottish	
570	Ambassador Programme	£5,000
	TOTAL	£10,000

**NAPP Pharmaceutical Group Limited** 

Corporate Membership

Patient Focus Group

11%	of	ou	r
2015	inc	con	ne

0	Patient Focus Group	£ 1,000
Proj	TOTAL	£6,000
:	Pfizer Ltd	
ਹ	Patient Focus Group	£3,750
Project	Radio Day Broadcast for world Arthritis Day	£3,000
P	TOTAL	£6,750
:	UCB	
+ +	In Tune Project	£15,000
jec	Great North Run Sponsorship	£500
Project;	TOTAL	£15,500



# A Message from the Chairman of the Board

There can seldom have been a more difficult climate for charities than has existed in recent years. The need for, and range of, our services continues to grow, new channels need to be developed to keep our members and users informed and involved and our supporters and donors face increasing demands for their help at the same time as their income, and therefore their ability to help, is reduced.



It is against this challenging background that the success of NRAS in 2015 must be judged. The budget for the year was scrupulously observed and, through real dedication by all the staff, the work of the charity continued to flourish. By the time the year ended, a good surplus had been recorded and so the reserves remain strong.

There is much to be proud of in the achievements of the year both the continuation of our key services such as the NRAS Groups, and the projects through the year which are adding to the support that people with RA and JIA, their families and the health professionals supporting them can derive from NRAS. Most notable among these initiatives are the JIA&ME Art Competitions and the development of our supported self-management products.

NRAS has always had a close family feel with the whole team committed to the charity's vision and helping to deliver it. I first became aware of NRAS online in 2006 when I was diagnosed, then I went on the RA self-management programme and first met the team. I have now been a trustee for the last seven years, six as chair of trustees.

I am immensely proud of the work that NRAS does for people living with RA and in recent years also for JIA and of the people who are NRAS. We have recently appointed a number of great new trustees who are filled with enthusiasm to take NRAS through the next stage of its development.

Seven years as a trustee has been a great experience but I have decided that it is time to make way for fresh talent. Accordingly I have stepped down as chair and as a trustee, in effect, from the end of the year covered by this review. There are many great trustees, past and present, with whom I have worked and many great members of the team, again some have inevitably moved on and others remain. In wishing NRAS well for the future, which is assured I know, I want to pay tribute and extend my thanks to these people who have made NRAS for me, and for you.

## Graeme Johnston Chairman of the Board

## NRAS Advisors and Staff



#### Medical Advisors

Chief Medical Advisor Prof Peter Taylor

**Prof lain McInnes** 

Dr Asad Zoma

**Prof Kuntal Chakravarty** 

Dr Christopher Deighton

Dr Christopher Kelsey

Dr Patrick D W Kiely

Dr Gulam Patel

Dr Richard Reece

**Prof Peter Taylor** 

Dr Richard A Watts

Dr Lesley J Kay

Dr Alaa Hassan

Dr Yasmeen Ahmad

**Prof Ernest Choy** 

**Dr Lorraine Croot** 

Dr Marwan Bukhari

Dr Richard Haigh

Dr Stefan Siebert

Dr James Galloway

Dr Martin Lee

**Dr Ruth Williams** 

### Paediatric Medical Advisors

**Prof Tauny Southwood** 

Dr Gavin Cleary

Dr Clarissa Pilkington

Dr Janet McDonagh

Dr Nick Wilkinson

Dr Athimalaipet Ramanan

Dr Jane Willock

Dr Jeremy Camilleri

Dr John Packham

Kristina May

Dr Madeline Rooney

Dr Rachel Tattersall

Sarah Hartfree

### **Nurse Advisors**

England: Diane Home Wales: Suzanne Davies Scotland: Liz McIvor

N Ireland: Anne Quinn Ethnicity Issues in MSK

Clinical practice: Dr Kanta Kumar

### Allied Healthcare Advisors

Occupational Therapy:

Sandi Derham

Physiotherapy: William Gregory Podiatry: Robert Field

### **Founder Patron**

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

### Patron (Medical)

Prof Gabriel Panayi Prof David G I Scott

#### **Patron**

Mr Mark Liddell

#### **Trustees**

Mr Graeme Johnston (Chairman of the Board)

Mr Andrew Kennedy

Ms Di Skingle

Mr Steve Crowther

#### ors

Ailsa Bosworth

Chief Executive and Founder

Clare Jacklin

**Director of External Affairs** 

**Denise Pointon** 

Finance Director

Phil Baker

**Director of Commissioned Services** 

Conn O'Neill

Public and Policy Affairs Officer

Chivam Arar

Web and Digital Media Officer

Oliver Hoare

Fundraising Manager

Anne Gilbert

Youth Family Services Manager

Gill Weedon

External Projects and Groups Supervisor

Victoria Butler

Senior Information and Support Coordinator

Emma Seymour

Individual Giving and Memberships Officer

Nicky Freemantle

PA to the Chief Executive

Valerie Eyre

**Events Fundraiser** 

Bronwen Cranfield

Community Fundraiser

Mark Arnold

Trust and Grants Fundraiser

Nikki Tee

Fundraising Assistant

Kim Fitchet

External Affairs Coordinator

Lorraine Tanne

Information and Support Coordinator

Beverley Briggs Information and Support Coordinator

Tammy Mallo<u>wan</u>

Office Administrator







11 CYCLIST

Completed the RideLondon100 Cycle Ride

## In 2015: NRAS provided

both patients and experts for the NICE Multi Technology Appraisal for: 'Abatacept, Adalimumab, Etanercept and Tocilizumab for the treatment of Juvenile Idiopathic Arthritis'.

## 10,510 Unique **Visitors**

to our JIA website. Launched online community for parents of a child with JIA



I also just want to say how much I really appreciate everyone at NRAS's hard work they do. You are all simply amazing.





Thank You!



National Rheumatoid Arthritis Society

General: **0845 458 3969** Free Helpline: 0800 298 7650 e: enquiries@nras.org.uk w: www.nras.org.uk

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