

Annual review 2019



nras
National Rheumatoid
Arthritis Society

JIA 
JUVENILE IDIOPATHIC ARTHRITIS

NRAS Fundraiser Nicola Cromwell with
her Husband at Everest Base Camp 2019

FROM THE CHIEF EXECUTIVE



Clare Jacklin, CEO

2019 was a year of substantial change for the charity as NRAS Founder, Ailsa Bosworth MBE, handed over the role of Chief Executive to Clare Jacklin, and Ailsa took up a new role as NRAS National Patient Champion. For many organisations a change in senior leadership can be unsettling and can result in a period of adjustment, fortunately the transition for NRAS was relatively smooth as Clare has risen through the ranks having joined NRAS in 2007 as the Volunteer Manager. This, therefore, ensured that for service users, Trustees, employees and the wider rheumatology community there was a familiar face taking over, offering reassurance and continuity. The board and the senior management team agreed that 2019 was to be a year of consolidation rather than growth allowing for the leadership transition.

With the charity in a strong financial position and having truly established itself as the leading patient organisation for those living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) it had strong foundations for the new CEO to take NRAS forward into the next decade.

Despite being a year of consolidation, the charity had many notable successes in 2019 which deserve recognition. Here is a list of just some of them:

- Health Care Champions awards held at the prestigious Leathersellers' Livery Hall acknowledging the amazing work of rheumatology healthcare professionals as individuals and as teams who have made a significant impact on people living with RA or JIA. The winners of these coveted awards are nominated by their patients and nominations are judged by a panel of their peers, patients and Clare Jacklin, NRAS CEO.
- NRAS collaborated with a number of other auto-immune disease specific charities working alongside NHS England to develop a suite of resources for the introduction of the biggest nationwide biosimilar switch. Together with Crohns' & Colitis UK, National Axial Spondyloarthritis Society and the Psoriasis Society, NRAS undertook a nationwide survey of patients with immune mediated conditions to gather their experiences of the 'switch' process.
- We continued to develop our campaigning networks in the devolved nations as well as in Manchester where health and social care is also devolved.
- A highlight during 2019 was the good fortune to have been chosen for a charity open day at Frogmore House which was a terrific success and was enjoyed by hundreds of our Members.
- NRAS hosted JIA family days, Bushcraft days for teenagers with JIA and a number of RA patient days called 'Rheum For You' across the UK during the year.
- Supporting the European League Against Rheumatism (EULAR)'s Don't Delay Connect Today campaign themed for 2019 as Time to Work, NRAS hosted a very successful event at the Kings Fund.
- Two major NRAS awareness raising events – RA Awareness Week – themed as AnyoneAnyAge and Wear Purple for JIA were once more great successes with the latter raising in excess of £40,000.
- Two new services were launched to facilitate the ease of referral of patients from rheumatology to NRAS for support and self-management education. The New2RA Right Start and the Living Better services have both been successful. Outcome measures and impact of those being referred to the Right Start service are being analysed by Kings College London against a control arm of those patient reported outcome measures being captured in the British Society for Rheumatology (BSR) National Early Inflammatory Arthritis Audit.

Following an application to EULAR, Ailsa our National Patient Champion was appointed as convenor for a EULAR 12 month project to develop recommendations for embedding self-management into clinical pathways. A taskforce with patients and 20 health professional members from across the rheumatology multi-disciplines from 11 countries is now working on this project.

Looking ahead for 2020/2021 the core objectives were to build on the existing work of developing e-learning modules; re-modelling our JIA services to incorporate delivering care and support to all young people with JIA and RA; invest in staff development; launch two new websites and invest in a marketing strategy that would give us greater reach to the 400,000+ people living with RA and the 12000+ children and their families living with JIA in the UK.

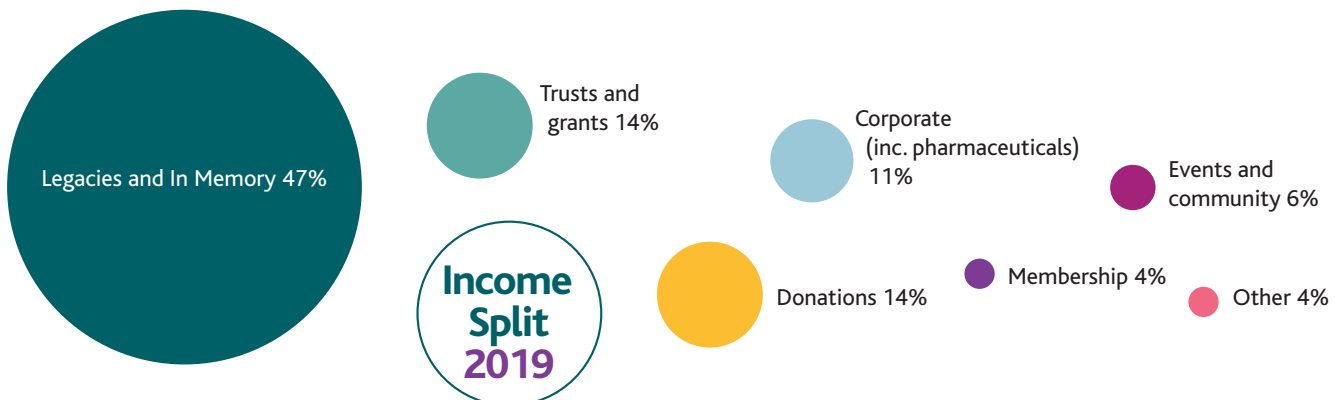
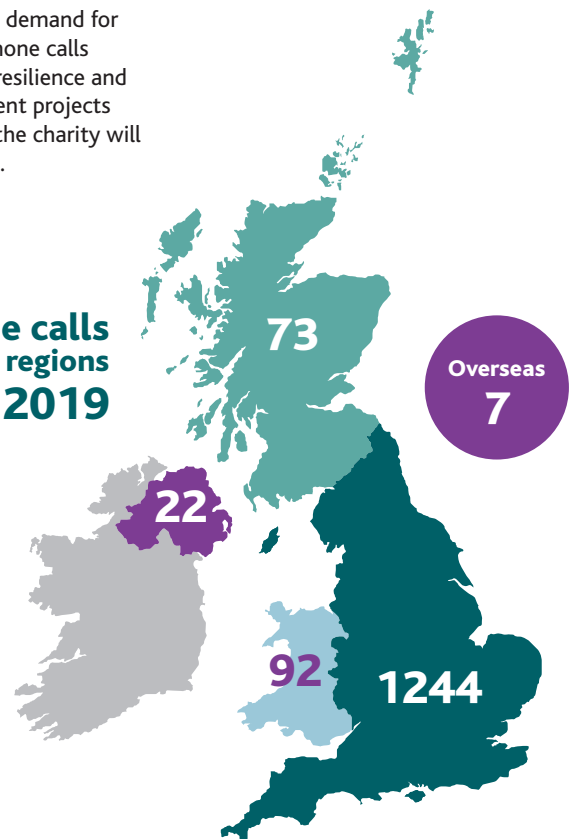
At the end of 2019, however, we heard about a virus in China that was spreading fast and killing hundreds, little did we know then or anticipate what was going to face the entire world in just a matter of months. The objectives for 2020 soon had to take a back seat as the focus needed to be on the survival of the charity. Fundraising events were cancelled but demand for our services increased at an unprecedented level seeing a 600% increase in telephone calls alone during March! These early months of 2020 were a real test of the charity's resilience and resourcefulness. We had to pause a good number of our expansion and development projects however we are optimistic that due to the proactiveness of all within NRAS that the charity will survive this crisis and we can now focus on the following core objectives for 2021.

- Successfully launch a suite of e-learning modules
- To diversify our income streams to ensure our sustainability while facing an uncertain COVID and Post-COVID future
- Deliver the recommendations to EULAR of how to embed self-management into treatment pathways
- Launch the remodelled services for young people and their families living with inflammatory arthritis (JIA and RA)
- Deliver a marketing strategy that will reach a more diverse population of people living with inflammatory arthritis
- Establish and market NRAS as a trusted and reliable research partner for clinical trials, academic studies and social research
- Demonstrate through our investment in people approach that NRAS truly lives up to our values of being an organisation that our staff, board members, volunteers, members and service users find is nurturing, reliable, aspirational and supportive

Website visits increased **13%** in 2019



Helpline calls from the regions in 2019





ELEANOR'S STORY

Eleanor was diagnosed with juvenile idiopathic arthritis (JIA) at age 2, after struggling with joint pain. She underwent several rounds of treatment, including steroid injections under general anaesthetic to get her symptoms under control. She was placed on Methotrexate from age 3 but was able to phase out the methotrexate between ages 5 and 6 and has been in unmedicated remission ever since. Eleanor loves gymnastics and dancing. She is on a par with, and even ahead, of her peers in some respects and no longer needs the aids previously provided by the school.



While on holiday Eleanor (7) along with her friend Jess (6), sister Caitlin (3) and their families climbed to the top of Mount Snowdon, a distance of 8.5 miles and height of 1085m - no mean feat for little ones! Eleanor decided she wanted to make this challenge a fundraiser and a way of telling more people about what really happens when you are diagnosed with JIA at just over 2 years old.

'We thought we would start a JustGiving page not only to celebrate their achievement but raise money for the NRAS charity, who provided our family (along with many others) with support in understanding Eleanor's diagnosis and gave us the opportunity to meet other families in the same situation. Eleanor is such a determined young lady and raised an amazing £375! Snowdon gave her a taste for mountain climbing and in July this year, aged 8, she climbed England's tallest mountain Scafell Pike (3,209ft) again with her sister Caitlin, friend Jess and they were joined by another friend, Toby.'

To sustain NRAS long into the future please consider leaving us a Gift in your Will. Any amount is greatly appreciated.

NRAS National Patient Champion



Ailsa Bosworth,
NRAS National Patient Champion

Halfway through 2019, at the AGM in June, I stood down as CEO of NRAS after 18 years in the role. It was a rather strange and difficult moment in many ways, but one I had been working towards since 2017. The best bit about it however, was the fact that my good friend and colleague, who had been my Deputy CEO and with whom I had worked very closely for nearly 13 years, had been selected by the Board to take my place. I knew that I was handing over the organisation I founded in 2001 which was so much part of my life and so important to me, to someone I could trust and who, I knew, would look after it with the passion and drive it deserves and take it forward.

My new role from September, 2019 is that of National Patient Champion. I wasn't ready to retire and had things I still wanted to do and research interests to pursue. So, what does a National Patient Champion do? It's really very satisfying in many ways, to have the possibility and opportunity of stepping down from a role you've loved, but which is all encompassing and very frequently time pressured, to be able to focus on doing the things which you find particularly interesting, leaving the management of the organisation and its staff to someone else! Not many people get to write their own job description and I consider myself fortunate to have been able to do just that!

One of the things that has always been a priority, and important to NRAS, and still is, is contributing our representative voice to national standards and guidelines, whenever they are being developed or reviewed. This is work that I continue to do, as well as being a lay representative at all NICE technology appraisals, to assess the cost effectiveness and safety of all new drugs coming into the NHS in respect of RA and, where relevant, in JIA. I am working with



Garfield Weston
FOUNDATION

The Garfield Weston Foundation supports vital NRAS services

A very generous grant of £50,000 from the Garfield Weston Foundation enabled NRAS to continue to provide our dedicated helpline team, hold activity days for children and young people with JIA and provide informative webinars, NRAS support groups, printed information resources and patient information events.



Top 3 ways people got in touch with NRAS



Membership



Hospital



Web search

Social Media Community grew by **22%** in 2019

82p of every **£1** we spend delivers services to our beneficiaries



colleagues with NICE, NHS England and the BSR towards gaining access to biologics and advanced therapies for people with RA at an earlier stage than is currently possible and we are also looking at how pathways of care and access to medicines can be improved.

Another long-standing area of interest is supported self-management. I have over many years developed, with colleagues, a range of supported self-management (SSM) programmes, which were delivered face to face, in group format. I know first-hand the positive difference SSM has made to me and can make to the lives of people with long-term conditions like RA. In 2018, we took the decision to convert these face-to-face programmes into e-learning modules as we were unable to get commissioners to fund these programmes. We wanted as many people as possible to benefit from this kind of education and support, and the only way we could achieve this aim was to put the programmes online. In 2019, we received 2 generous grants to enable us to get started on this important work. We selected a suitable supplier in autumn 2019 and this became my major project, to deliver, over the next 2 years or so, a complete suite of e-learning modules in RA. The work started to flesh out ideas and determine which tools we would use to evaluate the programme over the winter, and the plan was to launch the first 2 or 3 modules at the British Society for Rheumatology congress in April 2020. That was before COVID!

I am actively involved in a number of research projects and it is great to be able to devote more time to this continuing area of interest. I am the convenor of a EULAR funded study entitled 'EULAR Recommendations for the implementation of self-management strategies in patients with Inflammatory Arthritis (IA)' which involves the development of a number of recommendations for health professionals to include the provision of education about and sign-posting to sources of self-management support for their patients, as part of routine, more holistic care. This is in collaboration with a 20-strong team of British and European health professionals and we held our first meeting in London in September 2019. Our work will be published in spring 2021 and presented at EULAR 2021.

In addition to the above areas of work, I am also involved in advocating on behalf of individual patients when the need arises and supporting other colleagues in NRAS in areas where my experience of living with RA, or my experience as former CEO of NRAS can help to inform projects they are doing. Having the flexibility in my new role as NRAS National Patient Champion, means I can support the NRAS team in whatever ways I can contribute best to the people we serve.

RA Services

Iain McNicol
Director of RA Services



The year has been one of development and innovation. NRAS continued to push the boundaries, promoting and advocating for the RA community. This was seen most clearly with the launch of the Emotional Health and Well-being Matters report.

Social research

Launched in December 2018, at parliament this report placed a flag in the ground for the mental and emotional wellbeing of the RA community. A total of 1,999 people from NRAS communities were engaged in completing an in-depth survey. Two of the key findings were 50% of those with clinical anxiety and 69% of those with clinical depression, according to the HAD scale, had not formally been diagnosed with a mental health condition despite meeting the criteria.

Campaigning

During 2019 we have actively lobbied and promoted the need to integrate a mental health assessment into a patient's annual review. NRAS continues to play a vital role in the self-management of peoples' RA. We have long known that the wellbeing and holistic outcomes of our community are improved with early engagement after diagnosis.

Helpline

Our telephone support service increased its capacity as we increased resources and staffing levels. This service continues to be a main stay and incredibly valued provision of NRAS. We have seen increased activity this year and will be considering how we can further increase capacity within an increasingly challenging economic environment.



New to RA Right Start Programme



Many newly diagnosed patients naturally become anxious and deeply concerned about the impact of RA on their life. How it will affect relationships, employment, fertility and their ability to live life as they previously did.

Our ability to access patients soon after their diagnosis can significantly improve their understanding of the diagnosis contributing to improved wellbeing. We also know that failing to get access to good support soon after diagnosis can reduce adherence to prescribing regimes, increased anxiety leading to depression and a sense of isolation.

It was these factors that underpinned the development of a new service seeking to provide early access to NRAS resources, access to our telephone support team as well as an option to discuss their RA with

a trained telephone peer with lived experience of RA. The Right Start Service was launched in May 2019 at the British Society of Rheumatology Conference. It was offered to healthcare professionals (HCPs) as a resource to support them while providing early access to NRAS for the newly diagnosed.

The service enabled HCPs to refer newly diagnosed patients through the NRAS website. Issues of general data protection were overcome to ensure a smooth referral model. On receipt of the referral, the patients receive a tailored assessment from the telephone support team who dedicate an hour appointment to assess their needs during this early stage of their diagnosis.

These patients receive paper-based resources, leaflets and publications

relevant to their unique needs, access to a range of digital resources including webinars and apps and access to the largest global online RA community. In addition, they can access an NRAS group, which are run throughout England, and speak with a trained telephone peer.

This amazing service cements our role in their ongoing support and care, our journey together, starts at the beginning with their period of diagnosis.

By the end of the year we had 24 active hospitals, who had made a total of 97 referrals.

This service has demonstrated the need for NRAS to become more aligned with NHS provision and develop new partnerships and collaborations which give us better access to new and existing patients with RA.

The future

Next year we want to build on the Right Start service and consider new self-referral programmes providing easy access to the RA community at times of need. We want to cement new relationships enabling us to reach more of the estimated 400,000 RA population in England.

We will also look to expand our digital service provision, perhaps developing a new app, or enhancing access to important resources and needs.

Volunteers continue to be critical in our evolution. We will review the existing Volunteer strategy and update it with the

aim of embedding Volunteers in all our work. Increasing their voice and ensuring we are led by their needs. Gathering this data will be crucial in challenging the decision and policy makers who influence the healthcare system and treatment options for the RA community.

We have been reviewing our current JIA service framework and will be doing further work on this project. Our aim is so to redesign the service, increasing engagement with young people. Once we are further along this path, we will form an advisory group made up of young people and those who have JIA. We want to ensure

any developments embrace the voice and thoughts of the people we serve.

All this work will be further complemented by our new JIA website and a new RA website (due to be published late 2020). These websites are more engaging and offer a personalised service matching resources to need.

We continue to recognise the importance of digital interventions in engaging and meeting the needs of our members and beneficiaries. New and exciting interventions will be born in 2020/21 which will broaden our digital footprint.

£50,000 for NRAS from QBE European Operations Foundation

On Friday 26th July 2019 at 4.30 pm Helen Saich (Senior Trust & Company Giving Fundraiser at NRAS) took a call from the QBE Foundation Chairman with the wonderful news that the QBE Foundation (the charitable arm of QBE Business Insurance) had awarded NRAS £50,000. This grant made a huge difference and allowed us to deliver our services to those who need our help.

We were so lucky to have been nominated by QBE employee, Jess Swallow, whose mother and grandmother are RA sufferers. There were a large number of nominations from QBE staff across the UK and Europe and luckily for NRAS, Jess's story from the heart, moved the judges and we were thrilled to receive the funds on 16th August 2019.

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

"My grandmother developed rheumatoid arthritis when she was aged 50. As with many diseases, one of the main factors that causes RA is stress, and when my grandmother was diagnosed, she was looking after my grandfather 24/7, who had suffered from a stroke and soon after passed away. Growing up, she tried where possible to look after us when my mum needed a babysitter, however due to her lack of mobility as the RA became more debilitating and things such as driving, picking us up, mowing the lawn, etc had to stop - this became hard. Watching her joints flare up and become misshapen over the years, and then watching her toes fold over so she is unable to walk properly is hard - we want to help her, but other than the many drugs she is on (which they never seem to be able to get right to suit her) which then causes other problems, I feel useless. It is hard to watch as those you love most struggle with this degenerative disease and I want to do everything I can to protect them, and others that it affects daily. I don't feel as many people know about RA, and so it is unlikely people would donate to their charity. I want to spread this awareness and help boost the morale of those with the disease. Thank you for the opportunity to apply for funding."

Jess, her mum and nan came to visit us at our offices in Maidenhead in November 2019. It was so lovely to meet them and find out more about their experiences of RA and the time together just flew by. We are delighted that we are going to be working with Jess as she is very keen to help us raise awareness of RA and what it means to cope daily with this disease and the impact on the whole family.



Jess with her family

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

*Thank you Jess,
from all at NRAS and
all who use our services.*

Cost of Helpline
£324.46
per day



The David Brownlow Charitable Foundation kickstarts the new NRAS E-Learning project

Thanks to the tremendous support of the David Brownlow Charitable Foundation (DBCF), NRAS began a new and innovative project in 2019, an E-Learning programme that aims to help people with RA self-manage their disease by increasing accessibility to information resources via video learning.

With a total of £53,371 pledged by DBCF toward this project, NRAS could begin to build the E-Learning modules and create the video content. Thank you to everyone at DBCF for this incredible support, you are helping NRAS improve the lives of many people living with RA across the UK.

E-Learning

A major new project for NRAS

When it comes to supported self-management (SSM) programmes, much can be said about the benefits of being in the same room with other people, like you, who all live with the same condition. However, the difficulty of being able to get health commissioners to fund such programmes has become almost impossible, faced with the increasing pressures of a cash-strapped NHS. Instead of supported self-management being an intrinsic part of a person's care pathway when they have a long-term, incurable condition like RA, as laid out in the NHS Long Term Plan, it is treated as a cherry on the cake (a cake we are struggling to pay for).

Since 2008, NRAS has developed and launched 3 face-to-face supported self-management programmes and their value has been amplified by the many people who have had the opportunity to participate in them. In 2017 we came to the conclusion that the only way we could get these important services to many thousands of people living with RA, rather than a few hundred, would be to digitize them and create a new and unique e-learning resource.

After submitting several funding bids, we received two generous grants in 2019 to enable us to move forward with our goal to start developing SMILE-RA – the name for our new programme, which stands for Self-Management Individualised Learning Environment. It will sit within a new NRAS E-Learning portal on our website. Our plan in 2019 was to work towards being able to launch a number of modules at the British Society for Rheumatology, in spring 2020, aimed at the newly diagnosed. Whilst this annual review is reflecting the work of NRAS in 2019, it is being written in 2020 and of course, what we didn't know back in the winter of 2019, was that COVID-19 was coming down the line which would put a temporary stop to some of our key projects including SMILE-RA, during 2020!

In spite of the delay caused by COVID-19, we believe that when we can launch the first modules, this programme will be hugely welcomed, not only by people with RA (and other forms of inflammatory arthritis), but also the healthcare professionals (HCPs) who look after us. HCPs are under-resourced and time poor and being able to refer their patients to a high quality, evidenced based supported self-management programme like SMILE-RA, will help them to meet the quality standards and guidelines laid down by NICE against which they are audited by the National Early Inflammatory Arthritis Audit. It will be a very important new resource amongst the range of SSM services provided by NRAS.



Thank you from the Fundraising Team

From everyone in the NRAS Fundraising Team, please accept our sincere gratitude for everything you have contributed and achieved in 2019.

You have run, walked, cycled, baked, worn purple, held tea parties, let us share in your important celebrations, got together, climbed and collected all to do a wonderful thing and make a difference.

Thank you for supporting NRAS, without you we wouldn't be able to help the 400,000 people living with rheumatoid arthritis (RA) and the 12,000 children and young people living with juvenile idiopathic arthritis (JIA) in the UK, as well as their families, carers and the healthcare professionals who treat them.



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