































Clare Jacklin, CEO

A Year in Review

As we started 2020, we had vaguely heard some mutterings about a virus originating in China that may be heading across the world. Little did we know how quickly the entire globe was to be impacted by the spread of COVID-19. In January myself and the senior management team were looking forward with great optimism to a year of stability as well as launching some new services. Our plans, along with those of the entire nation soon had to go on the back burner as we were rapidly having to firefight a health crisis.

In March 2020 we took immediate action to protect the charity, and our colleagues, while still being able to respond to the growing demand for information and support from thousands of people living with inflammatory arthritis who were desperately seeking reassurance. Thankfully we had been well on the way to offering a more flexible working environment for colleagues anyway, using technology to facilitate more home working. This work was accelerated to enable all staff to work remotely with as little disruption to our service users as possible. The NRAS helpline staff experienced a deluge of calls and emails but were all able to respond to that demand from the safety of their own homes. The increased demand was exacerbated by the fact that the majority of rheumatology health professionals were being redeployed to the NHS front line COVID response leaving RA and JIA patients with little or no clinical support. If there were any positives to be taken out of a pandemic it is the validation of the incredible, vital role that the third sector organisations like NRAS played in bridging that information and support gap. At a recent Royal College of Nursing event NRAS was singled out for praise for our quick and balanced response to communicating to rheumatology patients appropriate information in a timely manner hence alleviating the pressure on over stretched NHS rheumatology services.

Being a medium-sized charity has its advantages in that we were able to be nimble and swift in making decisions such as stopping all non-essential spend in those early days; adjusting our workforce priorities to meet appropriate demand; collaborating with other stakeholders to align key messages; utilising Government emergency financial support packages and harnessing the financial support of industry partners appropriately to ensure the sustainability of core services, as well as embracing new ways of reaching those in need with technology.

I don't think I'd even heard of Zoom before February 2020 - now it is part of everyday life!

In the midst of all of this we did manage to keep many projects alive and delivered two new websites before year end, both of which have already proved immensely popular. While filming for the various e-learning modules was not possible due to COVID-19 restrictions, my colleague Ailsa has been able to continue developing the content so that as soon as restrictions allow, we can move ahead with the videoing of expert speakers and we hope to officially launch SMILE (Self-Management Individualised Learning Environment) in second half of 2021.

You can read more about how NRAS responded to the pandemic on page 10 but suffice to say I could not have been prouder of how my colleagues, the board of Trustees, the Members and Volunteers all rallied in a time of national crisis to support NRAS, the NHS and the people living with RA and JIA across the UK.

Message from the Chair of Trustees

This has been a very tough year for the charity sector as a whole and NRAS has been no exception. Whilst demand for our services increased because of the pandemic, our normal sources of funding were severely impacted, resulting in a serious reduction in our planned income. I am pleased to report however that NRAS weathered the impact of COVID-19 very well throughout the year as a result of the magnificent efforts of our colleagues and through timely and effective management interventions.

Our team demonstrated great flexibility in moving to home working, with no impact on service delivery, whilst rising to the challenge of increased demand; as an example, calls to the NRAS Helpline increased six-fold in the early weeks of the first lockdown. Recognising the impact that measures to combat the virus would have on our ability to raise funds, senior management took difficult early decisions to reduce expenditure by pausing some development activities and limiting spending as much as possible to focus on delivering our core services. We also owe thanks to all our supporters who contributed generously through our cash appeal and to other appeals made during the year.

As a result of these initiatives, I am pleased to say that we were able to complete the year without any adverse impact on our services and, importantly, without having to dip significantly into the charity's reserves, giving us a secure base for future planning. We will continue working closely with our partners and developing relationships with new funders to enable us to serve the whole RA and JIA communities, including reaching ethnic minorities and socially deprived communities that desperately need our help. With the timing of a return to old ways of working still uncertain, we will continue to invest in developing digital and remote technologies to deliver our services in future.

On behalf of the Board of Trustees, I would like to extend my sincere thanks to all colleagues here at NRAS, as well as to our Members and Volunteers, and of course our generous donors, who have all contributed and worked so hard to deliver vital services for those who need them.



Simon Collins, Chair

Volunteers step up to the challenge

He was very sympathetic, related my problems to ones he had experienced and suggested helpful things to try.

I felt a lot happier when I put the phone down



When the pandemic first hit back in March 2020, NRAS felt it was important to set up a dedicated telephone service to support those living with RA during such a challenging time. For it to truly make an impact, it was vital that the service was based around Volunteer-led peer to peer support so that those needing help had access to someone with lived experience of the condition. It was also essential that this service could be implemented quickly, as the hugely increased demand on our Helpline

showed the need for additional support. NRAS therefore began by approaching its already fully trained peer-to-peer support Volunteers for help and had a fantastic response; 35 responded almost immediately offering their services, and by April the NRAS 'Here for you' service was up and running.

Call recipients self-referred via the NRAS website and were quickly matched with a Volunteer who had availability at the call recipient's preferred time. Here for You Volunteers shared information about COVID-19, their personal experiences of living with RA, managing medications and general tips and tricks on feeling less isolated and maintaining a healthy lifestyle. NRAS Volunteers responded to 115 referrals from Mar-Dec 2020 and several Volunteers delivered ongoing support through follow up phone calls.



NRAS Groups

2020 was a challenging year for NRAS Groups as COVID-19 brought all face-to-face Group meetings to an abrupt end. Several Groups, including Croydon, Chesterfield, Oxford, Swansea and Worcester organised online meetings via Zoom in conjunction with the NRAS Engagement Manager. Group Leaders and their members also took part in NRAS organised online information and wellbeing sessions. Some groups also supported the work of NRAS by making donations from their local funds in recognition of the many additional services being provided by their Society.



Wellbeing Volunteers

NRAS was lucky to have many Wellbeing experts come forward in 2020 to offer their services on a voluntary basis to support those living with RA. Wellbeing was the theme of the 2020 RA Awareness Week in September and Volunteers stepped forward to deliver complimentary sessions on meditation, yoga, Qigong and nutrition to name but a few! Carolyne Bennett, Expert Coach, delivered her first 5-week Wellbeing online course in April and this was so well received future courses were planned. In November, leading international choreographer, Didy Veldman, ran a 4-week Dance & Movement online course, direct from a studio at the Royal Ballet School in London.



Volunteers who have participated in online focus groups, research projects, proof reading articles, project planning, awareness raising and much more.

- NRAS Advisory Panels' Members advising NRAS on future activities and resource development.
- The NRAS Ambassadors who advocate, campaign and represent NRAS on regional regional and local issues.
- The NRAS Board of Trustees who volunteer their time and expertise to oversee the Governance of the organisation

Our Inspirational Young Voices Panel

In May 2020, NRAS began recruiting young people to a special advisory board to act as the voice of young people living with JIA and RA. The aim was for the group to help inform NRAS on how to develop their services for teenagers, young adults, and parents of children with JIA.

They are an inspirational group of young people and even through the difficult times of living with JIA and RA they have all learnt how to thrive. At the first meeting in June, they decided to name themselves the Young Voices to reflect their role in raising awareness of the issues affecting young people living with these chronic conditions.

The Young Voices played an integral role in recruiting the Young Persons Project Co-Ordinator and started to influence service development at NRAS, putting together a service framework for the JIA and young people side of NRAS to take forward. For RAAW (RA Awareness Week) and Wear Purple for JIA they ran Facebook Live sessions where they discussed how living with JIA and RA has impacted their lives.



Eleanor Farr, Young Voices Panel

"Thanks to NRAS I now have an arthritis family.
A group of people who are there for me, give me information and advice and who never fail to support me. Knowing that I am not alone in this has kept me going through some difficult and testing times."

Annabel Longden, Young Voices Panel

"I got involved with the NRAS Young Voices Panel (YVP) because I wanted to use my time to help young people with arthritis and am so glad I am able to use my experiences to do this with NRAS. However, I didn't appreciate how much I would get from it – discussing shared experiences with the YVP has made me reflect on the past 15 years of having arthritis and appreciate how far I have come. Having such

a wonderful group of people to talk to is priceless and gives me hope for all the things we can achieve to help children and young adults with JIA."

5

"If there is ever anything I can do to support the work of NRAS, please do ask. Without your help, I cannot imagine what the picture would look like for us. We will be forever in your debt, and I mean that".

Your information is the best I have found for RA and I always recommend NRAS to fellow sufferers of RA. Well done

NRAS has provided the most comprehensive and up to date information on COVID-19 for our patients. We were struggling to keep our own information up to date so I felt confident signposting people to the NRAS website. Amazing work under such difficult circumstances. Thank you NRAS for all you do for our patients and for rheumatology.

Thank you so much for your reply. I had already a copy of the NRAS medicines book which is very informative. The NICE guidance link you sent me was the info I was looking for in terms of treatment pathways for me. I have downloaded it

From a rheumatology nurse

Where our money comes from

Thanks to the generosity of the public, companies and other funders, we raised £1.242.4 million of income in 2020.







A Family Affair



Wear Purple during 2020 was challenging for raising awareness and funds as the lockdown was still on but NRAS were amazed at the dedication and innovation of all our young fundraisers and their families. Too many to mention individually, but one young man Seth James age 10 ended up raising a fantastic £4,960.00, becoming our highest individual fundraiser for Wear Purple last year!

On 29th October Seth's mum Rhian set up a Facebook fundraising page and in three days they had already reached their set target! So, she upped the total to a staggering £4,000.00 and this set Seth a real fundraising challenge. However, he was not alone, and his family decided to support Seth – (who turned 11 during this time) through his epic challenge of running 500km (310.6 miles) during the month of November.

Seth had been diagnosed with JIA in 2019 starting with severe hip pain and initially he spent 1 week in hospital with this severe pain. He now has 2 affected joints and is a regular hospital visitor. His doctor had told him that he would need steroid injections into his affected ankle for the pain. He was initially told this would be towards the end of November but on the 20 November with still 10 days left to complete his challenge and 370km completed, he had to go into hospital for these injections! Undeterred he pushed on with the continued support of his mum, dad and siblings!

On 6th November, Wear Purple for JIA day, Seth's school got behind him and asked all the children in years 3 – 6 at Ysgol Bro Teifi to help Seth achieve his £4,000.00 target and donate £1 each!

Finally on the 29th November Seth completed his 500km with some very special help from his friends on his Footie team! Team spirit came to the fore and Newcastle Emlyn Under 11s donned their purple T shirts and 8 of them, who were in a school bubble, each ran 3km taking the overall total to the magic 500km!

Feedback on our Facebook Live Broadcasts with medical experts

"Thank you so much. This is super helpful and answers many questions".

"Great information, as I'm an NHS frontline worker, I'm happy now to have the vaccine with my RA medication".

"Thank you so much for your time and information, it has reassured me so much re having the vaccine".



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













Thank you from NRAS

We are very grateful for all the financial support we have received in 2020.

Without you, we would quite simply not be able to provide vital information and support to all those living with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) across the UK, as well as their families, carers and the healthcare professionals who treat them.

Our CEO, Clare Jacklin, would like to give special thanks to every individual, group, company and organisation that supported NRAS through a very challenging year.

NRAS would like to acknowledge the following organisations for their generous funding of various projects as well as donations that allowed NRAS to keep delivering our core services during 2020.

The National Community Lottery
Fund

The Schroder Foundation
The David Brownlow Charitable
Foundation

Health and Social Care Alliance Scotland

James Tudor Foundation
The Leathersellers' Company

The Leathersellers' Company Charitable Fund

Berkshire Community Foundation Peter Harrison Foundation

The 29th May 1961 Charitable Trust Children's Arthritis Trust

P F Charitable Trust

Edith Florence Spencer Memorial Trust

The John Coates Charitable Trust
Pilkington Charities' Fund

Buckinghamshire Community Foundation

The Roger and Jean Jefcoate Trust The Willie & Mabel Morris Charitable Trust

The D'Oyly Carte Charitable Trust The C M Lowe Charitable Foundation

Hospital Saturday Fund The Lady Hind Trust

Joseph Strong Frazer Trust

The Eveson Charitable Trust

John Swire 1989 Charitable Trust Doris Field Charitable Trust

The state of the s

The Oakdale Trust

Tesco Bags of Help COVID-19 Communities Fund

The Patrick Rowland Foundation

The Marsh Christian Trust

Sir Jeremiah Colman Gift Trust

Neighbourly Community Fund

The Michael and Anna Wix Charitable

Trust

Healthcare at Home

Royal Institute of Chartered

Surveyors

St John's Beaumont School

PhonicsPlay

Inmedix

Unity Lottery

Gregory and Yoxall

Personal Group (PACT)

AbbVie Limited.

Amgen Limited

Biogen

Bristol-Myers Squibb

Pharmaceuticals Limited

Eli Lilly and Company Limited

Fresenius Kabi Limited

Gilead Sciences Limited

Janssen-Cilag Limited

Medac Pharma

Pfizer Limited

Roche Products Limited.

Sanofi

UCB Pharma Limited

NRAS are truly grateful to all those individuals, friends and family members who lost a loved one in 2020 and chose to honour their memory with a donation to the charity.

We would also like to thank all the NRAS Groups throughout the UK who continued to support the charity's work with donations as well as maintaining a local NRAS presence in their communities.

Thank you to all our dedicated fundraisers who continued to raise vital funds. If you would like to support NRAS please visit **nras.org.uk** or **jia.org.uk**.

The Impact of our first RAAW Wellbeing Week

22
wellbeing sessions
hosted on Zoom
throughout RAAW

1,822 total session registrations "Thank you so much for everything you've done this week. I have joined a lot of different sessions and have thoroughly enjoyed all of them."

200 sign-ups to monthly digital newsletter (enews)

It was so good to be able to try these different things. I've signed up for ongoing qi-gong plus started tapping - who knew!

Helpline in lockdown

March 2020 saw an unprecedented 600% increase in calls to the helpline. All this whilst training up a new manager, upgrading technology i.e phone and database, and learning to do it all from home. To say it was exhausting is an understatement, but it brought with it so many opportunities, a sense of shared purpose and the knowledge that we were making a difference in the lives of people living with RA in the middle of a pandemic.

Each member of the team stepped up and worked harder and longer than they ever had before. Their flexibility rivalled that of an Olympic gymnastics team, and they certainly deserved gold medals. But they were driven by a desire to make NRAS a beacon of reliable information and compassion in a time when people were not able to get to see their rheumatology team as easily and some of the media coverage was causing anxieties.

The main themes of the year have been about where people with RA and JIA fit on the shielding/clinically extremely vulnerable list or those who are vulnerable, accessing health and social services, furlough and work-related issues. There were also the issues of managing mental health during lockdown and lastly the vaccine and access to it for people with RA. Not only has the number of contacts increased, but they have also become increasingly complex and requiring more time spent on many calls. The team would also like to thank the medical advisory board for helping us out on the more complex queries, even though they were under a great deal of pressure themselves.

by Nadine Garland, Support Services Manager

Helpline gave help and support to **3,849** people in 2020 – a 51% increase from 2019



FIRST CASE OF CORONAVIRUS IN THE UK

GOVERNMENT ANNOUNCES NATIONAL LOCKDOWN

VULNERABLE PEOPLE ASKED TO SHIELD

RACE TO FIND THE VACCINE

NEW VARIANTS DISCOVERED

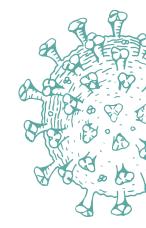
Impact of COVID-19 on NRAS

The financial impact of the pandemic on all industries has been enormous and the charity sector is no different. Many bigger charities are facing massive restructuring and redundancies and 71% of charities reported being concerned about funding now and in the future as a direct result of the pandemic. All fundraising events that would normally have brought in approximately 8% of our annual income were cancelled and it was therefore essential that we look for alternative sources of income. The charity pandemic cash appeal was a great success bringing in £45,000 and the request for emergency core funding from our industry partners was favourably responded to adding £90,000 to our income for 2020. Trust and grant giving bodies, that would under normal circumstances not consider supporting patient organisations, also responded well to our requests for support as they were made more aware of the essential support we were providing to people across the UK. This diversifying of income streams coupled with stringent expenditure control resulted in a relatively small annual loss compared to what we'd anticipated. Previous prudent financial management had also stood the charity in good stead to 'weather' the pandemic economic storm and should give future funders continued confidence in the financial stability of NRAS.

The personal impact of COVID-19 has not escaped us at NRAS, and we've lost friends, supporters and Members of the Society. Many NRAS staff have had to adjust to working from home, some juggling home-schooling their children or shielding due to their own health conditions whilst at the same time managing the increasingly demanding needs of our service users. Witnessing the often devastating impact of the pandemic on those living with RA as well as the issues facing rheumatology health professionals has driven NRAS to respond in innovative ways and seize upon new opportunities. Here are just some of the ways in which NRAS navigated the obstacles and issues being faced and delivered solutions to meet the increasing demand for support.

The property of the property o

Here for You – With calls to our helpline reaching an unprecedented 600% increase at one stage with many callers requiring reassurance and a supportive voice to reduce feelings of isolation, our trained telephone Volunteers were recruited into a new service. Individuals could self-refer via an online portal to request a Volunteer call. This meant that the calls to Helpline were reduced somewhat to more manageable levels allowing our Helpline staff to focus on the more complex queries regarding RA, JIA, shielding, COVID-19 and vaccinations.



COVID-19 updates and FAQs – With Government guidance being updated almost daily at the beginning of the pandemic and with so many people desperate for information we created a new website area that was regularly updated.

This section answered commonly recurring concerns such as

- how medications may or may not make people with RA or JIA more vulnerable to the virus
- work issues regarding shielding
- clarification on who should or shouldn't be classed as clinically extremely vulnerable
- many more similar questions about lockdown regulations in the 4 nations of the UK.

Facebook Lives - Weekly Facebook live broadcasts from March through to July then held monthly and had an average engagement of 3,348 viewers, proving Facebook to be an excellent platform for sharing information but also connecting people, reducing feelings of isolation.

Wellbeing Sessions - Our focus during RA Awareness Week was very much on self-care and self-management with many wellbeing sessions being hosted via Zoom.

RheumZooms –These virtual Zoom events replaced our in-person meetings that had been planned to take place on the South Coast and in Scotland and were highly successful. We also hosted one specifically for Northern Ireland. Such interactive and informative events will be part of NRAS's ongoing service offering as they have allowed those who would not normally attend such events, due to geographical or other restraints, to participate from the comfort of their own home.

The impact on already pressurised rheumatology services during the pandemic has also been considerable. Many UK rheumatology departments were signposting their patients for up-to-date COVID-19 information to NRAS via their answering machine messages and on patient letters. The steady increase of the number of rheumatology units referring to the New2RA Right Start Service is further evidence of the important role NRAS plays in supporting healthcare professionals to in offering holistic and all-round care to their patients. This relieves some of the burden on already overstretched specialist nurses in particular, to deliver quality self-management patient education.

In conclusion NRAS has adapted to meeting the needs of our beneficiaries while changing how the charity works – which is no mean feat. It is not surprising that our thoughts have turned to how NRAS can evolve and adapt to new ways of operating embracing new technology and flexible working for employees.

The continuing threat of a loss of funding plus huge demand continues to drive much of our decision making – NRAS has been presented with a unique opportunity to review what works and in doing so we will future proof NRAS so that we continue to strive for our vision of a World Unburdened by RA or JIA.







National Rheumatoid

Arthritis Society





RA services

The New2RA Right Start service (for newly diagnosed patients) & the Living With RA service (for more established disease RA patients) provides rheumatology healthcare professionals an online referral route to NRAS for their patients and both services continue to go from strength to strength. Working with 47 hospitals during 2020 we received 147 referrals. In 2021 we hope to further embed this intervention into routine rheumatology care in more hospitals, and develop an integrated model ensuring all newly diagnosed patients have access to the NRAS Right Start service.

NRAS peer to peer support -

During 2020 all NRAS local groups had to suspend their face-to-face meetings due to COVID and this gave rise to the establishment of virtual group meetings tailored to specific groups as well as enabling many of the local groups to continue their meetings online. The advent of virtual groups has opened up peer support to a great many more people who perhaps would be reluctant to attend face to face meetings even pre-COVID.





Following the development in 2020 of a group online seven-week supported self-management programme in Scotland we will be continuing with further pilots during 2021. The Group Online Self-Management learning will address many of the historical barriers, such as geographical location and transport links, experienced by patients in accessing RA education as well as provide opportunities for peer support.







Julie Begum Rheumatology Lead Nurse Chair Royal College of Nursing Rheumatology Forum Expert advisor to NRAS

Nursing during the pandemic

Supporting patients with rheumatoid arthritis (RA) has been difficult during the COVID-19 pandemic. Many rheumatology nurses were redeployed to the front line to care for those patients with coronavirus, our workforce was depleted, and we have had to think of other ways we could support patients.

As Chair of the Royal College of Nursing Rheumatology Forum, we identified that sharing the workload with our patient organisations was a good use of resource. NRAS are ideally placed to help people with RA/JIA with selfmanagement resources and advice on health promotion and it's great that rheumatology departments are able to partner with NRAS in this way. The volume of calls into our advice lines was particularly difficult to manage with a depleted workforce. We wanted to ensure that all patients were able to get a timely response to their queries, and this was achieved with the help of NRAS stepping forward to take some non-clinical calls diverted by rheumatology teams to their national helpline. As many of these calls were around patients' concerns regarding continuing rheumatology medications in the pandemic, the roll out of the vaccination programme or supporting those patients that were struggling in lockdown with anxiety and loneliness, NRAS were able to support and signpost appropriately, enabling rheumatology nurses to focus on those with clinical needs such as getting flares under control or who had specific issues with medication and needed to speak to their team.

If we were to look for any positives in delivering rheumatology care in a pandemic, I genuinely feel one would be the closer relationship we have developed with our patient organisations.



Dr Elizabeth MacPhie Consultant Rheumatologist and Chair of Clinical Affairs Committee at the BSR

Thoughts from the Chair of the Clinical Affairs Committee at the BSR

The pandemic has had a huge impact on many rheumatology departments. Many staff have been redeployed; services have been reconfigured with many appointments moving to remote and departments have struggled with the volume of calls through to advice lines and getting important messages out to patients. We very much appreciated how NRAS stepped up to support the rheumatology community, providing relevant and timely support for our patients with the COVID-19 updates on the website and Facebook Live sessions. We know many patients contacted the NRAS helpline for advice when they have struggled to get through to their local teams.

From our screen to yours

When Lockdown was first announced in March 2020, we realised people would have many questions on their treatment and what it meant for people living with RA and JIA, especially when shielding was announced. One of the ways we wanted to connect with people when we couldn't see them face to face was to use our platform on Facebook to

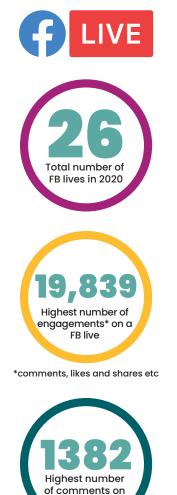
broadcast our Facebook Lives. We wanted to

reassure and support people who may have been feeling isolated and confused with the new rules we all had to adhere to. Our CEO, Clare, was regularly updating our followers on COVID-19 updates; we also had interviews with medical experts and we answered questions that were submitted. They were such a success we will continue to use this platform to help support









a FB Live



The NRAS virtual Christmas show was a fantastic ensemble of music, choirs, family fun quiz questions and humorous recitations from some very special guests. Rt. Honorable Theresa May, MP and actor Sheila Hancock both contributed poignant and witty readings. A letter of support from the Mayor of the Royal Borough of Windsor & Maidenhead, Councillor Mrs Sayonara Luxton was also a contribution to the event.

An amazing £16,773 plus Gift Aid was raised at our first virtual concert.



New Merchandise in 2020

In response to the pandemic we introduced products into the NRAS shop that would help keep our beneficiaries safe.

- NRAS Fluid Resistant Fabric Face Masks. Fluid repellent outer layer, washable and reusable. Sold to members of the public and at a discounted rate to all Members.
- The NRAS Hygiene Hook Keyring is a unique and new product that features a flat stylus tip, finger hole, keyring loop and handy door hook, all of which help the user reduce contact with commonly touched areas when out and about. The keyring is made from 100% recycled plastics which are inherently antimicrobial, helping to prevent the spread of germs.
- 'Keep your distance' Tote Bag 5oz Standard Cotton Shopper.

www.nras.org.uk/shop







Helpline: 0800 298 7650 General: 01628 823 524 e: jia@nras.org.uk w: www.jia.org.uk www.nras.org.uk Ground Floor 4 Switchback Office Park Gardner Road Maidenhead Berkshire SL6 7RJ





/nationalrheumatoidarthritissociety /iiaatnras



@NRAS_UK @JIA_NRAS



NRAS_UK jia_at_nras



healthunlocked.com/NRAS healthunlocked.com/JIA



linkedin.com/company/NRAS