



# ARMA 4thursday

## February 2010



### A message from ARMA Chair Prof Anthony Redmond

**The end of February, in theory at least, finally sees winter drawing to a close. There is though a distinctly chilly financial forecast still ahead for those of us in the public and third sectors, and we have had an eventful month at ARMA HQ.**

ARMA's campaigning activities continued on its main fronts with a range of activities targeting politicians and public awareness. At the heart of our efforts is the campaign to get the Department of Health to recognise the need for a National Clinical Director for Musculoskeletal Care (a musculoskeletal 'Tsar'). After a long period of resistance from the Department we have made some progress over the past few weeks, including a letter from the Secretary of State for Health, Andy Burnham, agreeing to meet a delegation to discuss this further.

This agreement arose out of activities undertaken through the combined efforts of BSR and ARMA, including a good deal of behind the scenes work and a letter signed by 12 chief executives from across ARMA's member organisations. This represents a genuinely positive development in what has been a long journey to-date and is a credit to the collegiality of the musculoskeletal community.

The NCD campaign is not an end in itself however and the underlying issues remain: better recognition of musculoskeletal disorders (MSDs), acknowledgement of the impact of MSDs on the working population and better quality of care for people with MSDs.

The "One in Four" reception in Parliament, hosted by Linda Riordan MP was aimed at raising the profile of MSDs in the minds of policy makers. The day was widely attended and both resulted in signatures to ARMA's pledge and to raising the profile of the Early Day Motion, which now has over 100 MP's signatures.

The publication of the Parliamentary Committee on Public accounts report into provision of service for people with RA was also a significant February milestone and generated both political heat and some broader publicity (see later in A4T). The report's findings on services for people with RA echo many of the concerns expressed by those in the MSD community and could be applied equally too many of the conditions of relevance to ARMA's members. ARMA will be working to ensure that the Department recognises and acts on the report and also that it hears the message that the problems are not confined to RA.

**Please forward this to any colleagues within your organisations or networks who may be interested in ARMA's work.**

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## A message from Professor Anthony Redmond continued...

Next month sees a series of events across England Scotland and Wales, launching the UK Work Charter, the British arm of a campaign coordinated across Europe, focusing attention on the impact of MSDs on working people, employers and economies. Members are welcome to attend events at the English Parliament, the Welsh Assembly and Scottish Parliament, please contact the office for details. We hope that the MSD community will help us bring the Work Charter to the attention of employers and will use their influence to encourage employers to adopt the Work Charter and factor MSDs into their staff welfare plans. We aim to launch the charter in Northern Ireland later this year.

Finally, ARMA would like to enlist the help of its member organisations to ensure that we are truly fit for the purposes you require of us. After two years which had seen a new Director, a new chair and essentially a new board of trustees take over at HQ, the board has instigated a strategic review of ARMA's direction and processes. As part of the review, assisted by an independent third-party

(Marion Allford Associates), all of our members organisations will have an opportunity to let us know what they would like to look like and what priorities they feel ARMA should pursue. We encourage all our members to contribute their thoughts. The responses are anonymised through Marion Allford and we will not shy away from tackling issues raised by critical friends.

There is much to be done but much opportunity to exploit. I look forward to your continued support.

**Anthony Redmond**

Note : You may have noticed the acronym MSDs (Musculo-Skeletal Disorders) scattered through this missive. This reflects a request by the Bone and Joint Decade to standardise to a degree, the terminology used across the world. International and nationally, the use of standard phrases will help present a united front to policy makers and the public alike. ARMA has undertaken to try to submit to the discipline and although old habits are hard to break, we are encouraging other member organisations to do the same.

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## ARMA One in Four Reception

One in Four – Giving people with musculoskeletal conditions the care they need. On Tuesday 2<sup>nd</sup> February, ARMA held a parliamentary reception in the House of Commons hosted by Linda Riordan MP.

Our message was simple: Musculoskeletal disorders affect one in four of the adult population or more than 10 million people. The economic and social costs are huge and set to grow without improvements in the delivery of services and outcomes. Despite their importance in every constituency, musculoskeletal services have failed to get the attention they deserve.

The event was very well attended by cross party MPs and ARMA members. Guest speakers included:

- Linda Riordan, Labour MP for Halifax
- Dame Carol Black, National Director for Health and Work
- Anne Milton, Conservative MP, Shadow Minister, Health - Guildford
- John Pugh, Liberal Democrat MP for Southport

We asked MPs that attended our event to sign our pledge:

**I'm supporting the call for a National Clinical Director to help improve the quality of care for one in four people who have a musculoskeletal disorder including:**

- **Raised patient and public awareness**
- **Better clinical training**
- **Speedier diagnosis and treatment**
- **Improved information on spending out comes**

Eleven MPs signed the pledge:

- |                    |                   |
|--------------------|-------------------|
| Linda Riordan MP,  | Dan Rogerson MP   |
| Graham Stringer MP | Anne Begg MP      |
| Janet Dean MP      | John Pugh MP      |
| Linda Gilroy MP    | Richard Taylor MP |
| Bob Russell MP     | Jim Dowd MP       |
| Laura Moffatt MP   |                   |

We are continuing our efforts to secure a National Clinical Director to improve the quality of care for people with musculoskeletal disorders – if you have not yet encouraged your own constituency MPs to sign EDM 362 then I would urge you to do so. If you are unsure about how to contact your MP then please get in touch at [sarahrich@arma.uk.net](mailto:sarahrich@arma.uk.net)



### House of Commons Committee of Public Accounts

**Following the NAO report on Services for people with rheumatoid arthritis the Public Accounts Committee has published a report.**

Commenting on the Public Accounts Committee's report on *Services for people with rheumatoid arthritis*, Chair of the Arthritis and Musculoskeletal Alliance (ARMA) Dr Anthony Redmond said:

*"This report is a wake-up call for everyone involved in NHS musculoskeletal services. As well as the half a million people with rheumatoid arthritis there are almost 10 million people with other musculoskeletal conditions who will recognise the damaging impact late diagnosis, delayed treatment and haphazard back-to-work services is having."*

For some time ARMA has been calling for the Department of Health to appoint a National Clinical Director or 'tsar' for the musculoskeletal diseases. Dr Redmond concluded:

*"We need real national action, and the appointment of a national clinical director, to address the lack of joined-up thinking which has led to the inequity, inefficiency and the postcode lottery of care identified in this report."*

To read the full report visit [www.parliament.uk](http://www.parliament.uk) or use the following link:

<http://www.publications.parliament.uk/pa/cm200910/cmselect/cmpublicacc/46/46.pdf>



## Members: News and Resources

### NRAS

[www.nras.org.uk](http://www.nras.org.uk)

#### NRAS workwise workshops update

All dates are now confirmed for these evening workshops focussing on work issues faced by people with rheumatoid arthritis. There will be experts available for interactive discussions from the fields of human resources, occupational health and therapy, NRAS, Jobcentre plus, Employment law and many others. To register to attend any of the evening workshops all starting at 6.30pm for 2.5 hours please visit the NRAS website: [www.nras.org.uk](http://www.nras.org.uk) or email

[clare@nras.org.uk](mailto:clare@nras.org.uk).

#### **Dates of the workshops are as follows:**

London: Feb 24<sup>th</sup>; Bristol: Mar 10<sup>th</sup>; Cardiff: Mar 11<sup>th</sup>; Manchester: May 18<sup>th</sup>; Birmingham: May 19<sup>th</sup>; Nottingham: May 20<sup>th</sup>; Glasgow: June 22<sup>nd</sup>; Londonderry: June 23<sup>rd</sup>; Portsmouth: July 7<sup>th</sup>; Reading: September 28<sup>th</sup>.

### RSI Action

[www.RSIAction.org.uk](http://www.RSIAction.org.uk)

**RSI Conference on Saturday 20 March 2010, London from 09:15 to 16:45 - FREE entrance. A Conference and exhibition on RSI prevention treatment. See [www.RSIAction.org.uk](http://www.RSIAction.org.uk) for more details.**

Presentations include:

**RSI - From Partial Recovery to Complete Function** - Suparna Damany MSPT, author of "It's Not Carpal Tunnel Syndrome" ([www.RSIrescue.com](http://www.RSIrescue.com)). Suparna is a Physical Therapist who has successfully treated chronic, repetitive strain sufferers (often after failed surgical attempts) and instituted successful RSI prevention programs at major employers in the USA.

Suparna is a Certified Hand Therapist and a Certified Ergonomic Assessment Specialist, in private practice in Allentown, Pennsylvania, USA.

**Repetitive strain injury – a pain in the nerves!**  
RSI research - Dr Andrew Dilley, Lecturer in Anatomy, Brighton and Sussex Medical School.

**RSI Diagnosis** - Dr Michael Hutson, Consultant Orthopaedic Physician.  
Past president FIMM (International Federation of Manual/Musculoskeletal Medicine); Chairman FIMM Academy; Member of Academy of Experts. Author of book "Work-Related Upper Limb Disorders – recognition and management".

**RSI: Guidelines and assessment for safe work practices** - Peter Buckle, Professor Health Ergonomics, Robens Centre for Public Health, University of Surrey.

Please forward this to any colleagues within your organisations or networks who may be interested in ARMA's work.

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## Members: News and Resources

### Arthritis Care

[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

#### Involving Users as Experts

Involving Users as Experts is a programme developed by Arthritis Care and designed to empower patients and members of the public to become actively involved in the design and delivery of high-quality health services as expert patient representatives.

The programme was developed and delivered over three years with Department of Health funding, subjected to an independent evaluation and presented to an audience of NHS managers and health professionals at the recent NHS Alliance Conference in October. Arthritis Care is now about to launch a consultation with PCTs and key partners on developing this model of user involvement further: please see below if you're interested in taking part.

#### Background:

Between September 2007 and July 2009, Arthritis Care organised and ran five training courses for people with arthritis to enable them to become expert advocates on musculoskeletal services. These pilot courses, which were subjected to an independent evaluation, received excellent feedback from participants, and represent a very good model for Primary Care Trusts (PCTs) in

particular to genuinely engage with service users. In addition to its particular blend of knowledge and confidence-building, Involving Users as Experts offers PCTs the opportunity to achieve targeted, high-quality engagement with expert individuals who have received training and who are capable of representing not just their own interests as service users, but those of a much wider group of patients and members of the public.

Find out more:

You can download a copy of the presentation that was delivered to the NHS Alliance Conference from [www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

To take part in the consultation, please contact Federico Moscogiuri, Head of Policy & Campaigns: [federicom@arthritiscare.org.uk](mailto:federicom@arthritiscare.org.uk)

We are currently consulting with PPI leads, PCTs and partner organisations on how to develop this course further. We would greatly welcome and value your input.

Please complete our survey

<http://www.surveymonkey.com/s/JVBTPHN>

to take part in our consultation – it should take no longer than 15 minutes to complete. Please respond by **Wednesday 3rd March 2010**.

#### A letter to my pain – the Arthritis Care creative writing competition 2010

For the fourth year, Arthritis Care is running its annual creative writing competition. The competition aims to give people with arthritis the opportunity to write about their condition using a theme.

In 2010, the theme is A letter to my pain. We want people with arthritis to write about their arthritis using this theme. People might want to tell their pain about a new plan to keep it under control or just express how they feel.

For more details and for terms and conditions go to [www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

Please send entries, of no more than 750 words, to [Creative@arthritiscare.org.uk](mailto:Creative@arthritiscare.org.uk) or to Creative Writing competition, Arthritis Care, 18 Stephenson Way, London, NW1 2HD

Closing date for entries is 30 July 2010 and winners will be announced on 31 August 2010.

**If you want to be kept up to date about Arthritis Care's work, it's easy to sign up for our regular email updates. Just go to:**

[www.arthritiscare.org.uk/GetInvolved/Subscribetoouremails](http://www.arthritiscare.org.uk/GetInvolved/Subscribetoouremails)

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## Members: News and Resources

### Arthritis Care continued...

#### Arthritis Care pioneers Department of Health's Information Standard

Arthritis Care is one of only 38 organisations to become a founding member of the Department of Health's new Information Standard scheme. The Information Standard is a new certification scheme for health and social care information targeted at the public in England. The quality mark has been introduced to help people quickly and easily identify that information comes from a reliable trustworthy source.

Arthritis Care's Head of Information, Kate Llewelyn, said: 'There is so much information about long term conditions in the public domain, it's important people know they can trust what they are reading. The Information Standard ensures information providers have rigorous quality processes in place and that information is based on good evidence. It will help patients and health professionals identify providers who adhere to the strict Scheme rules and provide

evidence based information. Providing the very best information about all aspects of living with arthritis has always been at the heart of what we do at Arthritis Care, so we're really proud to be one of the first organisations in the country to receive this new certification.'

According to the Information Standard Team, about 500,000 organisations produce health or social care information for the public and there can be an overwhelming volume of varying degrees of quality. The Information Standard scheme gives organisations the opportunity to show the public that their information is clear, relevant, evidence-based, authoritative, complete, secure, accurate, well-designed, readable, accessible and up to date.

Arthritis Care's printed and online health and lifestyle information is covered by the Information Standard. Watch out for the logo appearing on all newly printed information soon.

#### Arthritis Care receives Quality Standard Award for its Helplines service

On 8 February, Arthritis Care formally received the Quality Standard Award for its Helpline service at a reception hosted by British Telecom for The Helplines Association. Presenting the award, Pippa Jaffa, Chief Executive of the Parents Advice Centre, reminded the audience that Arthritis Care's Helplines are really two Helplines in one: the generic Helplines service and Arthritis Care's unique "The Source" line, supporting parents and families of children diagnosed with arthritis and young people themselves (aged 15 to 25). Next year The Source will be celebrating 10 years of providing vital support to parents facing the trauma and uncertainties of their child having a difficult diagnosis.

#### About the Helplines:

Arthritis Care's helpline is a free, confidential service, which is open to anyone affected by arthritis. We provide emotional and practical support, and information by phone (in 150 languages) by letter and email.

Anyone can get in touch. We hear from people who have just been diagnosed; family members who want to know how to support a loved one; people who have had arthritis for some time and are looking for help; and health professionals also ask us for information.

You can call the Helpline on 0808 800 4050: (10am-4pm, free from BT landlines and mobiles using; o2/ Vodaphone/ TMobile/ 3 and Orange services).

<http://www.arthritiscare.org.uk/PublicationsandResources/Someoneotalkto/Helpline/Aboutthehelpline>

Please forward this to any colleagues within your organisations or networks who may be interested in ARMA's work.

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## Members: News and Resources

### Fibromyalgia Association UK

[www.fibromyalgia-associationuk.org](http://www.fibromyalgia-associationuk.org)

**Pam Stewart, Chair: As I look back at what FMA UK has achieved each year, I wonder how we managed it and if we will be as fortunate in the coming year.**

Our main areas of work are:

- Providing information about fibromyalgia
- Being a national voice for fibromyalgia

The information is provided in many different mediums in order to reach as wide an audience as possible. As well as our information booklet, the booklet for young people was completed and the booklet for medical professionals updated. We would like to provide information for employers and to children with parents with fibromyalgia.

The new venture of our own magazine is a very exciting challenge and we hope the mix we have included as a result of our recent survey proves to be successful.

The website has recently been updated and will continue to offer more services as further improvements are made.

We attended several professional conferences last year and have had an offer of shared stands for this year, We have found professionals want to know more about fibromyalgia and are eager to talk to us which is very encouraging.

We still have a long way to go on the political front both in the UK and as part of the European Network of Fibromyalgia Associations. We will keep lobbying for greater recognition of the problems faced by people with fibromyalgia with our politicians and provide opportunities through meetings and events to meet with them face to face. We cannot progress matters as quickly as we would like but we keep stepping forward and with the help of ARMA, progress is being made.

### PMR-GCA UK

[www.pmr-gca.org.uk](http://www.pmr-gca.org.uk)

**Polymyalgia Rheumatica and Giant Cell Arteritis UK (PMR-GCA UK) is a registered charity established to meet the needs of people with these debilitating conditions by promoting research, raising awareness and offering support.**

Our Charity is unique – the first in the world specifically set up for PMR and GCA

There is currently little information for the general public to make them aware they may have these conditions, and how important it is to seek help. It became apparent that patients had nowhere specific to obtain information or support for either Polymyalgia Rheumatica or Giant Cell Arteritis.

The two conditions are relatively unknown and

neglected, although widespread, and doctors on the front line often do not recognise the early warning signs of these conditions, or know about some of their more serious complications.

We feel that that there is a major unmet need for better service provision for the two conditions.

There is no known cause or cure, and there is a demand for much needed research.

With that purpose, our organisation has started part-sponsoring research into PMR and GCA.

The official PMR-GCA UK launch is taking place on Wednesday 10th March – to find out more contact Jayne Sibley by email at [pmrgca@googlemail.com](mailto:pmrgca@googlemail.com) or telephone 024 76 361 956

### EULAR - EDGAR STENE - Thank you to every one that entered!!

**We are delighted to announce that the national UK winning entry for the Edgar Stene Prize is Victoria Garrett from Wolverhampton. With over 35 essays submitted for the one UK entry place, the judging panel had a tricky task ahead of them but there was a unanimous vote for Victoria.**

The EULAR Standing Committee of People with Arthritis/Rheumatism in Europe has elected a jury to select a winner, to be announced by 15 April 2010. In addition to the prize of €2,000, EULAR provides the winner with travel to Rome and hotel accommodation in Rome for up to 4 nights as well as an invitation to attend the opening ceremony and the gala dinner at the Congress.

I hope you will join us in wishing Victoria every bit of luck in securing 1<sup>st</sup> place for the UK.



**Victoria Garratt**

#### **Working with Rheumatic Disease: My daily reality**

I am a branch manager responsible for a retail outlet that turns over twenty million pounds a year and employs one hundred and forty people. I am thirty years old and have scleroderma of the lung. I hope to give you an insight into my working life and how my scleroderma affects me on a daily basis.

I start the day by convincing my joints that getting out of bed and heading to work really is a better idea than staying in bed a little longer. I enjoy what I do and look forward to my journey to work, except when my car needs de-icing. I don't know anyone who enjoys this job but trying to de-ice your car when the circulation and feeling has gone from your fingers is quite a challenge.

My day at work begins with a walk across the shop floor. I say hello to all of my staff and check in with my managers that we will be ready to open. I then read emails, check sales figures and open the doors for another day's trading to begin. I enjoy this time of day as there is often so much information to take in, the whole shop floor to check over and a morning meeting to hold – I like it because by the time I take a break my joints agree with me that coming to work and walking around was absolutely the right thing to do.

I often welcome visitors to my branch, from other shops and from the local community. If you were to visit me at my branch, I would meet you at the customer service desk and you might notice that I'm wearing gloves that match my suit; you might also notice how cold my hands are when I take off my gloves to shake your hand. Our visit might start with a brief tour of the shop floor. I would be careful to set the pace of walking to a slow speed which means I can conceal my breathlessness. I hate people to see me breathless, I worry that it makes me look like someone who isn't well or worse someone who can't cope. I might take a quick break and go to the bathroom, I would check my reflection in the mirror, I'm not checking to see if my mascara has run or lipstick smudged, I'm checking that my red rash is concealed. I'm looking to see if I look like a girl with scleroderma or a leader of a business; I always hope it's the

### EULAR

latter.

Possibly the greatest challenge in my day to day life is managing people. I make time every day to walk the shop floor and ask my employees how they are, how their families are and how life outside work is. I believe that having scleroderma makes me a better manager, although it has taken me some time to arrive at this view. My initial feelings towards my scleroderma were to see how it limited me, how it interfered in my day to day life, how it always seemed to misbehave when I really needed to have a good day. I now believe that my scleroderma gives me empathy. A supermarket is like a microcosm, all of human life is here. Over the years I have encountered employees who are dealing with marital break-ups, ill children, domestic violence and serious health diagnoses. I think that my own experiences with my health help me to empathise with those facing difficult times. Let me be clear: I don't openly talk about my medical condition at work, I prefer people to regard me as the boss, as a capable manager rather than someone who has a rare medical complaint. That said, there are times when in order to allow someone to talk it helps to give something of yourself. I relate to them how I felt when first diagnosed how I cope and how I maintain that a positive attitude is the only option when facing life's inevitable challenges.

After spending time in the warm sanctuary of my ground floor office, I head out to the shop floor for a final check around. Scleroderma has taught me the power of delegation. I am a perfectionist and prior to my diagnosis I would try and do everything myself. I've learnt that this is often to the detriment of my team; my managers will not learn if I do not allow them to make their own

mistakes. I've learnt that I have to trust the people around me. I hand over to my duty manager, pick up some shopping and leave the branch. I've learnt that if I work excessive hours one day I won't be able to do my best the next day.

As I climb into my car a wave of fatigue creeps over me. As I drive home I reflect on the day I've had and I realise how lucky I am. I work for a business that has always supported me, that has promoted me in spite of my medical background that has given me my own branch that has no stairs. My employer has a holistic approach to business, where the happiness and welfare of the people who work for the business are as important as commercial success. I recognise that not everyone is so fortunate. And yet it is not the physical manifestations of scleroderma that pose the greatest challenges to me in the workplace. It is how scleroderma can make me feel. It causes me to ask questions, Can I do this job? Can I physically run around a shop and do a job I love with less than fifty percent lung capacity? Can I inspire and lead a team of people when I'm too breathless to speak?

I am a proud person. I take pride in what I do; my job is a central part of my identity. It gives me purpose and satisfaction and it is one of the reasons that I will continue to tenaciously manage my scleroderma in the same way I want to continue to manage my branch, irrespective of the hurdles and challenges that I anticipate my scleroderma will place in front of me.

For now though, as is often the case, my joints have the last word, and on this occasion they are absolutely right, a hot bath and an early night are exactly what I need.



## Other News and Resources

### EULAR

Message from Morteza Abdeli, a member of EULAR PARE

Bringing young people with Rheumatism together.

During the last APOM in Tallinn we decide to reorganize the IOYR (International Organization for Young people with Rheumatism). We would

like to start with a pilot project for networking young people with rheumatism from different European countries. For this pilot project we have established a IOYR group on Facebook. All young people (16-32) can become a member of this group and meet other members. Please use the link below:

<http://www.facebook.com/group.php?gid=105160039272#/pages/>

### PiF Annual Conference

**We are delighted to announce that the 2010 Patient Information Forum conference will be taking place on 11th March at the Aston Villa Football Stadium in Birmingham.** It's a fantastic venue with real 'wow' factor and is close to the city centre and transport routes.

The theme for this year's event is 'Beyond the leaflet' and focuses on alternative formats and approaches to information production, as well as an update on what's happening in consumer health information in England and Scotland - including the Information Standard and the development of NHS Inform.

Among others, there are practical sessions on using SMS messaging and websites, updates in Information prescriptions and social marketing, plus master-classes on harnessing the power of design and using shared decision making. There

will also be plenty of time for networking and a chance for you to tell us your experiences and talk about the issues in consumer health information using Voxur, a film studio in a box. There will also be a drinks reception post-conference.

Delegate fees are £199 +VAT for PiF members and £279 + VAT for non-members. For further information please <click on the link> or contact Nicole Naylor, PiF administrator on 07813 143 384 or at [secretary@pifonline.org.uk](mailto:secretary@pifonline.org.uk).

<http://www.pifonline.org.uk/about-pif/pif-events/2010-annual-conference/>



## Important Dates 2010

BSR Conference 20 - 23 April 2010

EULAR Conference 16 - 19 June 2010

## Contributions

If you have exciting news, resources or dates that you would like to share with the wider musculoskeletal community then please email [sarahrich@arma.uk.net](mailto:sarahrich@arma.uk.net).

We look forward to hearing from you.

## Thanks

Many thanks to our contributors this month.

## Staff at ARMA

Ros Meek  
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Isobel Gildon  
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Project Manager

## ARMA

### ARMA Local Networks

If you are interested in establishing an ARMA local network in your area or you are interested in being involved in an already established local network please contact Sarah Rich.

[sarahrich@arma.uk.net](mailto:sarahrich@arma.uk.net) 020 7842 0910

### More information:

For more information about ARMA, or if you have received this email from a colleague but would prefer to receive it directly, please contact Sarah Rich.

[sarahrich@arma.uk.net](mailto:sarahrich@arma.uk.net) 020 7842 0910

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