Welcome to the first issue of the JIA-at-NRAS e-News. We are really excited about the National Rheumatoid Arthritis Society’s (NRAS) new service for families living with JIA and will be working closely with health professionals and other charities to ensure we are all working towards the same goal “a better life for young people living with JIA”. We are working on developing a website which will provide information on all aspects of the disease, treatment pathways and day to day living with JIA and will also be working closely with our youth group to develop a tailor made service for young people to provide specific JIA information relating to wider adolescent issues. We are asking parents, young people and other family members, as well as professionals, to work with us to shape this service and we are excited at the prospect of getting to know you and working with you on this new adventure.

Introducing the JIA-at-NRAS Team

We are really pleased to introduce the JIA-at-NRAS team who of course, supported by the larger NRAS team.

Maria-Benedicta Edwards joined the team as its new Service Manager in December last year and worked for many years at the Hammersmith Hospital London in the cardiac surgical unit although, she has also worked in a number of other clinical specialities including rheumatology. Maria-Benedicta has extensive experience in health services research and project management and is passionate about improving JIA services for patients and families. She has a young family, loves horses, sparkly gems and cake but hates camping!

Harsha Sorathia is the newest member of the JIA team having joined us at the beginning of September as our Youth Network Liaison Officer.

Harsha studied forensic psychology and has considerable experience working with young people. She has worked as a Learning Support Assistant, a Community Panel Member and a Victim Support Officer with the Youth Offending Service.

In her free time Harsha tells us she’s a bit of a daredevil and has even done a skydive so, it looks as though we’ve found a fundraising challenger for JIA so let the challenges begin!

Nicky Kennedy is a retired clinical nurse specialist with a background in paediatric rheumatology. As well as working and advising the JIA and NRAS Helpline teams about related issues and treatments, Nicky spent most of 2013 travelling the country and visited 32 centres where children with JIA are seen.

Nicky spoke to health professionals, hospital managers, parents and young people about services for JIA in their area, what their ideals for future care would be and what they thought NRAS can or should do as part of the new JIA service.

In February this year our report ‘A Focus on Juvenile Idiopathic Arthritis’ was published. This is
the first in-depth evaluation of JIA services across the UK and has provided us with invaluable guidance on how we can help and support families living with JIA. We’re not sure Nicky’s quite grasped the idea of retirement though, as on the days she’s not working with us she’s running the community shop in her village and somehow also manages to find time to look after her six grandchildren!

**What have we done so far?**

Although we haven’t ‘been around’ for very long we’ve been very busy. We launched the service in July with a fun family day in Coventry and despite the torrential downpours it was such a fantastic day. We’ve had great feedback from both parents and health professionals who joined us on the day, including Dr Clarissa Pilkington, Consultant in Adolescent Paediatric Rheumatology at University College Hospital and Great Ormond Street Hospital and President of BSPAR, Dr Rachel Tattersall, Consultant Adolescent Rheumatologist at Sheffield Children’s NHS Foundation Trust and the physiotherapists, occupational therapists, clinical nurse specialists as well as the play therapists and wanted to share some of these with you.

“I’d like to thank you and the NRAS team for organising such a great event on Saturday. It exceeded all our expectations; the talks were incredibly useful, it was lovely to meet other families with children who have JIA and both our children had a super time. So much so that my daughter was very sad to go home at the end of the day!”

“I just had to drop you an email to say a huge WELL DONE to you and your team at NRAS. The event was brilliant and very well organised, the speakers were so very informative and gave us a huge amount of confidence and little more knowledge regarding this minefield of JIA. Again, a huge WELL DONE!”

“Thanks for a great day !!!! You organised a brilliant day !!!”

“Many congratulations on a successful day on Saturday. It has given me food for thought on the planning for our family day later in the year”.

“I hope that now the dust has settled you thought the launch a roaring success! We had fun and plenty to do”.

“It was wonderful to meet everyone on Saturday and I found the speakers both well chosen and very interesting, and on a personal front they have empowered me to ask for changes in my son’s care”.

“Please accept my thanks for a brilliant afternoon on Saturday – H really enjoyed herself with your team. I rarely get the chance to attend H’s hospital check-ups, so it was very useful to hear issues first hand, and meet the very dedicated professionals involved in JIA”

If you weren’t able to join us at our launch day but would like to see all the photographs and presentations please click here.
We've also published **Daisy B's blog** which is written by one of our youth members who has so far written two fantastic pieces about living with JIA. She has promised to continue writing her blog for us when she returns to Uni this September. Why not have a peek at **Daisy B's blog**.

Then there's a wonderful personal story written by a mother whose daughter, Summer, (see left) has JIA yet despite this, has gone on to represent Great Britain at netball. This **Mother's Story** is one many of you I'm sure will relate to.

We saw a great letter on Facebook which we thought parents might find useful in explaining to your child’s teacher(s) how JIA can affect them at nursery/school/college so please feel free to adapt it to suit your child’s needs.

**JIA in politics**

We've also been working closely with our **Government Affairs Team** who've been busy campaigning on behalf of families living with JIA. Even before our new service was launched they were talking to clinicians to establish core campaigning ‘asks’ in England, Scotland and Wales.

As a result:

- A number of Parliamentary questions have been tabled in Westminster, Scotland and Wales on the quality of JIA services
- Motions have been tabled in the three nations welcoming the publication of the NRAS report
- Presentations are scheduled to take place at Cross Party Groups in Wales and Scotland in October on the JIA report findings
- NRAS has commented on major policy consultation documents which include:
  - NHS England Paediatric Rheumatology service specification;
  - NICE guidelines on transition;
  - NHS England consultation on interim biologics statement; and
  - National Voices consultation on narrative of care for young people.

If that wasn’t enough, Norman Lamb MP, the Care & Services Minister, and Alex Neil, Scottish Cabinet Secretary for Health & Wellbeing, sent endorsements of JIA-at-NRAS on our launch day and Jamie wrote a fantastic blog which was published the day after our launch on a leading political blog, “Politics At Home”.

We've held two **Young Persons’ Focus Group** discussion meetings. The first in July and the second last Thursday. It was great to meet each other and the Skype discussion worked really well.

We had lively and enlightening discussions about the realities of living with JIA, what makes a good youth worker, what would make the launch a success, and how NRAS could help and support children and young people living with JIA as well as their families. The feedback from these meetings has been very positive and we’re all looking forward to catching up at the next meeting in October.
**Summer Events**

**Southampton Paediatric Rheumatology Unit Mad Hatters Tea Party**

Satnav ready for the first time this summer and set for a lovely little village hall in Romney, Hampshire where the Southampton Team had organised their annual summer get together. The theme this year was Alice in Wonderland and the kids had donned the aprons and made the most amazing themed cakes – the amateur photography simply doesn’t do these cakey creations justice by any stretch of the imagination! It was great to see so many families there and a great afternoon. We can’t wait for next year’s event especially if there’s going to be more CAKE!

**Children’s Arthritis Fun Day - 27th July 2014**

Setting the satnav again, we headed off to North London at the end of July to support Trish and Rohan, whose daughter Eliza was diagnosed with JIA at 18 months old. They had organised a fantastic fundraising afternoon in aid of NRAS to raise awareness of JIA and had coaxed a number of local retailers to donate some amazing auction prizes. Friends and family also pitched in to make the afternoon a huge success.

The weather was amazing, turnout was fantastic, everyone seemed to enjoy themselves and... of course there was CAKE! It was great to meet families living with JIA and also to speak to people who didn’t know children also get arthritis. As a result of all their tremendous efforts, the afternoon raised over £500 for NRAS and two other JIA related charities. Well done to Trish & Rohan and a huge ‘Thank You’ from us.

**External Events Calendar 2014/15**

**PRINTO (Paediatric Rheumatology International Trial Organisation) & PReS (Paediatric Rheumatology European Society)**

Sharon Douglas (BSPAR Parent Group) is representing families in Scotland and the UK as she heads out to Serbia on Friday 19th September for the PReS conference and SHARE project meeting.

**BSPAR (British Society Paediatric and Adolescent Rheumatology)**

Annual Meeting, Leeds 24-26th September 2014

**SNAC (Scottish Network for Arthritis in Children)**

Satrosphere: Satrosphere Science Centre, Aberdeen Sunday 5th October 2014, 2-4 pm. This event is open to children with JIA aged from pre-school to S2 and a parent. Places are free but limited so booking is essential. For more information and to book a place contact kateodonnell@outlook.com by Friday 19th September.

**Parent & Carer Information and Support Day**

SNAC’s Parent/Carer Day on 15th of November will be held in Irvine at The Menzies Hotel, 46 Annick Road, Irvine, Ayrshire KA11 4LD. Programme to be confirmed. Please emailtracyrendall@snac.uk.com or phone 07504 609510 for more information or to book a place.

**KLU (Kids Like Us)**

Fundraising Ball 3rd October 2014: Eaton Hotel, Hagley Road, Egbaston, Birmingham, B16 9NB. For more information please contact Gareth Dixon on 07789 516561.

If you’re holding an event, from a coffee morning, education sessions, kids sports events, social or fundraising activity or taking up a challenge for JIA, please do let us know so we can add it to our events diary and keep everyone posted on what’s happening in the JIA calendar around the UK.
NRAS Events Calendar 2014/15

Join us for some fun in the mud!

Calling all children – do you have a sense of adventure and want to have some fun? Why not take part in a muddy obstacle course challenge and raise funds for NRAS? You will climb obstacles, crawl through mud and so much more before you make it to the finish line. Become a super strong team and enter with your friends, or perhaps you would like to take the challenge on alone, you might even like to get mum and dad involved (what fun watching mum and dad getting muddy!) For more information email or call 01628 501547.

Calling all super hero fans

If getting dirty isn’t your idea of fun and dressing up as your favourite super hero is, we have an event for you - The Super Hero Run. It’s on 17th May 2015 in Regent’s Park, London. It’s a great way of involving all the family in what is a great run. You choose your distance, 5 or 10km, and this race is all about taking part, not winning, so walk, jog or run, you choose. You even get your super hero outfit provided for you on the day. Alternatively you can bring your own costume – all super hero costumes are very welcome! For more information, click here.

Whatever you choose to do we have an event that will suit you. There are events to suit all abilities and age groups. Bring family and friends along to support you, you never know they might sign up and take part in an event with you.

For other fun ways to get involved in fundraising and perhaps release the daredevil in you, contact Val on 01628 501547 or email to find out more details or register an interest in any one of these exciting fundraising activities.

Even better, if you have your own ‘wild’ idea then why not share it with us – we’re always game to hear new ideas for fundraising. Let the challenges begin!

Call Us: 01628 823 524
Email: Maria-Benedicta or Harsha on JIA@nras.org.uk