

Paediatric rheumatology newsletter

ISSUE
FOUR

Hello all...

and welcome to newsletter number four!! My huge apologies for the delay to this issue, I've been a little busy with the world of university and fundraising. So here it is, if a bit overfilled with info!

Sarah



Events

Another great BBQ in glorious weather!

I have to say we are so lucky. Thanks to all that attended, it looked like you all had great time. We should also mention the fantastic display of artwork shown at the BBQ, which really showed some true feelings your children are going through.

This year we have started youth drop-in sessions for children aged over ten. They can pop in and chat together about their feelings and any current issues or problems they are having. The first three sessions were really helpful and they will



continue to run. Dates will be sent out via forum page or email. If I don't have your details, please let me know.

A parents' debrief was run this year to allow parents to meet and chat about their feelings. Again, a great session and another will follow next year.

We now run a JIA Toddler group, the first one is about to run with plans to run every 2 months.

Education

This years education sessions have, at times, been moved around to help raise attendance numbers.

The team apologise for this, however we will always try to raise attendance numbers for a session to make it worthwhile for all.

Education sessions are a great way for you to ask questions and meet families going through similar situations.

All the sessions are run on a Saturday morning and start at 9.30am. Please let me know if you are interested in attending. Children are also more than welcome to attend and there will be activities organised for them to enjoy during the session. In the New Year, a list of education sessions will be sent out.

The team are proud to offer an education day to health professionals this year to promote disease awareness and increase their skills when reviewing children with JIA. We hope this will help educate other professions to support the work that we are doing.

Service

At long last, the yearly review is now up and running. This will be linked in with a normal follow-up appointment where your review will be very thorough. It will run on Friday afternoons.

For those on s/c treatment please allow for it to happen at this appointment and bring your medication with you.

Joint Uveitis clinic has started and is clearly having a few issues. Please bare with us we are trying to correct this as soon as possible.

University Hospital Southampton **NHS**
NHS Foundation Trust

Paediatric rheumatology Christmas event

We would like to invite your family to our paediatric rheumatology Christmas event at the Berry Theatre, Hedge End.

Pinocchio
Sunday
15 December
9.30 to 4pm

Activities in the morning will be followed by lunch and then an afternoon performance of Pinocchio.

You will also get to meet the cast and crew after the show.

Places are free but numbers are required. If numbers are high then tickets will remain free for child and guardian but others may have to pay. Please note, this has not happened so far!

Email sarah.hartfree@uhs.nhs.uk

The Berry Theatre

Fundraising

Thank you to everyone that has supported the service this year and we are delighted to report a strong level of donations.

We are lucky to have been nominated Rolls-Royce Motor Cars House Charity for 2013. Thank you to the Rolls-Royce team for their support, and especially the hard work of Mrs Sadler.

- HMS Edinburgh Warrant officers and chief petty officers mess raised £1,306.60
- Spinathon raised £455
- Samuel Adshead raised £750
- Charity Gala Masquerade ball raised approx £6,000
- 4th Romsey Scouts raised £500

Thanks to you all once again. The team are so grateful of all your support!

If anyone has any ideas please contact me and I am more than happy to help.

Art competition

Who would have thought the art competition was going to turn out so well! A huge thank you for all that joined in. I can't wait to get these up in January at Southampton Art Gallery. For anybody who hasn't done a picture and would like to please contact Sarah. Although the competition has finished, we would still like more artwork.



The Art Gallery open day is on 11 January at 10am.



www.uhs.nhs.uk



Contacting the team

My working days are generally Monday, Wednesday and Friday. Please contact the patientline if you have any problems and I will return your call within 24hrs. The number is **077 6015 8924**.

Alternatively, if your enquiry is not urgent then you can email s.hartfree@nhs.net.

Parents forum

For those of you who don't already know, we now have our own forum which is a great place for you to ask questions and speak to others in similar situations. Please contact me if you would like to join or visit www.uhs.nhs.uk/childrensrheumatology and follow the link to the parent's forum.

We also now have a youth forum. Please email me if you wish to join and I can let you in. Please note the youth site is not currently being used and may be stopped if not required.

"Help my child is having a flare"

TOP TIPS

- Analgesia (NSAID) are you using it the best way?
- Regular not one off doses are far more effective
- Correct dose? Check with the team. They should be on a much larger dose than on a standard packet so please check
- Contact team if no improvement with regular analgesia after one week?
- If brought in for urgent review please miss analgesia on day of review.

Nasal Flu Vaccination is LIVE. Please do not have if you are on methotrexate or biologic therapy. The flu jab is not lab and is ok to have.