



Welcome to the CHEERS newsletter

Welcome to the third edition of the CHEERS newsletter. Following feedback from our readers we have some new articles which we hope will feature in each newsletter. These articles are 'A day in the life of – a little bit more about my job' written by different members of the team, and patient stories. We hope that by including a patient story within each edition we can learn more about the benefits CHEERS has had, but also learn how we can improve the service to be even more effective for young people and their families.

A new aspect of the service we are launching over the next few months is parent involvement. As a service we are acutely aware of the wealth of knowledge and experience our parents have in looking after children with rheumatological disease. To date CHEERS has consisted of a group of healthcare professionals working together to improve the quality and standard of clinical care across the region. However going forward there are a number of improvements we would like to make to the configuration of care, and we want to ensure the voice of the family is heard. If you, as a parent, are interested in getting involved with the development of care for the young people with rheumatological disease in the East of England, please do get in touch with me and I can provide you with further information of how to get involved.

If you have any comments/questions about any of the content of the newsletter or if you have anything you would like to be included in future editions please feel free to get into contact with me via my contact details below.

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A little more about my job



Cathy Slynn
Clinical Nurse Specialist

Generally I work Monday to Friday 08:00 to 16:00 (with the exception of late afternoon clinics). I think it is fair to say that most of my work happens "behind the scenes". Day to day I carry out many of the time consuming tasks that keep everything ticking along.

What is the best thing about your job?

My most rewarding times are when I have trained children how to have their weekly injections- they are all terrified but with time, reassurance and my positivity they often leave happy and positive. Last week a 13 year old actually hugged me for making her give an injection to herself! It was really rewarding and worth all the hard work.

What does a 'normal' day look like?

On arrival most mornings I first check the team's answerphone messages and e-mails. We aim to answer all messages within 48 hours. Sometimes this can take 5 minutes but sometimes this gives me lots of work and can take 5 hours! I am that link between the Consultants and the families. I do also like to put families in touch with each other for support as well as be that ear for families to share their concerns with.

Beyond this consistent task, my days are quite varied and my schedule completely depends on the day and what clinic is running. Here are some examples of the different tasks I am responsible for on a 'normal' working day:

- ◆ I accompany Dr Armon and Dr Bale whenever they hold a clinic and see the patients as needed. This might involve helping a family following the new diagnosis of JIA, explaining a new medication or training a family and child how to have a new injection.
- ◆ I run my own clinic once a fortnight where I am able to see young people and their parents for check-ups, and new medication training.
- ◆ I co-ordinate all of the admissions of the young people who have regular infusions, so most days I spend time on Ward F3, the Children's day case ward. I write the all the required letters as well as prescribe the medication and discuss with pharmacy to ensure the medication is there ready on the day the patient arrives for admission- If this isn't done in advance then families can wait over 4 hours just for medication delivery!
- ◆ As a qualified Nurse Prescriber I ensure that the medication prescriptions for DMARDs (disease-modifying antirheumatic drugs) and Biologics are issued. Currently we have over 120 patients (and this increasing) that are receiving injectable medications in Cambridge alone.
- ◆ In order to prescribe the medication I also have to ensure every young person has had their required blood tests. Dependant on their condition and medication, patients require blood tests at different time intervals to each other. The lab that the results go to depends on where each individual lives, so I do spend a lot of time phoning these labs or writing to families advising blood tests are needed and asking for results.

If you could change one thing about your job what would it be?

Being the only Nurse in Cambridge means that I often have to act in a reactive way when urgent issues arise. I would much rather be proactive and prevent the need for me to have to react quickly to situations. As the service grows, the plan is to secure more nursing support here at Cambridge so I really look forward to that.

Family Fun Day



As mentioned in the last edition of the newsletter, CHEERS teamed up with NRAS for its 4th family fun day, this time in Newmarket! The event was really well attended and was a really profitable time for parents and young people alike. During the course of the event parents were given the opportunity to get to know other parents with children with JIA and begin forming friendships which we hope will be useful for sharing advice and experience. This was of course aided by the fabulous cakes that were provided by the venue!

The parents had a couple of short education sessions regarding the CHEERS network, common pharmacy questions including hints and tips for methotrexate injections and a general Q&A for parents to ask any question of the professional team.

While this was going on, next door the children were kept very busy with crafts, face painting and two fabulous magic displays by professional magician and entertainer Matthew Garrett (<https://www.professionalmagic.com>)! He was so good that none of the adult organisers remembered to take any pictures!

A big thank you to all who came and of course to NRAS for working hard to help all the details for the event come together.

The feedback from parents showed that everyone found the day useful and enjoyed meeting other families. We had a couple of parents feedback that they would appreciate an 'older' event as the majority of the children in attendance were very young. In August 2019, we have the adolescent independence weekend planned which will be open to all children within CHEERS between the ages of 12 and 16 who would like the opportunity to have a free activity weekend away with others their age. Invitations have been circulated to all families however if you would like further details, please feel free to email Laura at laura.howden@nhs.net.

"Thank you so much for today! It was an amazing experience."

"Fantastic day. Very informative. Looking forward to next year. Thank you!"

"Carry on doing what you're doing, Awesome Team. Fabulous opportunity to meet up and kids to see one another is so valuable. Thank you for your time."

JIA with NRAS' big event #wearpurpleforJIA is on 7th June this year, for further information and to order your free pack, please visit www.wearpurpleforjia.com

Network Education Day

On 12th March 2019 the CHEERS team from across the region gathered at the Evelina Hospital to meet with colleagues from the London and Southampton paediatric rheumatology networks.

The day was organised by Dr Nick Wilkinson, Evelina Hospital and Dr Bale, CUH. The day was a fantastic opportunity for the networks to discuss together the different ways in which they care for the young people with rheumatological disease within their region. Professional relationships were established between the networks and the various professionals were able to learn from one another. Talks were given by a range of healthcare professionals including clinical psychologists, consultants, physiotherapists and nurses.



Emily Earle, founder of JIA matters and parent to a child with JIA, attended the event with two other parents and fellow members of JIA matters. Emily gave a fantastic presentation about 'networked care' from an honest parent and family perspective. This was really well received by all attendees as it gave real insight not only into how JIA hugely impacts a family, but also how the decisions made by clinical services have further implications to each family it cares for.



Sarah!

Pseudonym

Background

- ◆ Sarah had always been a healthy little girl, and when she reached 12 months it was noticed that she wasn't sitting as would be expected for her age. Sarah was seen by community paediatricians and developmental physiotherapists for what was diagnosed as advanced fine motor delay, query gross motor developmental delay.
- ◆ At 19 months it was noticed that Sarah still wasn't walking, and after a busy week of exercise Sarah's parents noticed that her right knee was swollen, hot and that she was reluctant to weight bear on her right leg when standing. A week later they then noticed swelling of her left middle finger so they went to the GP with their concerns and were straight away referred in to their local hospital, a hospital within the CHEERS network.

CHEERS input

- ◆ When reviewed by their local General Paediatrician one week later, it was noticed that Sarah's knee didn't bend as well as it should and as well as the swelling that had been noticed before, she also had some swelling in one of her toes.
- ◆ Upon noticing these symptoms Sarah was urgently referred to a specialist Paediatric Rheumatologist, and Sarah had an appointment within four weeks at Addenbrooke's Hospital.
- ◆ At this appointment it was noticed that one of Sarah's elbows and one of her wrists had also begun to become restricted, warm and swollen. With a total of 7 joints in this condition and with clear signs of inflammation in her blood tests, Sarah was diagnosed with polyarticular Juvenile Idiopathic Arthritis (JIA).
- ◆ At the time of her diagnosis Sarah started steroid medication and methotrexate to bring her arthritis under control.

Impact

- ◆ Sarah responded excellently to the medication and within 2 days she was pulling herself up, 1 week she was cruising and within 11 weeks was walking independently.
- ◆ Sarah did not have gross motor developmental delay as originally suspected, but had likely not been walking due to having painful joints.
- ◆ Since then Sarah has had another flare of her arthritis which was picked up by the local team. Sarah was then seen at Addenbrookes by her Paediatric Rheumatologist a week later and was escalated to begin biologic therapy, Etanercept, a drug which can only be prescribed by Paediatric Rheumatologists.

Sarah's story highlights the benefit of good communication and speed of referral between professionals, from primary care through to network paediatricians and specialist paediatric rheumatologists. There is evidence to suggest that the earlier a child with arthritis receives the appropriate level of treatment the better their long term outcome, and this is one of the main aims of our regional service.

WORD Day Cake Sale!



The 18th March 2019 marked the very first WORD day which is the World yOung Rheumatic Disease Day, initiated by PRES, Paediatric Rheumatology European Association. WORD day has been set up to raise international awareness that 'children and young people get rheumatic diseases too'.

To mark the occasion the CHEERS team at CUH got out their baking tins and put on a cake sale! The cake sale was held in the entrance of the Rosie Hospital in Cambridge and raised a fantastic **£146.30**. It has been decided that these funds will go towards CHEERS' next awareness initiative, the Cambridge GP learning event.



GP Learning Event

During conversations at the family fun day and feedback received on an adhoc basis in clinic, it has become increasingly clear that there remain GPs who are unfamiliar with Rheumatological diseases in children and young people. This can lead to a number of issues for children with rheumatological diseases such as a delayed diagnosis and difficulty in treating other illnesses when a child is on a DMARD or biologic therapy. In response to this, the specialist team are working with the CUH paediatric orthopaedic team to host an MSK (musculoskeletal) primary care education event on Wednesday 26th June from 18:45 in Lecture Theatre Two, Clinical School on the Cambridge Biomedical Campus.

The event will be free and open to all GPs and trainee GPs in the Cambridge area however other healthcare professionals will be more than welcome to attend. It is hoped that the event will allow the specialist teams to educate attendees on the following topics, but also that the event will allow further networking between local GPs and specialist teams:

- ◆ Normal variants
- ◆ Back pain
- ◆ Hip/knee pain and limp
- ◆ Arthritis
- ◆ Non-specific MSK pain/symptomatic hypermobility and weakness

For all details of the event and to book on please visit the Eventbrite page: <https://mskgpevent.eventbrite.co.uk>

Donating to CHEERS



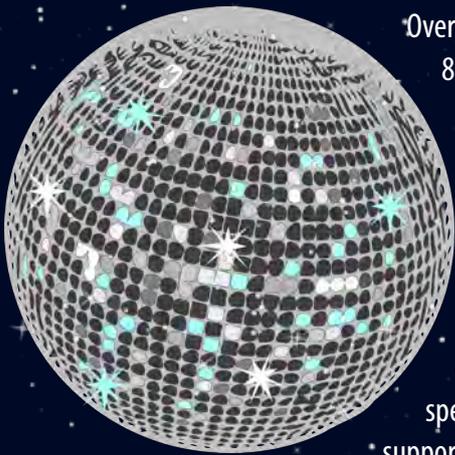
CHEERS works hand in hand with Addenbrookes Charitable Trust (ACT) and Norfolk and Norwich Hospitals Charity (N&N).

All CHEERS fundraising is paid into the CHEERS accounts managed by the two charities, therefore should you wish to raise and donate any money for CHEERS, this can be donated through the charity websites <https://www.act4addenbrookes.org.uk> or <https://nnuh.org.uk>.



For further information please feel free to contact ACT at hello@act4addenbrookes.org.uk or N&N at fundraising@nnuh.nhs.uk.

Water Lilies Summer Charity Ball



Over 100 guests will be joining their host, Teresa Griffin of **Water Lilies Swimming School**, on the 8th June at the glitzy Summer Charity Ball in Diss, Norfolk. The black-tie event is in aid of CHEERS and Parkinson's UK and aiming to raise lots of funds to help support local children and families across Norfolk and Suffolk. Teresa is also running a fabulous charity raffle as part of the event also, selling tickets across the Water Lilies swim school and wider to the local community.

Water Lilies Swimming School teaches children of all ages and abilities and is especially proud of its swimmers who have Juvenile Idiopathic Arthritis. The swim school regularly takes on challenges and activities to raise money for charity each year and every two years hosts their special Charity Ball. This year, Water Lilies Swimming School is keenly supporting the organisations supporting local families and the local children living with JIA.

If you know of anyone who may wish to support this special event, there is still time to donate a raffle prize, an auction prize or even a gift for the evening activities at the Charity Ball.

To find out more please contact the **Water Lilies Swimming School Office** on 01379 740489 or email treacle@waterliliesswim.co.uk