



Welcome to the CHEERS Newsletter

Welcome to our new, revamped CHEERS newsletter, keeping you updated on what's going on within the regional service.

Thus far our newsletters were primarily circulated for the benefit of the healthcare professionals within the region. We have decided on a slight change of emphasis; to use the Newsletters as a way to keep parents and families updated as well as the region's professionals.

The last year has brought with it many challenges for all of us, and the CHEERS service is no exception. This issue provides a whistle stop tour of the developments of the last year, a COVID-19 update and a patient story.

Staffing Update at Cambridge and Norwich

A number of the staff in each of the Cambridge and Norwich teams have changed. We want to take this opportunity to thank those who have left for their years of dedication and support to the children and families within the service. Whilst we are very sad to see them go and will miss them, they have left for new opportunities and we wish them all the best in their new adventures!

Nursing



Cathy Slynn and Sarah Cox left the Cambridge Team to pursue other opportunities with the Paediatrics department. At the end of the year, Lennina Alban will be leaving the Cambridge team to begin a new role as a community health visitor. We introduced Claire Ede as a new specialist nurses who hit the ground running and is a great asset to the team. Recruitment to fill the vacant post is ongoing.

Sarah King recently left the Norwich Team to pursue an opportunity within the local Community Team. Recruitment to this post has been successful and we look forward to introducing you to our new nurse soon.

Physiotherapy

We congratulate Rachel on her marriage! She has relocated to a Trust in Essex and we are excited that we can still work with her in her new hospital! Brooke Mara is currently on maternity leave (congratulations Brooke!), so the Cambridge physiotherapy team has completely changed. Jenny Becca Knowles, Faye Triggs and Jenny Kemp started in the early months of this year and have been incredibly flexible and reactive to the ever changing landscape.



Occupational Therapy

Daphne Wessels, our Cambridge based Occupational Therapist has taken up the challenge for more community occupational therapy work. Karen de Villiers has been appointed in her place and has quickly got up to speed and we are very grateful to have her working with us.



Karen

Medical

Specialist registrars in training in paediatric rheumatology usually change posts each year. We had to say goodbye to Dr Rosie Close and Dr Chantelle Richards (job sharing) and welcomed Dr Charlene Foley to the team. Dr Foley works full time and will be seeing children and young people in clinic alongside Dr Armon and Dr Bale.



Charlene

New Outreach Clinics

Dr Armon and Dr Bale have established outreach clinics at Queen Elizabeth Hospital, King's Lynn (QEHL) and East Sussex and North Essex, Ipswich Hospital. Over the past 18 months an additional 3 outreach services have begun.

James Paget University Hospital (JPUH), began an outreach service in the summer of 2019. Dr Armon and Lead Specialist Nurse at Norfolk and Norwich, Kit Tranter, attend JPUH every other month to run specialist clinics. Patients were previously travelling to Norwich for their specialist appointments but are now able to access the service much closer to home. Thank you to consultant paediatrician Dr Damodaran, and to the JPUH clinical and operational teams for helping set this up and supporting it.

Basildon and Thurrock University Hospitals (BTUH), started an outreach service in Autumn 2019. Dr Bale and Lead Specialist Nurse at Cambridge, Lennina Alban, attend BTUH every month to run specialist clinics. These patients would previously travel to Cambridge or London for specialist care, parents and patients have fed back their gratitude for the reduction in travel. Thank you again to Dr Gupta (paediatrician), Dr Bharadwaj Dr Gendi (rheumatologists) and their teams for facilitating and supporting this service.

East Sussex and North Essex, Colchester Hospital is the most recent outreach service to be set up. Dr Armon attends Colchester clinics twice a year, supporting the service delivered by Dr Walton (Rheumatologist) with Dr Rao (paediatrician). To see a Paediatric Rheumatologist, the patients at Colchester would usually have to travel to London or Cambridge. Thank you to the team and Anna Holliday (clinical nurse specialist) for their invitation and support.

Quick Emoji Quiz

Each sequence of emoji's in the quiz represents a well-known catchphrase ... see how many you can get! Answers are on page 4.

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Emily's Story

Background

- At 22 months, Emily became noticeably less willing to walk, slightly weaker than usual and was asking to be picked up and carried around more often.
- A month later Emily's face had become noticeably red and swollen and a rash had begun to develop. After two trips to their local A&E, firstly diagnosed as an allergic reaction and secondly a virus.
- Emily's family had a holiday planned abroad and Emily was confirmed to be safe to travel. 2 days after arriving on holiday Emily could no longer open her eyes, had a rash over her whole body and her limbs were very swollen. She was admitted to the local hospital.
- After extensive investigation Emily's diagnosis was confirmed as Juvenile Dermatomyositis (JDM), an incredibly rare inflammatory disease that affects 2-3 children per million (about 1

CHEERS Input

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- The team abroad contacted the CHEERS team in Cambridge as they recognised that this was her closest specialist paediatric rheumatology service in the UK. The clinical teams liaised closely until Emily was safe to be discharged. She flew home and was seen by the CHEERS team within 48 hours.
 - Emily was admitted to complete a number of investigations, meet the whole MDT and receive 3 IV steroid infusions, Emily continued to get better and began to be like her old self again, wanting to walk everywhere and climb over furniture!
 - During her stay at Addenbrooke's Emily was started on methotrexate medication for long term management of her condition.
 - continued to show significant improvement and began weaning off her steroid treatment a month later.

Impact

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- Ever since the correct diagnosis and treatment, Emily's condition has significantly improved and is now under control. Emily is now very mobile with good levels of energy and has her usual happy temperament back.
 - Emily continues to be under the care of CHEERS at Cambridge and can also be seen at her local hospital as part of the outreach service, allowing the family access the specialist care closer to home.

COVID-19 Update

As well as regular updates being sent out to parents via email and post, all up to date COVID-19 guidance for Paediatric Rheumatology patients can be found on our [website](#).

Throughout the lock downs, Paediatric Rheumatology has continued to see all urgent referrals and urgent returning patients. Since July, the service have been working towards getting back up to pre-COVID-19 operation. This has been a mammoth challenge due to the new social distancing and footfall restrictions in clinics, but we are now back to seeing routine follow ups and working through the backlog that formed.

In order to assist our Doctors with seeing patients and families, Cambridge University Hospitals launched Attend Anywhere in the Springtime. This is a platform to conduct safe video appointments. Although in the majority of cases Dr Armon and Dr Bale do need to see patients face to face for physical examination, there remain a number of appointments that have been able to utilise Attend Anywhere.

If your child's Doctor assigns one of your child's appointments to a video clinic, you will be informed of this in the appointment letter and will receive an email. The email will contain a link which you will need to press at the scheduled appointment time, you will require Google Chrome or Safari, along with a camera and audio connection. When you open the link you will enter the virtual waiting room and when the clinician is ready, you will be virtually moved into the consultation. When the consultation is finished, the lead clinician will end the call.

There are many benefits to virtual appointments including reduction in travel time (often resulting in less time off school), parking, being in a more relaxed setting and less face to face exposure during the pandemic. At present all attendees over the age of 11 in the clinic are required to wear a face covering, this is not required for video appointments.

We would like to take this opportunity to thank the parents of our patients for their help, support and understanding through this challenging time.

CHEERS Steering Group Update

The CHEERS network is led by a Steering Group made up of clinical and non-clinical representatives from around the region. At present the group members include Dr K Armon (Chair) , Dr Bale, Paediatricians, an adult Rheumatologist, specialist nurses, physiotherapists, occupational therapists, clinical psychologist, network pharmacist and the network manager. The Steering Group reviews the progress of the network and oversees it's development, the group meet on a quarterly basis.

Although the steering group is very varied in membership and roles, to date there has been no patient or parental representation. Initially we would like to welcome parent representatives to the group for a two or three year tenure to help shape the service and to be the voice of the patients and families we work with. As such, we are currently recruiting parent representatives and would like to invite any parents interested in joining the group to get in touch with us via: laura.howden@addenbrookes.nhs.uk.

