



## Exeter CF Newsletter

Autumn 2018

### New team members



A big welcome to Jackie Cornwallis-White (CF MDT co-ordinator), Tom Kent (Exercise Therapist), Hannah Pike (CF nurse specialist) and James Rutherford (CF service manager).

Jackie is on a secondment from the Emergency Department where she has been for the past 18 years, whilst Sally is on maternity leave. Although she has many responsibilities, you will most likely get to know her for her role in booking your clinic appointments and helping with your phone enquiries / taking messages for the team. She can be contacted on 01392 402 726 or via email:

rde-tr.exetercf@nhs.net

Tom is our new Exercise Therapist who has come over from Torbay community physiotherapy. He has a background in Sports Therapy and will be the point of contact for patients needing support with exercise and will carry out the CPET testing at the RD&E.

Hannah has been working with the CF team for over a year now. She has spent the last 16 years working as a Paediatric nurse on Bramble Children's ward at the Royal Devon and Exeter Hospital. Originally, starting out with the Paediatric team for two days a week, Hannah is now working full time across both the Adult and Paediatric CF service. This is currently to cover maternity leave.



### Thank you Elodie!

Two-year-old Elodie has helped to raise an incredible £800 for the Cystic Fibrosis unit at the RD&E.

Accompanied by friends and family, the group cycled for 18 miles from Dawlish to Exeter and back again to raise money for the unit where she is treated.

Elodie sang all of the way! Thank you all.

### Guest Wi-Fi during ward admissions.



You will be pleased to hear that a Free NHS Wi-Fi service was launched on Thursday 23rd August.

This will replace the guest wireless option and you will be able to self-enrol by selecting the NHS WIFI option when searching for available wireless networks on your devices. You will then be prompted to complete some details before gaining access.

Each session will last for 4 hours, after which you will automatically be logged out, and will be required to login again to restart a new session. The process is very simple and is being tested hospital-wide in in patient areas, with very positive feedback.

The new service will be available across the Wonford, Heavitree and Community hospitals/sites.

### ...and farewell to Rowenna



Rowenna Rutherford has done a sterling job as our CF service manager.

'My highlights have been attending the parents evenings, hosting the CF Trust visit and getting the CF website made! (Soon to be live). I've loved it and am sad to be leaving the team and the service but I'm incredibly proud to have been part of the team and all the brilliant work they do to care for our patients... at least I will still hear what's going on!'

Rowenna will be greatly missed but we wish her all the best in her new role as Obstetrics and Gynaecology Service manager.

### 41st European CF conference; Belgrade



Dr Chris Sheldon, Dr Guy Mizon and Jayne Trott, Prof Craig Williams and Owen Tomlinson attended the European CF conference in Belgrade In June. Exeter was well represented with 2 posters being accepted from the CF physiotherapy team. Craig, Owen and former PhD student Zoe Zaynor all presented work in one of the sessions. Jayne and Zoe presented a poster on the non-compliance with CPET in CF. They looked at data from 179 individuals with CF. Out of 138 individuals who were age appropriate for a Cardiopulmonary exercise testing (CPET), 68 did not complete a CPET and 73 did. Reasons behind non-compliance ranged from clinical reasons 40%, Refusal 20% and miscellaneous 32%. Feeling unwell or being on IV's at the time of a CPET appointment formed the largest clinical reason for non-compliance.

## Research update



We've been very busy with trials here in Exeter, with 36 people currently taking part in CF Research.

The Clinical Trial Accelerator Platform (CTAP) is now fully up and running, and we hope to include patients from other centres around the South West.

Taking part in research can vary hugely in terms of commitment, ranging from completing questionnaires as a one off, to studies lasting a few weeks, to long term trials that can last many months or years. Clinical trials can have many specific criteria such as genetics, age and lung function, and even which bugs people grow, so although there may not be something you or your child can be involved with immediately, opportunities are changing all the time. Thinking about research prior to taking part can make potential trials easier to consider.

If you have any questions about research or are interested in taking part in a study (now or in the future), please contact me (Sophie – CF Trials Coordinator) at [s.whiteley1@nhs.net](mailto:s.whiteley1@nhs.net), or discuss research with your team at your next clinic appointment. You can also access more info on the CF Trust website <https://www.cysticfibrosis.org.uk/clinicaltrials>

### Here is a short summary of current and upcoming trials running at Exeter:

Adult trials that are open to new patients:

**Living with CF:** A Quality of Life measurement for people aged > 16 years with CF, in the UK CF Registry. Taking part involves completing an online questionnaire at annual review. Is your annual review coming up? If so, please get in contact if you would like to hear more about this study.

**Hope-1 Study:** This study is looking at the effect of a new nebulised treatment vs placebo (a dummy treatment) on lung function in people 18–50 years old with an FEV1 between 50–80%. Trial involvement lasts around 2 months.

Paediatric trials that are open to new patients:

**Gilead Alpine 2:** This study is looking at whether 14 days or 28 days Aztreonam Lysine (Cayston) is effective and safe for treating new onset Pseudomonas infection in children who haven't grown Pseudomonas in the last two years (or ever).

**CF Start:** This study is looking to compare two strategies for giving antibiotics to new babies with CF, "Prevent and Treat" flucloxacillin prophylaxis (standard care in the UK) vs "Detect and Treat" antibiotics, prescribed depending on microbiology results.

Upcoming trials:

**Vertex NextGen:** This study is looking at the effect of a new triple therapy treatment in those aged 12 years+. This trial is planned to start in the Autumn.

**Proteostasis:** This study is looking at the effect of a new triple therapy treatment in adults 18+. This trial is planned to start in the Autumn.

**OligoG:** This study is looking at a new inhaled treatment for treating chronic pseudomonas in those aged 12 years+. Date of recruitment start in Exeter not yet confirmed, but you can find further information about the study here: <https://oligopivotalcf.eu>

## Autumn advice from the dietician



**1) Creon 40 000:** The problem with supply of Creon 40 000 is envisaged to last approximately 4 months. Please contact the CF Dietitians if you need advice regarding transferring to Creon 25,000.

**2) Beginning a New Term:** If school keeps a pot of Creon for your child as an extra/spare supply, we would suggest replacing this with a fresh pot when they return to school. Considering how hot the Summer has been, there is a risk that the Creon has got warm and may not be as efficient.

**3) Starting College/ University:** For those with CF leaving home, the CF Trust have produced a helpful leaflet, 'Leaving Home and Eating Well.' This leaflet is available to download from the CF Trust website. It gives some helpful ideas and is also mindful of managing food on a budget.

**4) Keeping Creon Cool When Travelling:** There are a range of useful 'pencil case' size wallets for Creon, whose coolant can be activated by running under cold water. These will keep medicines between 18–25 degrees C for 2–3 days! They are made by a company called 'FRIO' and recommended on the Diabetes UK website (<https://shop.diabetes.org.uk/collections/frio-wallets>) to carry Insulin.

## East Devon Cystic Fibrosis Quality of Life Fund – EDCF AGM



The trustees of this fund invite you to attend an Annual General Meeting on Wednesday 17th October at 7.30pm, for a prompt 8pm start. RD&E, Centre for Women's Health, Seminar room 1.

This wonderful charity have supported people with CF in Devon for over 10 years. Please come and find out more and join the discussion about its future and how we can keep it thriving.

Please text 07876 560 546 or email the CF team on [rde-tr.exetercf@nhs.net](mailto:rde-tr.exetercf@nhs.net) to confirm attendance.

Royal Devon and Exeter NHS Foundation Trust, Barrack Road, Exeter EX2 5DW, 01392 411611. **Exeter Cystic Fibrosis Team:** for advice regarding CF – 01392 402726; this number has an answerphone and messages will be checked regularly. For other numbers see your clinic letterhead. For **non-CF illness** please access healthcare as you would normally, and let your CF team know of your admission.