Exeter CF Newsletter

Spring 2018

An invitation to the next parent support and network evening

The next parent support evening is on **Wednesday 11th April, 19.30-21.30 in the Centre for Women's Health**. This is an informal space that we provide for parents to meet other parents, to share tips and advice and discuss relevant topics.

Alongside the usual conversation and Easter-themed cakes, we hope to explore whether this continues in its current format, or would benefit from a 'make over'! We would like people's thoughts to ensure that it remains well attended, helpful and sustainable in the long term. We will need to consider whether it is something that we continue to plan, if we cannot encourage better attendance, as the number of team members has often outnumbered the parents!

Please can you RSVP to the paediatric CF nurses' mobile on 07876 560 546 to confirm if you plan to attend, or if you have any feedback you would like to share if you cannot be there in person.

Physiotherapy resources

The Cystic Fibrosis Trust have worked with the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) to produce a series of leaflets to complement the advice and teaching physiotherapists give to people with cystic fibrosis. The information in these leaflets is based on clinical best practice and consensus of opinion by physiotherapists within the ACPCF.

This series includes nine leaflets, and while only seven are available at present, the other two will be available shortly.

Leaflets will also be available to order in hard copy from our helpline soon – please check back for further details.

Please see the link below:

https://www.cysticfibrosis.org.uk/the-work-we-do/clinical-care/supporting-clinicians/resources-for-clinicians/physiotherapy-leaflets

CF Warrior on a mission

Some of the members of the physio team attended a talk at Exeter university with Josh Jones. As you probably know, Josh is a fitness advocate who has CF. He has completed a number of extreme exercise challenges, most recently 24hours4CF.

He is an inspirational young man and has set up a charity called CF warriors. Their next challenge is a team challenge over 24 hours. He is on Facebook, Instagram and Twitter, and alongside his next challenge is setting up virtual challenges on 29th June this year. His twitter account is @Joshj24 for anyone that wants to follow him or get more motivational information.

Skype clinics

The Exeter CF centre are following the footsteps of the Royal Brompton Hospital (London) in implementing skype facilitated clinics.

https://www.standard.co.uk/news/health/
fibrosis-patients-to-be-treated-at-home-using-new-smartphone-scheme-a3752076.html

Clearly, this isn't appropriate for all of those with CF and it might not be something that those who are, want to participate in. If you are interested, please discuss this with your CF team.

Feedback for the ACPCF

Miriam and Jayne attended our annual conference in Birmingham. The theme was Non-invasive ventilation, the psychological implications of transplant and advanced care planning. The CF Trust in conjunction with the Royal Brompton CF team, have created an excellent leaflet around end of life planning / things to think about:

https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/planning-for-end-of-life

And now for some science...!

There are lots of CF studies going on in both adults and paediatrics at the Royal Devon and Exeter Hospital.

We will shortly be recruiting to the ALPINE study. This is for those aged 3 months to 18 years who have their first ever or new (after more than 2 years of being culture negative) isolated of Pseudomonas aeruginosa in their sputum. This is the first study to evaluate eradication rates achieved with a 28 day course of AZLI (nebulised aztreonam).

The START study is also opening shortly. This study hopes to determine the safest and most effective way to treat infants diagnosed with Cystic Fibrosis (CF) with antibiotics. At the moment infants in the UK are prescribed an antibiotic, usually flucloxacillin, every day to prevent infection with a bacteria (bug) called Staphylococcus aureus (SA).

Although this approach appears to help prevent SA infection, there is a worry that it may make earlier infection with other bugs, such as Pseudomonas aeruginosa (PsA) more likely.

This trial is designed to test if infants with CF are more likely to get an earlier infection from PsA if they are taking flucloxacillin on a daily basis ("Prevent and Treat") or Antibiotics in a more targeted manner ("Detect and Treat"). See http://www.cfstart.org.uk/

We will of course approach you if we feel that you are eligible to enter into one of these. If you would however like to know more about forthcoming studies, please ask your CF team.

Changes to available vitamin K preparation

There is a current shortage of Phytomenadione (Vitamin K1) tablets until at least October 2018. National and European guidelines recommend Phytomenadione over menadione salts, as it is the best absorbed form of Vitamin K supplementation.

In the short-term, we would however advise that you use menadione salts. Please discuss this with your GP or with the CF team if you have any questions.

Gold star physiotherapy service

Congratulations to Our CF physiotherapy team. They have received recognition from their registered body (The Association of Chartered Physiotherapists in Cystic Fibrosis) for their use of full cardio-pulmonary exercise testing (CPET) in annual review assessments.

http://www.csp.org.uk/news/2017/11/01/pspearhead-delivery-gold-standard-cystic-fibrosis-assessment

We are one of the first centres in England to offer gold standard care as routine care rather than as field exercise tests in patients old enough to take part.

Do you have CF related diabetes?

If the answer is yes, then you are entitled to yearly checks at your GP surgery. Your practice nurse should see you to review your blood tests and also to check your feet.

You should also have a yearly photograph of the back of your eye (retinal screen), checking for early signs of any changes due to diabetes. This is important as early treatment protects your eyes if there are problems. Your GP can arrange this.

If you have any questions about this, please speak to the CF team and we can explain further.

How do you feel about physical activity...?

How do you feel about physical activity? Do you *LOVE* it? Or *HATE it? Or something in between* Researchers at the University of Exeter in collaboration with the Cystic Fibrosis Trust are looking for volunteers with between the ages of 12 and 18 years with cystic fibrosis to take part in a photography study. The study will involve taking photographs of anything that can explain how you feel about physical activity For more information please contact Dr Sarah Denford at the University of Exeter on: **01392 725906 or S.Denford@Exeter.ac.uk**

This study has been approved by NHS ethics.

Adonis raises the bar!

For those of you who didn't see this on the CF Trust website – Adonis and his brother were previously under the care of the CF team at the RDE.

https://www.cysticfibrosis.org.uk/news/ac
raises-the-bar

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.