

# CYSTIC FIBROSIS NEWSLETTER

## Contact Details

Children's CF Team,  
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Leicester,  
LE1 5WW

Tel/Fax: 0116 258 6694

Email:  
childrenscfteam@uhl-  
tr.nhs.uk

Mon-Fri 08.00-16.00  
Messages will be dealt  
with within 48 hours.

Emergency and out of  
hours  
Children's Accident and  
Emergency :  
01162520085

## Thank you

A big thank you to all our families that have fundraised for us in 2018-2019- we have been able to purchase equipment for our physiotherapy gym, nebulisers, equipment to enable the team to complete more home visits and school visits. We really appreciate all your fundraising efforts and we hope to be able to spend this on equipment for all of our families in Leicestershire and Kettering area.



Leicester and Kettering CF  
Kids

If anyone would like to hold  
any fundraising events  
please get in contact on  
[www.lkcfkids.org](http://www.lkcfkids.org)

## The CF team

Dr Erol Gaillard, Dr Kamini Jain & Dr  
Imad Ahmed – Consultants  
Dr Ramya Nair – CF Registrar  
Dr Debbie Modha – Consultant Micro-  
biologist  
Dr Kate Roscoe – Clinical Psychologist  
Claire Shentall – CF Clinical Nurse  
Specialist  
Naomi Dayman & Olivia Wardle – CF  
Clinical Specialist Physiotherapist  
Rachel Fox – CF Clinical Specialist  
Dietitian  
Sarah Popple – CF Clinical Specialist  
Pharmacist  
Sejal Patel – CF administrator



## CF website

We have a children's CF webpage that  
has helpful information about the team,  
what to expect when coming into clinic or  
being admitted to a ward, physiotherapy  
videos and how to contact the team.

[https://www.leicestershospitals.nhs.uk/  
aboutus/departments-services/childrens-  
services/childrens-cystic-fibrosis-service/](https://www.leicestershospitals.nhs.uk/aboutus/departments-services/childrens-services/childrens-cystic-fibrosis-service/)

## iNeb Update

For all of our patients that use an iNeb, we have recently been informed that the company are no longer supporting patients that no longer have promixin nebulisers. If this applies to you, please contact the CF team and we will arrange for you to continue with your usual medications that you take through the iNeb. Please try and give us plenty of notice if you need new chambers or more discs as we are having to order from the company and give out so the turn around will not be as quick as it has been previously when ordering from the company directly. Any problems please contact Naomi Dayman on 07487506537/ 0116 2585714 or contact the office if no reply.



## CF Related Diabetes (CFRD)

For children over ten years we are changing the way we test for CFRD. Children will continue to have the OGTT but will also have a Continuous Glucose Monitor (CGM). CGM gives more accurate information about glucose (sugar) levels in the blood which helps us to identify if there are any problems early on. If we are concerned about your child's lung function or weight gain, we may also consider using CGM under ten years.



May– October

It's time to re-start taking your  
salt. For more information see  
the 'Salt in Summertime'  
information booklet.

## Getting your medicines if there's a no-deal EU Exit

The government is working closely with the NHS and suppliers to make sure medicines and medical products continue to be available in all scenarios. The Hospital Trust has taken steps to secure additional supplies of medicines that are only available to us from Europe.

Please keep ordering your repeat prescriptions and taking your medicines as normal.

We will keep you informed if there are any changes and don't anticipate there being many problems with the usual medicines used in CF.

It's very important you don't order more medicines than normal. If you do, then it may mean that other people won't be able to get their medicines as it will have a knock on effect to the suppliers.

The government has asked suppliers of medical goods to build up at least 6 weeks' worth of extra stocks above usual level.

It has also bought extra ferry capacity so medicines and medical products will be prioritised for import for patients to continue to receive medicines on time.

Occasionally, the NHS does experience temporary shortages of some medicines.

If this happens, you will be prescribed the best alternative to your usual medicine or advised by the team of what to do, as happens normally.

More info available from NHS.net at: <https://www.nhs.uk/conditions/medicines-information/getting-your-medicines-if-theres-no-deal-eu-exit/> or from NHS England at: <https://www.england.nhs.uk/eu-exit/>



## Open Access

**The Children's Admissions Unit (CAU) closed last year.**

Your child still has open access to the Children's Hospital this is now via Emergency Department (ED)

## **Out of hours only**

01162520085

01162520156

01162520157

**During normal working hours call the office**

01162587758/6694