



West Midlands Adult Cystic Fibrosis Centre Newsletter

December 2023

Merry Christmas
and a Happy New Year!

From your Cystic Fibrosis team.

Christmas Poem from our Physiotherapy Team

Merry Christmas to all from your CF Physiotherapy team,
2023 went so fast it feels like a dream.
Many thanks for all of your cough swabs and sputum samples each clinic,
These (especially sputum) ensure we know which antibiotics will do the trick.
Thank you for doing your home spirometry before virtual reviews,
It's one of the most important measures we use.
Do call us if you need more supplies of nebs during the festivities,
If you can collect from the hospital it saves the cost of deliveries.

May your Christmas be bright and your New Year be merry,
We will always be here if you need us with advice and solutions at the ready.
May your spirometry be stable,
and we hope that in 2024 you feel able,
to fulfil all your goals,
especially those,
that include persistence with airway clearance,
and nebuliser adherence,
Rob and Charlotte's virtual exercise classes,
or braving the gyms with the new year masses.

Finally,
Thank you to each of you for making our work so rewarding.
We feel lucky to work at this CF centre when we arrive here each morning.
Merry Christmas to all
Ho Ho Ho!



Congratulations to
Physiotherapist Nicky,
who gave birth to a
beautiful baby girl Rosie

Annual reviews

Following the feedback received in our patient survey last year, and a review of our current service, we are changing the way we carry out annual reviews in 2024.

Annual reviews are vital as they allow us to closely monitor your health and clinical trends and allow us to continue to safely prescribe your essential medications. This monitoring may include taking blood tests, checking spirometry (lung function testing), collecting sputum samples, monitoring blood sugars, completing chest X-rays etc., as well as providing education and support.

The results from the survey suggested that most patients want their annual reviews to be completed during their usual CF clinic reviews, rather than attending an extra "Annual Review" appointment.

In response to this, starting in January 2024, the team will aim to complete

your annual review during your usual face-to-face clinic visits. You may find that you are in clinic for a little longer than previously, but hopefully this will mean you need to make fewer journeys to the hospital. If you have any questions or concerns about this new system, please do not hesitate to contact a member of the team.

Are you prescribed a lubricating eye gel or do you purchase these over the counter?

If you do, please read this important information.

The UK Health Security Agency (UKHSA) is investigating a small number of cases of a bacterial infection **Burkholderia cenocepacia** in the UK. These cases may be linked to the use of carbomer containing lubricating eye gels used to soothe dry eyes, though this link has not yet been proven.

People with CF are more likely to become seriously unwell with this infection.

As a precautionary measure, and until further information is available, we recommend that individuals with CF avoid using carbomer containing lubricating eye gels where possible.

Specific batches of carbomer-containing lubricating eye gels branded Aacarb, Aacomer and Puroptics are being recalled as a precaution due to possible microbial contamination.

[You can find out more here.](#)

If you have CF and are currently using eye lubricating gel and are unsure if this is carbomer containing or have any questions concerning this, please speak to your CF Pharmacist – Shradha Shah (Tel: **0121 424 1732**).

For more detailed guidance please look at the CF Trust website: [UKHSA information for CF community – carbomer eye gels \(cysticfibrosis.org.uk\)](#)



Social work

Jacqui, Kaywane and Stacy would like to wish you all a very merry Christmas and a healthy 2024. We hope some of you will have had chance to meet our student, Stacy whilst attending the centre. Stacy is our first ever social work student. We hope to have many more in the years to come.

We know that the cost-of-living crisis has not gone away and we would urge you to contact us if you're struggling financially. There is help there and advice we can give to make life a little easier.

You can contact us by phone **07740066704** or **0121 424 2998** or via cfsocialworkers.email@uhb.nhs.uk



Online group support session

We would also like to remind you all that our online group support sessions are taking place each month with local Psychotherapist, Claire Nash.

If you haven't already joined one, then why not give it a go! You can find out more details about the upcoming sessions here. www.heartlandscf.org/news/online-support-group-for-people-living-with-cf



Festive food

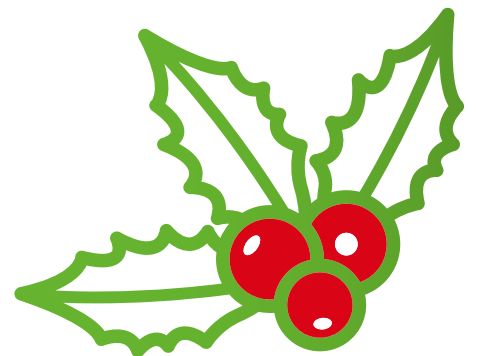
Creon 25,000 supply issues

We are still getting calls regarding the national Creon 25,000 shortage – we know most of you have swapped to a supply of an alternative preparation. The date for this to be resolved has not been confirmed. Please contact us if you have any further issues obtaining a supply of your usual pancreatic enzyme replacement therapy. [You can access our ready reckoner conversion chart here. Creon 25,000 Supply Issues | West Midlands Adult Cystic Fibrosis Centre \(heartlandscf.org\)](#)

Festive food

Food is a big focus for most people over the Christmas period and this can also be challenging for one reason or other. Enjoy the festivities and be kind to yourself.

Remember Christmas food is often higher in fat and sugar. Check the amount of fat and sugar in the foods you eat over the season, as they are probably foods you don't eat all the time. You can make sure your enzyme and insulin dosing is as accurate as possible so you can continue to join in with all the festive fun!



Festive wishes from Claire, Katie, Liz and Jo

Merry Christmas

from all the Dietitians!

Research

Have you heard about our new research project?

Jo Barrett, CF Dietitian has been awarded an NIHR (National Institute for Health and Social Care Research) Doctoral fellowship to develop a diet and physical activity programme with people living with CF on CFTR modulator therapies.

[You can find out more about the project and how you can be involved here.](#)

Could you help decide how we deliver this project by answering six quick questions?

[Complete our anonymous survey here](#)

Share your views on this research with our online discussion group on 18th January 2024.

Jane and Carly are Lead Research Partners for this research project. In this role they will be working together with Jo Barrett to plan how the research is delivered. They will be holding a 'drop in' session to chat to you about your views on this research and about their experiences of weight changes since CFTR modulator therapy on 18th of January. We will send the link to this online meeting by text message in January. We would welcome involvement from all of you, as well as families and carers of people living with CF.

[Find out more here](#) or email Jo Barrett for more information about the project:

joanne.barrett@uhb.nhs.uk



Jane B



Carly Beale

CF Research Opportunities

Thank to all those who have taken part in clinical research this year; your contributions are greatly appreciated! Research opportunities can be discovered via the CTAP Trials Tracker on the CF Trust website. Here are a few of the studies ongoing at Heartlands Hospital:

→ NIHR BioResources: Rare Diseases

The BioResource provides a unique and ground-breaking opportunity to join up existing clinical data registries, providing information on the characteristics of CF, with genetic data. Ultimately, this will drive the development of more targeted CF therapies and large-scale clinical trials.

After signing a consent form, participants will be asked to provide a small blood sample and share their contact details with the research team. This information will be stored and used to invite them to future research studies investigating CF and potential treatments.

→ CF STORM

CF STORM is a study which aims to find out if stopping certain daily nebulisers (DNase, hypertonic saline or both) is safe for people with CF taking Kaftrio. As part of the study, individuals are randomly allocated to

either stop or continue their DNase/hypertonic saline for 52 weeks and will also be asked to complete some questionnaires during this time. There is no requirement for additional clinic appointments or blood samples.

For more information on CF STORM visit the website by scanning the QR code:



If you are interested in participating in either of these studies or have any questions about clinical research, please get in touch with our CTAP co-ordinator Aoife Neal via email:

Aoife.Neal@uhb.nhs.uk

Want to make a difference to people living with Cystic Fibrosis in the West Midlands?

Become a Heartlands Cystic Fibrosis Centre Charity Trustee!

The Heartlands Cystic Fibrosis Centre Charity supports patients who are cared for at the West Midland's Adult CF Centre.

What is a Trustee?

A trustee is an unpaid volunteer who sits within a group of Trustees, who help ensure the Charities' success in fundraising and supporting patients, but also ensuring that the charity works effectively and within the laws required. [What does being a Trustee involve? Find out more here](#)

Over the Christmas period, a normal CF service will run, with the exception of weekends and bank holidays. If you are unwell over the weekends and bank holidays during the Christmas period, you will need to contact Ward 26 and speak to the nurse in charge: ☎ 0121 424 0226. For more information visit www.heartlandscf.org