



West Midlands Adult Cystic Fibrosis Centre Newsletter

www.heartlandscf.org Autumn 2024

Hello!

I hope you all had some sunshine this summer as we go into the autumn term.

Welcome back to Dr Laura Jones, who returned from maternity leave in June. I'd like to update you on research opportunities. Our CF team are doing lots

of clinical research and we are passionate about enabling our patients to take part in the latest trials.

– Dr Jo Whitehouse

The research projects that we are recruiting to at the moment

HIT CF CHOICES: A study to look at different modulators for those people with CF who don't have a suitable genotype for Kaftrio/Ivacaftor. One of our patients (of only three in the UK) has been chosen to take part in this study.

YOGA-CF: Aims to identify what effect the practice of yoga has for adults with CF on respiratory health-related quality of life. People with CF are recruited to 12 weeks of yoga or usual clinical care.

Coming Soon...

Recode: A study to find out whether nebulised mRNA can correct CFTR in adults with CF who have genotypes not suitable for current modulators. We will update you when the trial opens and will be approaching people with suitable genotypes to take part.

More Life with CF Study: A study about what people living with Cystic

Fibrosis (CF) eat and how active they are on Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) modulator therapy.

Jo Barrett, CF Dietitian, will shortly be inviting patients to take part in a study which aims to find out what people with CF eat, how physically active they are, and what influences their eating pattern, food choices and their physical activity habits.



The results will inform the development of a programme to support people with CF to manage their weight. It will be co-produced with people living with CF and CF Health Care Professionals.

Watch this space to find out how you can take part in this study and opportunities to work with Jane and Carly our lead CF partners on developing this programme.

You can read Jane and Carly about Jane and Carly's stories and their involvement in the project [here](#).

You can find out about what co-production is [here](#).

Fancy a chat with Carly and Jane?

They will be holding an informal online chat with others who have CF, a chance to swap stories on 6th November at 7pm. You can join the session [here](#).

Social Work Team

It has been a busy few months for us social workers. Kaywane has completed his PE1 training at Birmingham University and now is accredited to have students on placement with us as part of the team.

The next student will arrive in January 2025. Jacqui completed the Birmingham

Half marathon in May and raised nearly £900 for the Heartlands CF charity.

We are also really excited to have launched the next programme of online group support sessions run by Claire Nash.

The topic sessions vary from 'Body image & CF' to 'The Young ones' – a session for



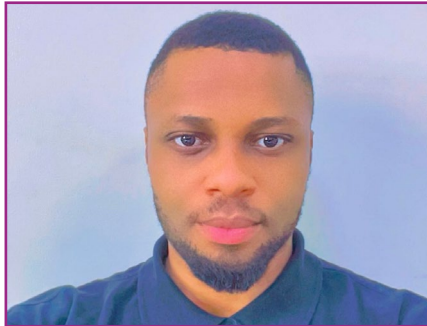
the under 25's. All details are on the [website](#) or please contact us for more information via email:

✉ jacqui.wainwright@uhb.nhs.uk /
✉ kaywane.wickham@uhb.nhs.uk
or by phone on ☎ **07740066704**.

Dietitians

Welcome to our new team member Chidiebere Ukwuoma (Chidie). Chidie is the newest member of our team. He has worked as a dietitian in Nigeria for several years, in general medicine, before joining our team in May.

Welcome Chidie!



Administration and Secretarial Team

In June we said goodbye to Denise Moore who retired after many years working at the centre. We also recently welcomed some new people to our team:

- **Kalvin Mak** – CF Database Administrator



- **Izaskun Berrade** – CF Physio Admin and CF Database Coordinator
- **Henna Azam** – Medical Secretary Supervisor and Dr Whitehouse's secretary

Just a quick reminder that if you have a change of address, email address, your phone number or GP please let us know so we can update your records.

If you need to get in touch with our medical secretary team, they can be contacted by

✉ cfsecretaries@uhb.nhs.uk or
phone ☎ **0121 424 1746**.

Creon Supply Update

We are aware that many of you are having trouble obtaining a supply of your usual pancreatic enzymes (Creon) from your community pharmacy. This is a national supply issue.

If you are struggling to obtain a supply of pancreatic enzymes, find out what to

do [here](#) or alternatively contact the CF Dietitians on

☎ **0121 424 1796** or

☎ **07794 375776**

Please take a few minutes to complete the [CF Trust survey](#) about your views and experience of the current Creon and pancreatic enzyme supply issues.

Kaftrio Bloods

If you are prescribed Kaftrio, please remember that there is a minimum requirement to have your liver function checked with a blood test, once a year for your Kaftrio prescription to continue.

If any of these blood tests are abnormal it may be necessary for your bloods to be monitored more frequently.





European Cystic Fibrosis Society Conference 2024

In June 2024 several members of the CF Team attended the 47th European Cystic Fibrosis Conference in Glasgow. Many of us

participated in oral and poster presentations of work and research we completed. Attending this conference allows us to learn

about current research, new treatments, and network with other CF centres and healthcare workers worldwide.

Heartlands Fundraising

You can now support Heartlands Cystic Fibrosis centre by buying our [merchandise](#)! We have pens, trolley coins, water bottles, mugs, insulated cups, tote bags, sports t-shirts and running vests.

If you would like to purchase any of these items, just ask a member of the



team, they will be available to purchase in clinic.

Do you have any fundraising ideas?

We'd love to hear about them! Contact our [Charity Administrator](#) who can support you with fundraising events. You can find out about our current fundraising events [here](#).

Diabetes

Freestyle Libre Update

The [Freestyle Libre 2](#) Plus is now available for people with Birmingham GP's. It still

works with the current Freestyle Libre Link app and Freestyle Libre 2 reader but has 15-day sensor wear duration.

