



West Midlands Adult Cystic Fibrosis Centre Newsletter

www.heartlandscf.org Spring 2025



Spring has finally arrived and so did some sunshine

We have lots of updates for you, including research studies we are recruiting to and a survey on digital health monitoring. Holiday season will soon be here and if you are planning a trip this year, please read our top travel tips.

Hellos and Goodbyes



Michael and Tom

Welcome to our **new rotational physiotherapists Michael and Tom.**

Welcome to our **new medical secretary Bethany Harding.**



Katie

Good bye and Good Luck to CF Dietitian Katie who has worked at the centre for 5 years and is moving to Coventry University to teach the next generations of dietitians.

Research trials we are now recruiting to....



More life with CF Study

Would you be willing to share your story about your experience of managing your weight since being on Kaftrio/Kalydeco/Symkevi, Jo Barrett, CF Dietitian, is currently recruiting participants to a research study that aims to explore the experience of weight gain on CFTR modulator therapy in people living with CF. To find out more and if you are eligible, please contact Jo on **07867143787** or email joanne.barrett2@nhs.net or go [to our website](#).

reducing respiratory exacerbations (chest infections) in other lung conditions. The aim of the study is to see if this medication reduces how often people with CF have a chest infection. The study involves 10 visits to Heartlands Hospital every 8 weeks for up to 80 weeks. Participants will be reimbursed for their time and travel expenses. To enquire about taking part in this study, please contact a member of the team.

Airtivity trial

We are seeking volunteers for the trial of a new anti-inflammatory treatment. A similar treatment has been found to be successful in

Online pain survey

Online survey to explore the experience, occurrence, severity and various types of pain experienced by adults living with CF in England. [Find out more and how you can participate here.](#)

Fancy a chat...

Fancy chatting to other people with CF? Jane and Carly will be holding more online chat events.

Please email joanne.barrett@uhb.nhs.uk, to join the mailing list and be invited to the next event.

Digital health monitoring

We want to hear your thoughts on how we can improve CF care.

We're interested in your views on using digital tools (like apps or online programs) to monitor your health and how these fit (or could fit) into your care. Your feedback is really important to us and will help us develop better services for everyone. **Please complete the short survey by using the QR code.**



Social Work Team news

We know that the cost of living continues to be high, and financial pressures do not go away just because we are not in the winter months!

We would urge anyone who is struggling to give us a call to discuss options available on **07740066704** or to email us: **jacqui.wainwright@uhb.nhs.uk** or **Kaywane.wickham@uhb.nhs.uk**

We are also really excited let you know that we have now published



our next programme of online group support sessions run by Claire Nash (a local counsellor with experience of supporting people with CF). **[All details are on the website here](#)** or please contact us for more information on the details given above. If you've been thinking about giving a session a go, why not join one soon?

Planning a holiday?

If you have a holiday booked there are a few things to consider, before you go. It's important to allow plenty of time to prepare for your holiday as some things can take several weeks to organise. Please contact our secretarial team to request a travel letter which will detail your medical conditions and medication, well in advance of your holiday. They will need a minimum of 2 weeks' notice.

The team can be contacted by email: **cfsecretaries@uhb.nhs.uk** or phone **0121 424 1746**.

If you think you may need any additional health assessments for travel, once again please speak to a member of the CF team well in advance of your travel dates and they will be able to advise you.

[Read our top tips on preparing for your trip and staying well.](#)

[The CF Trust also have lots of useful information about going on holiday.](#)



Can you help our tree to grow ?

The West Midlands Adult Cystic Fibrosis Centre, at University Hospitals Birmingham NHS Trust Heartlands Hospital Birmingham, has been very kindly donated a spectacular 'Tree of Inspiration' to help raise funds for our CF Centre. **[Find out more here and how you can support the centre by purchasing a leaf here.](#)**



Dietitian Virtual Clinics

Do you feel you would benefit from more time to speak to a CF dietitian 1:1 outside of your regular clinic appointments?

We now have a dietitian only virtual clinic each week. [Find out more here.](#)