WEST MIDLANDS CF CENTRE NEWSLETTER 2020

West Midlands Adult Cystic Fibrosis Centre

www.heartlandscf.org for info on our service and 'Heartlands Cystic Fibrosis Centre' charity

CONSULTANTS

We have had a very busy year at Heartland's Hospital. When 'lockdown' started in March 2020 we switched to virtual investigations, virtual clinic appointments and home spirometry monitoring. Kaftrio was licensed in August 2020 and from September we were able to start prescribing for our patients, a process which took three months for nearly 300 patients. Dr Nash left the Trust in October 2020. Thank you from the team to Dr Nash for his kind and caring input to our patients over the years and in particular for leading the clinical trial work for CF. Dr Laura Jones started work as our new CF consultant in December 2020 and is expecting her first baby in January 2021. Double congratulations Laura!

Merry Christmas to you all and best wishes for a happy, healthy 2021

CF SPECIALIST NURSES

A poem by the CF Nurses

Christmas, I can't believe it's here
A year which was full of mixed cheer
COVID came, Oh what a nightmare!
But we were still here to care
Introduced were virtual clinics
Both telephone and video
This gave us a chance
To catch up and say hello
Kaftrio, a new drug by name
A COVID vaccine finally came
We hope this allays all our fear
So Merry Christmas, hope to see you in the
New Year! (Mob: 07971 329933)

Over the Christmas period, a normal CF service will continue with the exception of weekends and bank holidays. If you are unwell over the weekends and bank holidays of the Christmas period please contact ward 26 on 0121 424 0226 and speak to the nurse in charge.



PHYSIOTHERAPY TEAM

What a year! 2020 has brought with it so much change and we have been working hard to adapt our service to the new situation. Issuing home spirometers and providing training, organising postal sputum specimen packs and doing video and telephone consultations have been a large part of our work.

Rob and Nicky have worked very hard to set up 3 times weekly virtual exercise sessions; spin/exercise bike, strengthen/stretch and cardio/boxercise. There is a class to suit all but if you would like some one- to- one sessions to get you started please do get in touch. Although we have enjoyed catching up with you virtually, we've really missed seeing you all face to face. Let's hope we can do this in 2021!

We wish you and your families a Merry Christmas and a Happy New Year. We hope that our ward carol singing will be allowed again next year!

The CF Physio Team (Mob: 07772 137613)

CF DIABETES NURSE

A Sweet message from your friendly CF Diabetes Specialist Nurse 'Show you care by sharing your cookies and all things nice with Santa!!!!' Have a Merry Christmas and a Happy New Year to you and your family. Best wishes, Harbinder (07772 137600)

DIETITIANS

Have you seen the #12DaysofCFChristmas Countdown over on our twitter @CF_Dietitians? Head over and learn more about CF nutrition whilst counting away the time until the Big Day!

All the CF dietitians are wishing you a joyful & merry (but not too merry!) Christmas! Enjoy the food (we know that's our favorite part) and cherish the time you have with whoever you are spending this festive period with. We will see you all in the New Year! (07794375776)

PHARMACY

2020 has been a challenging year. However in the midst of it all, we had fantastic news with approval of gene modulator therapy – Kaftrio by NHS England! Wishing all our patients a Merry Christmas and a Happy New Year! We look forward to seeing what further exciting developments there will be for 2021! (0121 424 1732)

Secretarial and Admin Team

2020 has certainly proved to be a challenge for us all with new ways of working and new systems to deal with. However the secretarial and admin team remain committed to ensuring all your correspondence and appointments are delivered to the appropriate people in a timely way. We also remain a point of contact between you and the rest of the CF Team should you need us.

Useful contact numbers for you are:-

CF Centre Manager 0121 424 0086
Outpatient Appointments 0121 424 1693
CF Secretaries 0121 424 1746
0121 424 1669
0121 424 3007

Wishing you all a very Merry Christmas and here's to a brighter and safer 2021

PSYCHOLOGISTS

We have missed seeing you face to face this year but have been thinking about you all during this challenging time. Hope you are doing ok but please do let us know if you are struggling. We are still here!

Wishing you and your loved ones a very Merry Christmas Georgina (0121 424 2530) and Anna (424 2987)

CF SOCIAL WORK

We have missed seeing you all this year and we hope you are keeping well through these difficult times. We have welcomed a new social worker this year, Kaywane Wickham who some of you may have seen on your virtual clinic appointments. Please feel free to get in touch with us with any queries you may have relating to finances, work or anything else and we'll do our best to help. And finally, Merry Christmas and here's to a brighter 2021. (07740066704)

CFHEALTHHUB

We are very excited to now have 120 adults at the centre using CFHealthHub which has been extremely useful in virtual clinics. Having adherence data, lung function and weight trends available on one platform helps us to provide more individualised support with your nebulised treatments. If you would like more information about getting a brand new nebuliser that links to a personalized app on your phone please contact jocelyn.choyce@heartofengland.nhs.uk

PPI GROUP

We are excited have launched the West Midlands Adult CF Centre PPI (Patient and Public Involvement) Group recently which will be used to gather feedback and input from patients regarding; the services in general, how we spend money raised by the charity and ensuring the research studies we develop are worthwhile and feasible. If you are interested in taking part please contact Jo Barrett joanne.barret2@nhs.net or Jocelyn Choyce Jocelyn.choyce@heartofengland.nhs.uk

