



The last few months have been very challenging but together we have successfully overcome the peak in COVID infection and made the best out of a difficult situation. In March we implemented radical changes to the way we work to ensure a continuation of high standard of care. It has been wonderful working with you all and we have appreciated your engagement and encouragement at this time. We have never closed our doors, and have maintained inpatient and outpatient care throughout COVID. We have found video, text, and phone consultations highly effective and will continue to build this technology into our future clinical practice. **Please download the Whereby App as it will make your video consultations easier.** If you would be interested in accessing your blood results online please discuss this with the doctor at your next appointment.

This month sees the relaxation of shielding, and we know that this will be an anxious time for many of you as you navigate what that means for you. There are lots of unknowns and not many answers - the only thing for sure is that we are facing this together, and the Team are here to offer support and guidance if you need it. Social distancing, wearing a mask and hand washing is going to be with us for a while. We will be restarting our face to face clinics in August—there will only be seven slots available in each clinic, so that each room is only used once. It is really important that you come at your appointment time so that we can limit any potential for cross infection. Please wear your mask when you arrive and, if you are able, keep it on until we do your lung function. We will be wearing the appropriate PPE as well.

We look forward to seeing you all soon!

EFFECTIVE TREATMENT FOR ALL

We are fully committed to finding effective treatment for all PWCF.

We know that it is a difficult time for those patients who do not have eligible mutations for the new modulators.

Clinical trials are ongoing, and we will be in touch with any exciting new prospects. #watchthispace

KAFTRIO

The final list of eligible mutations for Kaftrio treatment has not yet been finalised by NHS England. We should find out soon and will keep you informed. We are planning how we can start everyone who is eligible for Kaftrio in the swiftest, safest and fairest way possible. In an ideal world we would love to start everyone on the same day—but that is not possible. We will be in touch with appointments for you as soon as we have the go ahead. Again—you will not all hear from us at the same time—please be sensitive towards other PWCF who may have to wait longer, or are not eligible for treatment.



NEW APPOINTMENT

Giulia will be taking up her new role as Consultant in Cystic Fibrosis and Primary Ciliary Dyskinesia in August. We want to take the opportunity to congratulate her on her appointment, and to formally welcome her as a permanent member of the team.

CF ZOOM EXERCISE TIMETABLE

Table with 5 columns (Monday to Friday) and 2 rows of exercise sessions. Monday: Exercise Session 10am. Tuesday: Exercise Session 10am, ZOOMBA 2pm. Wednesday: TRIAL 8am Morning Exercise Session, Changeable weekly sessions 2pm. Thursday: Exercise Session 10am. Friday: (empty)

A huge thank you to everyone who sponsored us for our virtual cycle ride. It became a whole team event—we covered a massive 4250km and raised £1327 for Cystic Fibrosis Care



Thank you to those of you who responded to the survey about our ZOOM exercise classes. We have adjusted the timetable so that it is sustainable for us, and to give us some flexibility to try new things! If there is anything that you might like to try message us—we can't guarantee that we can do it, but you won't know if you don't ask!

Contact the physios for log in details