Carly's Journey

Hello! My name is Carly, I'm 37 years old and I am a patient at Heartlands with CF and Diabetes. At home I am married, have a 13-year-old son, a very cute Cockapoo and I work full time as an accountant. I love to travel and explore new places, as well as catching up with friends at every opportunity. My busy lifestyle motivates me to take care of myself both physically and mentally, so that I can live life to its fullest making as many memories as possible along the way.

Taking part in and supporting research is something I am always keen to do. Back in 2013, I was 1 of 44 people in the world to take part in the first trials for the CF Modulator called Orkambi. The trial had such a positive impact on my health that I led the CF Trusts' national "Stopping the Clock" campaign for access to precision medicines, delivering a 100,000-signature campaign to 10. Downing Street. As you will know, the success of the trial and campaign led to further research, development of and access to Kaftrio.

I feel extremely lucky to have been taking Kaftrio since September 2020, as it has enabled me to experience some positive physical and mental health benefits. Although, at the same time I have also been navigating challenges such as an overwhelming amount of change, processing stored up emotion and getting to know the post Kaftrio version of me. The biggest challenge of all being my newfound ability to gain a huge amount of weight!

At the beginning of 2023, I was completely fed up with myself and embarked on a lifestyle change to improve my mental health and overall fitness. Over a period of 4 months, I improved my lung function and diabetes management, as well as losing over 2 stone in weight. It wasn't easy and my personal experience is the reason I took on the role of lead partner in this programme. Not only is the role a continuation of a research journey that started for me 10 years ago, but it's also an opportunity for me to further support those in the CF community who would benefit from the development of a much needed accessible and effective weight management programme.

I am very proud to be part of such an important collaboration and I cannot wait to see its success!