

## Will the dose of flucloxacillin change during the study?

On their third birthday, the dose of flucloxacillin will increase to 250 mg twice a day.

## What happens if my child needs an extra antibiotic?

If your child develops a cough or grows a bug from a respiratory sample, your CF team may advise giving an extra antibiotic. You should continue the flucloxacillin unless advised otherwise by your CF team.

## What happens at the end of the study?

When your child is four years old they will be at the end of the study. Your CF team will discuss treatment options with you at that point.

*During the study you will attend the hospital for standard outpatient appointments and the CF team will record your infant's progress on the national registry.*

*If you give any courses of extra antibiotics it will be helpful for the CF team if you can make a note of the start and finish dates so that they can record them accurately on the Registry.*



The cystic fibrosis (CF) anti-staphylococcal antibiotic prophylaxis trial (CF START); a randomised registry trial to assess the safety and efficacy of flucloxacillin as a longterm prophylaxis agent for infants with CF

## Parent/ Legal Representative Support Leaflet "Prevent and Treat"

*Thank you*  
for enrolling into  
CF START

Your child has been allocated the  
following treatment:

## *“Prevent and Treat”*

---

### **What does this mean for you and your child?**

Infants in the *“Prevent and Treat”* group of  
this study will be prescribed an antibiotic  
which they should take twice a day.

### **What is the name of the antibiotic and where do we get it from?**

The antibiotic is called “flucloxacillin” and  
you will be prescribed this  
antibiotic by your GP, who will also provide  
a repeat prescription for you. You will be  
able to get the antibiotic (along with the  
other CF medicines) from your local  
pharmacy.

---

### **What is the dose of the flucloxacillin?**

The dose is 125 mg twice a day.  
Flucloxacillin is a suspension (liquid) and  
there are a number of different brands  
available. For most brands, this will be  
equivalent to 5ml volume of medicine.  
Some brands are more concentrated and  
for those brands, 125 mg would be  
equivalent to 2.5ml volume.

### **What if my baby doesn't like flucloxacillin?**

Parents report that flucloxacillin  
suspension is not a pleasant taste, but  
with some perseverance most infants will  
eventually accept it (and some even like  
it!). Parents report this can take two or  
three weeks. If you are struggling, talk to  
your CF team and they will give you  
advice. It may be worth trying different  
brands, which may have different tastes,  
or trying a brand that is a stronger  
solution, so you only need to give the  
2.5 ml volume. Finally your CF team may  
advise giving the flucloxacillin by a small  
soft syringe so that it is easier to deliver  
the liquid towards the back of the mouth  
for swallowing.