

## EXCELLENCE OF CARE SURVEY

Both the pediatric and adult Cystic Fibrosis centers are participating in the Excellence of Care project (XoC). After your clinic visit, in-person or virtually, you will be invited to share your feedback about your appointment through a survey sent via text message or email.

We check the survey results quarterly to see your feedback and determine what changes we can make to clinic to better serve you.

We want to hear everyone's voice, but at last review out of 66 surveys sent for pediatrics only 14 responded. The adult team received 18 responses out of 79 surveys sent. Please take a few moments to share your thoughts by clicking the link in the email or text message you receive. The text message will come from the phone number 1-844-293-0122.

Please help us, help you!



## CF RESEARCH UPDATES

The research team here in Tucson has been busy with ongoing, new, and upcoming trials. We are currently involved in several Vertex trials including the conclusion of Vertex 105—the original Trikafta trial, Vertex 112—the Trikafta trial in children ages 2–5, and Vertex 121 102/103—a new triple combination therapy that has some elements of Trikafta as well as some new portions. We are also actively recruiting adults for our Aridis study which is a new inhaled therapy for Pseudomonas. We are excited to be in the start-up process for a new gene therapy trial, the first we have done here in Tucson. Soon we will also be starting a trial looking at novel ways to measure nutritional health in CF and a trial looking at choices of IV antibiotics for individuals in the hospital. You might also get asked to participate in some studies looking at quality of life in the Trikafta age because we want to better understand the true impact of this drug on our families.

Overall, the TDN and CFF are investing in a lot of new trials for gene therapy, for infection and for inflammation, the key areas where we really need new therapeutics. We look forward to being able to offer more of these new trials in Tucson.



# NEWSLETTER

September 2022

## UPCOMING EVENTS

### **December 12, 2022 at 6PM:**

Join us for the CF Caregiver Holiday Party. Watch for details on the Facebook page (link and QR code right) or ask in clinic.

### **April 15, 2023:**

We are hosting another CF Education Day. Mark the date on your calendar and watch for details as we get closer.

## STAY CONNECTED ON FACEBOOK

Connect with others in the Tucson CF Community and learn of upcoming events by joining the Tucson CF Families. To join, scan the QR code with your smart phone or using the following link:

[www.facebook.com/groups/TucsonCFFamilies](https://www.facebook.com/groups/TucsonCFFamilies).



The University of Arizona  
Pediatric Pulmonary Center  
1501 N Campbell Avenue  
Tucson, AZ 85724-5073  
520-626-2962/Fax 520-626-5942  
0709-3036570 PPC