

CF Adult Center PFAC

Fast Facts

- PFAC = Patient & Family Advisory Council
- 6 CF patients compromise the PFAC
- Acts as a sounding board for initiatives within the clinic
- Some initiatives just need a brainstorming session
- Other initiatives can benefit from people with patient experience

Project 1: Advanced Care Planning

- Everyone is about to die at some point- having CF, that might come a little sooner for us!
- However, no matter when it happens, ***Advanced Care Planning* gives your care team the best chance to act in the way you prefer to be cared for** in a case where you can't advocate for your own care.
- Currently ~ 10% of the CF Clinic's patients have a documented plan
- GOAL: end 2024 with 90% of patients having a documented plan

Project 2: Pediatric-to-Adult Transitions

- Moving into adult care with CF is a large step in a patient's life
 - You have to start managing your medicines
 - You have to decide how much to tell the clinic team
 - You have to start scheduling your own appointments and making choices in your own care
 - You have to get used to calling insurance to figure out which pharmacy you're allowed to fill your medicines at because even though Trikafta can be filled through Walgreens Community, Pulmozyme is just too awesome and needs to be filled at CVS Specialty to then be shipped to normal CVS.
- We're looking to give another outlet for patients going through the transition to ask questions without the pressure of a parent or clinic staff.
- Our goal is to provide a mentoring chance for patients to more comfortably navigate this big step in their CF care
- In-progress work is determining how structured or unstructured this is.

Cough at Us! (Not actually please...)

- Email us with questions or ideas for how we can better represent the whole Stanford CF community.
- Join us on the PFAC! Talk to Kate about getting involved- it's not just for patients, but can also include caregivers and family members who fight the disease alongside patients
- kyablonsky@stanfordhealthcare.org