

# NEWSLETTER

## 5 WAYS TO PARTNER WITH YOUR CF CARE TEAM



The Tucson CF team is working to improve partnerships with our patients and families. The CF Foundation has some tips to help you partner with your CF care team to create a treatment plan that fits your life.

### 1) Ask for Help When Adjusting Your Care Plan

Your team can't improve your care if they don't know what to help you with.

- I don't like how these vitamins taste. Is there another type I could try?
- Doing treatments after work is hard. Can I do treatments at a time when I'm not as tired?

### 2) Share What's Going on in Your Life

Life changes so your care plan should change to keep up with you.

- I just started a new job and haven't been sleeping much lately. What are your thoughts?
- We adopted a dog last week. I'm wondering how to fit him into my exercise routine.

### 3) Communicate Between Clinic Visits

Managing your CF happens in daily life, so why wait until clinic day to ask questions?

- I've been getting more headaches after my last antibiotics course. Are the two related?
- I'm not sure if my nasal rinse is working. How do I know if I'm doing it right?

### 4) Invite Different Perspectives

You may not always notice small changes in your health or how your surroundings affect you.

- I can't tell the difference, but my sister thinks my cough sounds wetter. Can we call her?
- There may be something going around at school. Should we check with the school nurse?

### 5) Approach Difficult Conversations with Respect

You and your care team are motivated by a shared goal: improving your health.

- I'm really upset about these results and need a moment to process before discussing.
- Being a vegan is important to me. Can we look at these ingredients for better substitutions?

For questions on how to partner in care, email [PSDCteam@cff.org](mailto:PSDCteam@cff.org) or visit [cff.org/PartnersInCare](http://cff.org/PartnersInCare)

## SHORTENED POST-CLINIC SURVEY

The CF Foundation has been conducting a Patient and Family Experience of Care Survey (PFEC) by having a third-party company call patients and families after clinic visits twice a year to get their opinions about their experience.

Recently, they have shortened the PFEC survey by reducing the number of questions. We appreciate you taking the time to participate, as your feedback helps us improve your clinic experience.

## CO-PRODUCTION INTERVIEWS

The Tucson CF Center staff, patients, and family partners have teams up to improve patient care, and we're looking for research study participants.

We will be calling randomly selected patients, parents, and teens for a telephone interview about your challenges with routine clinic visits. If you do not receive a call and are interested in participating, please call Katie Katsareli at (520)490-9802 or email [katsarel@email.arizona.edu](mailto:katsarel@email.arizona.edu).

Interviews will be scheduled at your convenience, and participants will receive a gift card.

An institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.



## UPCOMING EVENTS YOU DON'T WANT TO MISS

### **ResearchCON - February 28, 2019 - Virtual Event**

People with CF and their family members age 16 and older are invited to join this free online event on Thursday, February 28 from 7-10:30 p.m. ET.

ResearchCON is the first virtual event dedicated to CF science and research. Clinicians, researchers, and community members will co-lead this online event to share the latest around infection research with the CF community.

The event features renowned CF clinicians, keynote sessions, panel discussions with Q&A, small-group video breakouts and group chats. Topics include the state of Cf infections and treatments; an introduction to the facts and fictions of CF infections; NTM myth-busters; CF and the gut Microbiome; antimicrobial resistance in CF; and more!

Visit [cff.org/ResearchCon](http://cff.org/ResearchCon) for more information and to register.

### **Tucson CF Education Day - April 27, 2019 - Kiewit Auditorium at the AZ Cancer Center**

The Tucson CF Education Day is right around the corner. On April 27 from 9:30-2:30pm we are inviting family and friends of people with CF to join us for a fun day of community building and education.

The event will feature presentations about integrative medicine presented by Dr. John Mark; alternative medicine presented by Dr. Hanna Phan; and quality improvement and clinical research updates. There will also be a community building activity led

by a CF parent to start the day and facilitated table discussions between presentations. In addition to exciting talks and fun activities, there will be a continental breakfast, lunch, raffle prizes and vendor tables. Child care reimbursement and travel reimbursement are available upon request.

Please RSVP to [ajsharpe@email.arizona.edu](mailto:ajsharpe@email.arizona.edu) if you will be attending. We look forward to seeing you there!

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