

NEWSLETTER

JOIN US AROUND TUCSON FOR CF SUPPORT GROUP

Support group is a time for family members and friends of CF patients to spend time and create community. This year we are moving support group around Tucson to enjoy different locations and activities together. Support group is always from 6pm-8pm on the 4th Monday of every other month. The dates and locations are as follows:

February 24, 2020
Union Public House
4340 N. Campbell Ave.

April 27, 2020
Sabino Canyon Recreation Area
5700 N. Sabino Canyon Rd.

June 22, 2020
Beyond Bread
6260 E. Speedway Blvd.

For more information or for childcare reimbursement for support groups, please email Amanda Sharpe, our Family Partner, at ajsharpe@email.arizona.edu. You can also join the local CF community Facebook page at <https://www.facebook.com/groups/tucsoncffamilies/> for updates about all of our CF events including support groups, education dinners and education days.

HELP IMPROVE PATIENT CARE AND THE CLINICAL EXPERIENCE

We currently have two opportunities for patients and families to help improve patient care and clinical experience:

The Patient and Family Advisory Committee (PFAC)

The Patient and Family Advisory Committee (PFAC) works to maintain a collaborative partnership with the Tucson CF Care Team by engaging in decision making, facilitating support, creating an empowering environment, and ensuring quality of care for patients and families/support systems. This committee meets the second Monday of the month from 6-7:30PM near the intersection of E. Speedway Blvd and N. Wilmont Rd. A one-year commitment to the PFAC is required. All are invited to join.

The Quality Improvement Team

The Quality Improvement Team is made up of the Tucson CF center pediatric and adult CF teams, as well as CF patients and family members. It works to improve the care provided to patients through systematic and institutional change. This team meets every Thursday morning from 8-9AM at Banner University Medical Center. Patient and family team members are compensated for their time.

To get involved, please email ajsharpe@email.arizona.edu.

ARE YOU RESPONDING TO THE 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. The feedback you provide through these surveys helps us improve your clinic experience. Currently, we are not getting enough respondents to be able to use our data for improvement efforts. We are hoping to have more patients and families participate in order to effectively use this data for your benefit. If you have any questions about the post-clinic surveys or are not receiving a phone call, please let us know in clinic!



PEDIATRIC PULMONARY CENTER

ONLINE RESOURCES

www.uappc.peds.arizona.edu
The Pediatric Pulmonary Center's website

www.CysticLife.org
A social network for the cystic fibrosis community

www.CFF.org
The Cystic Fibrosis Foundation website

CONTACT INFORMATION

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CFF GREAT STRIDES 2020

Join the Tucson CF Community at the CFF Great Strides Walk on May 2, 2020 at Reid Park, Tucson, AZ.

For more than 30 years, Great Strides – the Cystic Fibrosis Foundation's largest national fundraising event – has supported the Foundation's mission to cure cystic fibrosis, a rare, genetic disease that has robbed people of tomorrows, progressively limiting their ability to breathe and tragically shortening life.

Great Strides provides a fantastic opportunity for family, friends, students, and colleagues to come together and make a difference for those with CF. The event harnesses the power of people with a shared vision and encourages collaboration, team building, and leadership, as we collectively take steps to find a cure.

Registration is free, but walkers are encouraged to raise funds. Your support will help the CF Foundation pursue new therapies and provide vital support to meet the needs of our community. We are committed to exploring all science that has real potential to deliver a cure and the funds raised at Great Strides will help us reach our goal.

Sign up to walk in Great Strides today by visiting <https://fightcf.cff.org/>