

[Para boletín del PAC de Enero en español haga >](#)

## The CF PAC is now the CF FAC

As Children's Health<sup>SM</sup> continues to transform into a leading consumer centric pediatric health system, we know the success of our effort relies on one indispensable element: understanding the experiences of our patients and their families. As we move forward with new changes you will notice our group will now be called the Cystic Fibrosis Family Advisor Council (CF FAC).

Children's Health created a structure for all patient and family advisor groups under the [Family Advisor Network \(FAN\)](#). FAN allows us to partner with those who share the passion for making life better for children. FAN has seven groups under their network umbrella including:

- Family Advisor Boards (FAB)
- Family Advisor Councils (FAC)
- Family mentors
- Virtual advisors (FAN Insiders)
- Hospital committee/council advisors
- Short term project advisors
- Story sharing advisors

While our name is changing, the work that we will continue. If you have questions about joining any of our other FAN groups, please email [FAN@childrens.com](mailto:FAN@childrens.com).

## COVID-19 update

Much of the United States is experiencing an increase in COVID-19 cases, and the Centers for Disease Control and Prevention (CDC) has noted the rise in cases to be particularly rapid in Dallas County. The CDC recommends COVID-19 vaccination for all eligible people ages 6 months and older, and to maintain appropriate booster dosing for the best immunity and protection. With the start of school, this is an ideal time to begin the primary series of vaccination or get necessary boosters for the best protection. Please reach out to the clinic for any specific questions you might have.

[Dallas County COVID-19 updates](#)

## Welcome new hires

### Raquel Martinez, RRT



Raquel has 19 and a half years of experience, starting her career at Parkland Hospital. Most of her time was spent in the burn intensive care unit (ICU). When COVID-19 hit she transitioned to the COVID-19 unit (TCU), and her last year was spent on the pediatric extracorporeal membrane oxygenation (ECMO) team as an ECMO specialist. She is new to the cystic fibrosis world but is loving it!

She has been married to her wife for 11 years and they have two beautiful pups, a German Shepard, named Nahla, and an Australian Labradoodle, named Diego. She loves being outdoors, golf and hanging with her friends.

### Jacy Wright, RRT



Jacy has been a Respiratory Therapist for 5 years. After joining Children's Health in 2018 she has been working with inpatients on the D9 and ACS floors and recently transferred over to the Cystic Fibrosis Clinic from Our Children's House. Getting to work with the cystic fibrosis population was how she wanted to get involved with respiratory so she's extremely grateful to be here and work alongside our providers and staff.

Outside of work, she's a daughter, sister, aunt, fiancé, friend and dog mom. She loves to be around her family and friends. She enjoys working out with Camp Gladiator and trying all the food spots around Dallas.

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## Member spotlight

Hi, my name is MaDonna Turner and I serve on the Children's Heath Cystic Fibrosis FAC.

### Current role on the FAC?

Secretary

### How long have you been on the FAC?

This is my first year.

### Tell us about your children

I have two children. Brianna, who is 13 years old with cystic fibrosis, and her sister Sarah, 16 years old, who is a huge supporter of her sister.

### Why do you serve on the FAC?

I serve on the FAC to help out where I can and it's something I find supportive for my daughter and others. I am passionate about healthcare and willing to help whenever needed.



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## Back to school tips

Summer vacation has come to an end and kids are heading back to school. Below are some back-to-school tips to help make the transition as easy as possible.

[School transitions for cystic fibrosis](#)

[Cystic fibrosis teacher tips](#)

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## 504 plan reminder

The start of school is just around the corner, and it may be time get your child's 504 plan accommodations in order. Section 504 is a federal law that prohibits discrimination against a person because of a disability by any group that gets federal funds. 504 plans detail how medical treatments or absences for clinic visits or hospitalizations are managed at your child's school.

[Learn more about 504 plans](#)

Please contact your social worker if you need a 504 accommodations letter for the new school year. Please allow two weeks to receive your letter.

[Stacey Gallegos, LMSW](#)  
214-456-2843

[Dianna Greenland, LMSW](#)  
214-456-3264

Please contact your social worker if you need a 504 accommodations letter for the new school year. Please allow two weeks to receive your letter.

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## Cystic Fibrosis Information Time

On May 5, the clinic hosted their virtual Cystic Fibrosis Information Time (CFIT). Thank you to all those who attended. A special thank you to Amy Van Vranken, with the Cystic Fibrosis Foundation chapter, for hosting and Kelli Williams, RN, for moderating.

We'd also like to thank our speakers:

- Traci Liberto, CF FAC
- Susan Attel, CF FAC
- Preeti Sharma, M.D.
- Kelli Williams, RN
- Juliana Alba-Saurez, PhD
- Jordan Robinson, RD
- Meghana Sathe, M.D.
- Aarti Shakkottai, M.D.
- David Willcutts, M.D.
- Joe Woolley, M.D.

The event covered updates from the FAC, the Cystic Fibrosis Clinic and Trikafta, information about fibroscans and the new experience of care survey (XoC). Our keynote speaker, Jordan Robinson, spoke about her cystic fibrosis journey. We ended the night hearing about results of

a research study that looked at teen perspective on communication with providers. We are hoping to have this education event in person next year.

[Watch the recording](#)

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## Survey opportunities

### Share your experience with CFTR modulators therapies

The Cystic Fibrosis Foundation is interested in learning more about the decision-making process related to starting or declining cystic fibrosis transmembrane conductance regulator (CFTR) modulators, as well as the experiences of people with cystic fibrosis who are ineligible for CFTR modulators.

They are conducting [short telephone interviews](#) with people with cystic fibrosis, caregivers and cystic fibrosis care team members. They are interested in recruiting people who are eligible for CFTR modulators but are not taking them or ineligible for CFTR modulators.

[Participate in the survey](#)

### Attitudes and prevalence of marijuana, vaping, tobacco and CBD use in cystic fibrosis

Researchers at University of California San Francisco (UCSF) are conducting this survey and are looking for children with cystic fibrosis 13 years of age or older. This one-time survey that is completely anonymous and takes about 15-20 minutes.

If you have any questions, please contact [Sanaz Vaziri](#).

[Participate in the survey](#)

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## Clinic reminders

### Medication refills

- If your child needs a refill on a medication and has not had an in-person clinic visit or a telemedicine visit within six months of requesting a refill, the refill will be denied. Patients need to be seen at least every three to six months to ensure good health, depending on their progression of disease.

- We understand that there can be unexpected situations in which it's difficult to come to the clinic. Prior to denying the refill, we will contact you, via phone or MyChart. If we are unable to reach you, the refill will be denied until seen in clinic.

## Lab work

- We like to ensure that we get all necessary routine lab work or imaging while you are at a clinic visit. Due to certain insurance plans, lab work and/or imaging done at Children's Health facilities may result in a higher bill than anticipated.
- Please make sure if your are changing plans or at the beginning of each new year to check your insurance policy for any changes to provider coverage, pharmacy benefits, co-pay and deductible charges. You can check if your insurance policy has a more cost effective or in-network lab for routine lab work or imaging.
- If your child is due for lab work or imaging, please notify the clinic where you prefer to get those done, options include QUEST or LABCORP.

## Clinic closure

The clinic will be closed Monday, September 5, for the Labor Day holiday. There will be a physician on call for urgent needs.

## Questions?

For any further questions you may have regarding these updates, please contact [the clinic](#) at 214-456-2361.

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## Make every day meaningful

Join the Children's Health team and help make life better for children. We're currently hiring both clinical and non-clinical positions. [View and share our job openings today.](#)