

## BACKGROUND

The Children's Health CF Parent Advisory Council (PAC) started in 2014 with a group of parents that wanted to enhance family centered care and quality of life by improving collaboration with the pediatric CF healthcare team. The Children's Health CF Center joined the CF Learning Network (CFLN) in 2016, with a team that included a parent from the PAC. As part of this initiative, the PAC decided to focus on improving communication with parents and families by sending relevant CF-related information. To achieve this goal, the PAC first needed to establish connection between the PAC and families in our CF community.

## PAC E-NEWS EXAMPLE FOR 2017

PAC (Parent Advisory Council) e-News  
Children's Health Dallas - July 2017

You may want to know....

**\*Plano location -**  
The CF Clinic at Plano has moved to the 1st floor on the Specialty Building 1.

**\*Dallas location -**

- The parking lot at the Dallas Pavilion is under construction. You may want to plan on arriving 5 minutes earlier to your CF Clinic appointments, because parking may take longer.
- Medical District Drive between 35 and Harry Hines, will be under construction soon, which may increase traffic in the area. You may need to add a few minutes when driving to a CF Clinic appointment or to the hospital.

**Summer and CF**

**\*Increase fluid intake** through the day. Remember, caffeinated drinks don't count. Drink before and after you exercise. Babies need extra fluids too.

**\*Add salt** to your diet and eat salty snacks.

**\*Store your medications properly.** Some medications are sensitive to temperature. Keep medications cool while on the go.

**Projects at our CF Center**

- The staff team at our CF Center has been working on making sure all patients ages 10 to 17 get an annual Oral Glucose Tolerance Test (OGTT), per CFF guidelines. The clinic has shown sustained improvement and they are now doing annual OGTT assessments to more than 60% of the patients in that age range (up from close to 0% in 2012), this is higher than the National average. The OGTT is done on patients younger than 10 that show an elevated Hemoglobin A1C level and they are referred to Endocrine Dr. Melissa Ham. The clinic is also working with Dr. Ham to have 2 monthly CF Related Diabetes (CFRD) clinics (currently there is one).
- The CF Center is currently working on pre-visit planning: asking parents some questions prior to their CF Clinic visit (about medication refills, specialists they wish to see, etc). The survey is sent through MyChart, 2 weeks before the appointment, and once parents fill it and return it, the staff meets to make sure they cover everything. Please help them out by filling out the questions and returning them through MyChart!

**Advocacy**

The last few months have been a difficult and uncertain time for CF patients and families with the US Congress taking up repeal and replace bills for the Affordable Care Act. Unfortunately, these new bills have been written in a way that they jeopardize care for CF Patients. The CF Foundation has come out in strong opposition to these bills including the most recent Better Care Reconciliation Act (BCRA). Fortunately, the voice of the people has been heard and the BCRA is no longer under consideration! The CF Advocacy effort was passionate about opposing these bills. If you took time to call your representatives or helped oppose these bills, you have our sincerest thanks. However, this fight is not over. Please continue to make your voice heard and insist our Congress provide adequate care for CF Patients. To learn more about how you can get involved in CF Advocacy, please go to the following website: <https://www.cff.org/Get-Involved/Advocate/>

**Clinical Trials**

The CF Center is increasing their participation in clinical trials and they have several new ones that are starting. If you are interested in your child participating, please contact the CF Clinic for more information.

**Blue Caboose**

Has a CF parent support group that meets the second Monday of each month. Next meeting is on August 14, 2017 at La Madeleine on Mockingbird in Dallas. All CF parents are welcome to attend (adult only meeting).  
Facebook Page: [Blue-Caboose-for-Cystic-Fibrosis](#)

**Patient and Family Experience of Care Survey (PFEC)**

Quality Data Management is a vendor hired by CFF to manage the collection of PFEC. A customer service representative will contact you twice a year, through phone or email asking you to complete a survey (internet survey takes 5-10min less than phone survey). Please make sure the clinic has your current email address. The CF clinic team uses the data collected to make improvements such as reducing time in waiting room, wearing gown and gloves, and having the doctor spend enough time with you. It's a long survey... but please consider participating.

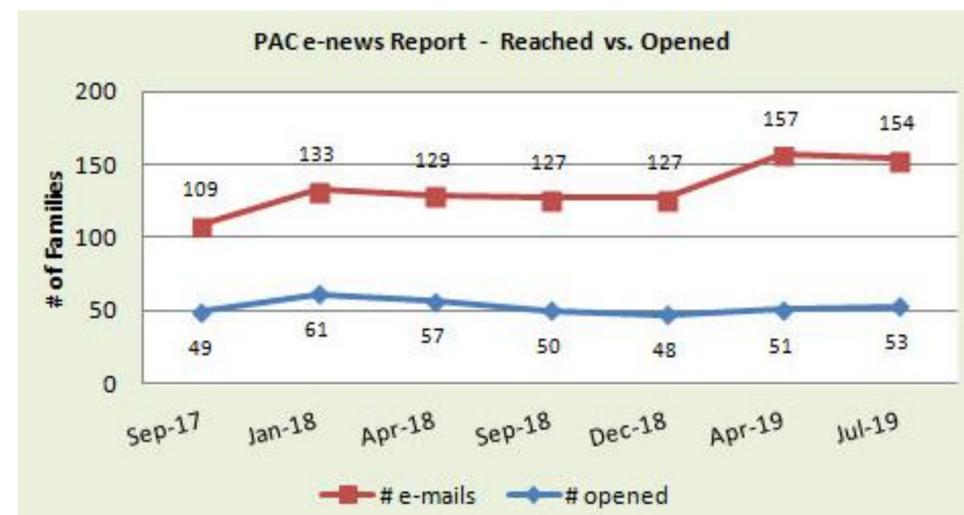
## AIM

The primary aim for this project was to send an independent newsletter from PAC to at least 50% of CF center families every month and sustain or improve this rate over 6 months. This aim would allow the PAC to educate family to family on CF related issues, aid in promotion of CF related events and collaborate in quality improvement projects.

## INTERVENTION

We set out to collect emails from our CF center families in clinic between January and March of 2017. Additional email collection was completed annually at the December Holiday Party (2016-present) and the CF Education Day in April (2017-present).

After the CF Center started a quarterly electronic newsletter, we changed our goal from a monthly to a quarterly educational e-news email. The PAC e-news is purposely sent on different months than the CF Center newsletters. Additional quality updates included switching to a newsletter software and adding Spanish translation during the first year.



## ACKNOWLEDGMENTS

We would like to thank the CF Learning Network and Children's Health CF Clinic for supporting the development and growth of the PAC. Special thanks to Sylvia Mazuera and Cecilia Lozano for continued translation of PAC Newsletters. Finally, thank you to our families living with CF who inspire us every day.



## RESULTS

### September 2018:

- We changed our goal from monthly to quarterly e-news to better compliment the quarterly CF Center newsletter and increase overall sustainability of the project.
- Added Spanish translation to reach all our families.
- We started using a e-news software for easier distribution.

### July 2019:

- PAC collected emails for 151 parents.
- We regularly communicate with 52.2% of the 289 families at our CF Center.
- PAC has sent quarterly newsletter in English and Spanish through 2018 & 2019.
- The PAC Newsletter has been sustained even through changes in PAC leadership.

## NEXT STEPS

- Continue to collect parent and family emails
  - 75% by end of 2020
- Continue to reach CF families in new ways:
  - Social media (Facebook)
  - Text to phone option for families that are not active e-mail users.
- Survey families on satisfaction with PAC e-news
- Continue to work with Children's Health to overcome challenges in reaching more families