

NEWSLETTER

A FAREWELL AND THANK YOU FROM OUR PHARMACIST

Dear Tucson CF Center Patients and Families,

I wanted to take a moment to THANK YOU for 12 amazing years in partnering with you in your / your child's health care. In August, I will be moving to Michigan to join the CF Center at University of Michigan/Michigan Medicine. Please know that it was one of the toughest decisions I have had to make in my life and that the relationships I have developed as part of the Tucson CF Center will last a lifetime. I have learned so much from you and am honored to have had the opportunity to be part of your lives. In sharing challenges and celebrations with you over the years, I have truly grown as a professional and person. Honestly, words cannot truly express how much I appreciate you.

I feel that this quote is very fitting in this time of transition, "How lucky I am to have something that makes saying goodbye so hard." – Winnie the Pooh/A.A., Milne. For me, the "something" is the time and space I have been fortunate to share with you.

This change is truly bittersweet. I will miss you all so much but also, I look forward to the opportunity to contribute to CF care at my alma mater and return to family and friends in Michigan.

With warmest gratitude,
Hanna
Hanna Phan, PharmD, FCCP, FPPA
Your CF Center Pharmacist

THANK YOU AND FAREWELL FROM OUR PHARMACIST

In the last few weeks, have you looked around and thought, "this isn't what I planned!" or "when will we get back to normal?" Is there a big gap between the reality you have and the reality you want (Harris, 2011)? When the world is turned upside down and many things we enjoyed and took for granted are gone (e.g. playing with friends, going out to dinner, team sports, hugging people), grief is a common experience. Grief is a process of adapting to losses, developing new meaning, and finding things that give us joy, while not losing touch with what we had. While adapting to a new reality, you may experience a variety of emotions and thoughts, including anger, denial, bargaining, depression and acceptance (Kubler-Ross). You may cycle in and out of any or all of these separately or together. You may feel them yourself and observe these cycles in others. Examples: Denying the virus is real; anger, including feelings of outrage, unfairness, and resentment; bargaining includes "if only someone had taken this more seriously than"; depression, not clinical depression but feelings of sadness, fear, anxiety, sorrow; and acceptance when you make peace with reality.

Know that if you are experiencing this emotional roller coaster, you are NORMAL and YOU ARE NOT ALONE! The question becomes, where do you put your attention and energy? You could focus on the past, what you had, what you did, who you used to spend time with. The difficulty with this is you can't change the past and you can't get it back by thinking about it. You could focus on the future thinking, "when this is over, I'll..." But what if the reality gap doesn't close? What if the pandemic continues or a new one comes along? We have no control over many of these things, the ONLY thing we can control is NOW. What we do, how we live, and who we care about.

Realize that you are not alone in your emotional roller coaster, but focus on what you can do and can change, which is here and now. Build a new way of living with what we have and don't wait for the pandemic to be over and life to 'return to normal' because we can only know, change and experience the present.

COVID-19 AND CYSTIC FIBROSIS

The Cystic Fibrosis Foundation sends Registry-recorded COVID-19 information from the CF community.

Registry reported COVID-19 cases: The following includes cases reported to the Registry from the beginning of the pandemic through July 30, 2020:

Tests conducted for COVID-19: 2,596 (of which 2,138 are unique patients)

Confirmed as positive cases: 122

Of the positive cases:

Pediatric: 39

Patients hospitalized: 33 (pediatric: 7)

Patients with advanced lung disease: 18 (death: 1)

Patients post lung transplantation: 5 (death: 1)

To receive weekly updates, please go to cff.org and sign up for their mailing list.

UPDATE ON CF CLINICAL TRIALS

CF clinical research continues despite COVID 19. Studies that were already in progress have continued, but like clinical care, many of the visits are virtual. In certain studies, visiting nurses have been employed to gather labs and home spirometry units or scales have been sent to participants. No study has been stopped during COVID. Here at the University of Arizona, the recent surge in cases has led the research group to stay virtual and to not start any new studies. We have several studies including SIMPLIFY and STOP-PEDS almost ready to go and will likely start these in the fall when our COVID numbers get better. The SIMPLIFY study will study taking away therapies on individuals stable on Trikafta and the STOP-PEDS will look at the timing of oral antibiotics for exacerbations in children. The CF Foundation is supporting all of its research sites to restore full in person clinical research whenever the sites are ready. Please continue to participate in CF clinical trials. Your involvement is vital in getting new therapies!

SHARE YOUR THOUGHTS: MENTAL HEALTH RESEARCH PRIORITY SURVEY

The CF Foundation and the Mental Health Advisory Committee are deploying a broad survey to identify research priorities in mental health for the people with CF and their caregivers. Results of the survey will help guide the CFF in funding decisions based on priorities identified by the entire CF community.

It is important that the CFF hears your input! If you are interested in participating in this opportunity, please go to <https://www.surveymonkey.com/r/SJFDQS5> to take the 10-minute, anonymous survey by Monday, August 17th at 11:59 p.m., ET.

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