

CF Connection

Winter/Spring 2019

University of Florida Pediatric Pulmonary Center

Meet Chris and Kelly!

Have you ever wondered about the friendly voices on the phone when you call our CF Center? Read on to learn more about Chris and Kelly!

How do you like to spend your free time?

Chris: I like to relax by playing games, reading books, and listening to music.

Kelly: I spend my free time Latin dancing around Gainesville, doing homework, and taking care of my teacup Chihuahua Luna Lovegood.

Where are two places you'd like to visit?

Chris: Gibraltar and Rome.

Kelly: I would love to go to Ireland and Scotland one day.

If you could instantly become an expert in something, what would it be?

Chris: Aviation...I'd love to learn to fly planes.

Kelly: I would like to become an expert ballroom dancer so that I could dance professionally.

What do you enjoy most about your job?

Chris: Getting to speak to and meet new families from all backgrounds.

Kelly: I love the environment around the office and the people because they are so close with one another and are so friendly. I also love interacting with patients because it will definitely help my career after I graduate school.

What's a fun fact about you?

Chris: I can play the violin!

Kelly: I have webbed toes! My mom, brother, and I all have our second and third toes webbed.

What's the best piece of advice you've ever been given?

Chris: Carpe Diem – Seize the day!

Kelly: When I'm stressed, remember to take a deep breath. My dad always says, "Remember, if it's not literally the end of the world, everything will work out in the end."



Flu Shot—It's Not Too Late!

It's important for people with CF and their family members to get the flu shot every year. It's not too late if you haven't already gotten it (ask your primary care doctor or local pharmacy). People with CF can develop severe pneumonia from the flu. Please let your CF care team know if your child has flu-like symptoms such as fever and body aches.

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We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 4 or e-mail them to hillajb@peds.ufl.edu.

Hello and Good-Bye

Unfortunately Dr Light and Dr Abu will be leaving our team soon. Dr Abu leaves this month to practice in Qatar; Dr Light will move to Aruba in April to teach at a medical school. We will miss them and wish them best of luck in their new adventures. We are excited to introduce several new members to our CF care team! You may have met some of them already; if not, you may see them at your next visit. Please help welcome:



Carmen Leon-Astudillo, MD

Dr Leon-Astudillo received her medical degree from Universidad del Azuay, in Ecuador. She completed her pediatric residency at Cincinnati Children's Hospital Medical Center and her Pediatric Pulmonology fellowship at Boston Children's Hospital. When she is not taking care of patients, she enjoys playing the piano and traveling with her husband.

Brittany Knight, ARNP

Brittany is our new CF Program Coordinator. She was born and raised in Gainesville and in May 2019 will be a triple University of Florida graduate (Go Gators!). She has worked in Pediatrics since 2006. Her passion is care coordination and she is excited about her new position. She has 4 sons and 2 step-daughters and lives on a farm in the country. With her husband they grow their own produce and raise cows, pigs, and chickens.



Al-Humiari, Mohammed, MD

Dr Al is our new Pediatric Pulmonology Fellow. He is from Tallahassee and went to undergraduate and medical school at Florida State University. He did his pediatric residency in Arnold Palmer Hospital for children in Orlando before moving to Gainesville to complete his training in pediatric pulmonology. He plans to stay in Florida as he enjoys the outdoors. Some of his favorite hobbies include surfing, kayaking, hiking and playing sports such as soccer, volleyball and tennis. He also likes to travel.

Tatianna Pulcini, LCSW

Tatianna is excited to be our new social worker. During graduate school, Tatianna worked with Susan Horky as a trainee and is very happy to be working with the CF clinic again. For the past 4 years, she has worked for UF Health in outpatient pediatrics and currently shares her time between the Pediatric CF Clinic and the Pediatric Craniofacial Clinic. She was raised in Bradenton, FL and is from a large, blended family. She obtained her Bachelor's degree from University of Florida and her Master's degree from Florida State University. In her free time, Tatianna enjoys reading, baking, yoga, watching Netflix, and traveling with her husband and one-year-old daughter.



Upcoming Events

ResearchCon — Feb 28 Virtual Event on CF Infection Research

People with CF and their family members age 16 and older are invited to attend **ResearchCon** on **Feb 28, 2019** - the first virtual event dedicated to CF science and research.



Clinicians, researchers, and community members will co-lead this free, online event to share the latest around infection research with the CF community. This event will feature a keynote presentation on the current state of infections in the CF community and what is in the pipeline, followed by breakout sessions on topics surrounding difficult to treat infections such as NTMs and antimicrobial resistance, the role of inflammation, sinus disease, and more. **Check out the agenda and register now at www.cff.org/ResearchCon**

11th Annual Ft White Car Show — Race for the Cure March 2nd

Race for the Cure in memory of David Brown with a car show and silent and live auctions at the Ft White Community Center from 9am to 2pm on March 2nd. For more info please email cbrownsracing@aol.com.

Five Feet Apart — Coming to Movie Theaters in March

Five Feet Apart, a film about two teens with CF starring Cole Sprouse and Haley Lu Richardson, will be in theaters nationwide on March 22. Themes in the movie include cross infection, lung transplant, emotional wellness, and mortality. One of the main characters in the movie is waiting for a transplant; the other is on a clinical trial for a drug to treat a *B. cepacia* infection. The film is a work of fiction and it has been significantly dramatized for the sake of the story.



The CF Foundation created www.cff.org/FiveFeetApart as an informational resource to those unfamiliar with CF. Currently, it contains some facts and basic information on CF, cross-infection, and lung transplant. If you have any questions about the movie, please ask your CF Care Team.

Great Strides Walk — Coming to Gainesville April 13th



It's time for Great Strides – the CF Foundation's largest fundraising event! Each year, more than 125,000 people participate in over 400 walks across the county to support the Foundation's mission to cure CF and raise awareness of this disease. Please join us in Gainesville on April 13th or find another walk in your area to help raise money to end CF. For more information, please visit: <http://fightcf.cff.org/>

University of Florida Pediatric Pulmonary Center

Family Corner

Family Advisory Council

The UF CF Center wants your help to make life better for our patients with CF. Consider joining our Family Advisory Council! For more details, contact any member of your child's CF team.



Florida Family Leaders' Network

The UF Pediatric Pulmonary Center is working with Florida Children's Medical Services (CMS) to create a network of family leaders. Family leaders are people who use the skills they have learned taking care of their own child to then help other children and their families. As an example, some people have set up Facebook groups or are involved with the Cystic Fibrosis Foundation. For more information, please email or call our Family Partner, Angela Miney: aminey@peds.ufl.edu or 352 273 8508.

MyUFHealth (MyChart)

The patient portal at UF Health is a great way to stay in touch with your healthcare team. We used to call it MyChart, now we call it MyUFHealth. You need an email account and an activation code to get started. Follow this link: <https://ufhealth.org/myufhealth-login> to request an Activation Code, Sign up, and Login.

In MyUFHealth you can:

- ✓ Email with your healthcare team
- ✓ Look up test results
- ✓ Request new prescriptions
- ✓ Manage appointments
- ✓ Look at and pay bills online

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