

# CF Connection

Fall 2016

University of Florida Pediatric Pulmonary Center

## An IEP or 504 Plan—Does My Child Need One?

With the start of school, parents often wonder how best to make sure that their children will be able to get the CF-related assistance they need at school. Public schools are legally required to provide accommodations to children with chronic illnesses. School accommodations are provided through “504 plans” (the name relates to Section 504 of the Americans with Disabilities Act) and “Individualized Education Plans” or IEPs (mandated through the Individuals with Disabilities Education Act). These plans are developed during a meeting between the parents and school staff. They list the accommodations that the school will make in order to ensure that the child has full access to his or her education. Typically, the accommodations for children with CF include nursing help with enzymes (for younger children), free access to the restroom, double portions at breakfast/lunch, additional snacks or nutritional supplements during the day, and help making up school work after days missed for CF exacerbations. Based on your child’s individual needs you may want to discuss other accommodations with your child’s school. Some children, for example, get a bolus g-tube feed or do a vest treatment at school.

Parents may verbally request a 504 or IEP planning meeting with the school. The school then faxes a form for the physician which documents the child’s health condition(s). If

your child attends a private school, there is no legal requirement for the school to provide accommodations. However, most private schools are willing to meet with the parents to discuss accommodations.

If your school does not respond to your request for a planning meeting, please contact Susan Horky, the PPC Social Worker (352-273-8506; [Chauncey@ufl.edu](mailto:Chauncey@ufl.edu)).

More information for parents and teachers about school-related issues can be found at: <https://www.cff.org/Living-with-CF/CF-and-School/>. Please feel free to ask Susan Horky for additional brochures on 504 plans and IEPs.



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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](mailto:hillajb@peds.ufl.edu).

## Welcome New Team Members!

You may have noticed some new faces in our CF clinic and in the hospital or heard new voices on the phone. Please help us welcome these new team members!

### Dr. Michael Light, Division Chief

Dr. Light qualified at Guy's Hospital, London in 1967. Then he spent 3 years in Europe in adult medicine before joining the Brompton Chest Hospital, London and did the equivalent of a fellowship in pediatric pulmonary and critical care. In 1973 he went to Hawaii and the 1970's were mostly spent directing Neonatal ICU, and the 80's directing the Pediatric ICU. In 1989 he joined the University of California, San Diego and for 8 years directed the pediatric pulmonary program. The next 11 years were spent at the University of Miami, first in pediatric pulmonary then in adult pulmonary. He participated in multiple CF clinical research projects at both San Diego and Miami. Dr. Light was chairperson of the pulmonary section of the American Academy of Pediatrics from 2004 to 2006 and was editor-in-chief of the AAP Handbook of Pediatric Pulmonology. In 2011 Dr. Light joined Ross University Medical School in the Commonwealth of Dominica, West Indies, where he was medical director of the student health clinic.



### Dr. Silvia Delgado-Villalta, CF Center Co-Director

Dr. Delgado is originally from El Salvador, where she graduated from University Dr Jose Matias Delgado. She did her residency in Pediatrics in SUNY Downstate in Brooklyn, then a fellowship in Pediatric Pulmonary in Children's National Hospital in Washington DC. She has been interested in Cystic Fibrosis since medical school in El Salvador. She wants to improve the quality of life and care of people with CF.



### Dr. Dima Ezmigna, Clinical Assistant Professor

I moved to Florida after I finished my pediatric pulmonary training from the University of Arizona in Tucson. I'm excited to be part of the team in Gainesville, where everyone is so enthusiastic and committed to providing the best patient care! And it's a nice place and close to all the fun! I enjoy cooking and traveling.



### Dr. Yanerys Colón-Cortés, Pulmonary Fellow

I joined UF Shands to continue my education in Pediatrics as a Pulmonologist. I'm originally from Puerto Rico where I did my Pediatric Residency. Since working at UF I have dedicated most of my research experience in gene therapy and cell physiology for CF. I guide my motivation by making patients feel better, happier, providing love, care and hope. When not at work, I spend my time with my 11-year-old boy and my husband who is also a physician at Shands.



### Dr. Brandon Seay, Pulmonary Fellow

I'm originally from Atlanta, Georgia. My medical school was St George's University on the island of Grenada. My pediatrics residency was at Morehouse School of Medicine. I am interested in health advocacy and am active on Twitter @BSeay05, sharing pediatric and pulmonary info and advocacy efforts. My wife Mary-Ann also works for University of Florida as an adult neurology resident.



## Welcome New Team Members! (cont.)

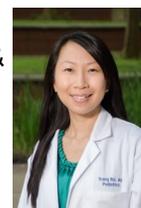
### Dr. Matthew Pertzborn, Pulmonary Fellow

Dr. Pertzborn completed medical school in four great years at UT Galveston near the beach and is happy to be continuing his training in sunny Florida! Outside of medicine, he enjoys running, tennis, outdoor activities, and spending time with family and friends.



### Dr. Trang Bui, Pulmonary Fellow

Dr. Bui was born in Kansas, but has called Georgia home for the past twenty years. On her first visit to UF & Shands, she was immediately impressed by the positive atmosphere; the residents and faculty were all supportive, enthusiastic, and clearly dedicated to quality teaching and excellent patient care. Trang enjoys going to concerts, cooking with friends, and going to the beach.



### Christine Mullally, BSN, RN, CF Coordinator

I have been a pediatric nurse for 30 years. I grew up in Gainesville and have recently moved back with my family. I am married with 2 children, who are both in college yikes!, 2 dogs and a cat. I love to be outside, travel and spend time with my family. I am excited to be a part of the pediatric pulmonary team and have the opportunity to build new relationships with our patients!



### Alicia Hardy, RN, Asthma Educator

I am an enthusiastic nurse who was an LPN for 9 years and eventually returned to school to pursue an RN degree. I used to care for adult patients in the hospital and clinic settings, but I've found a sparked interest in the care of patients with severe asthma. I am proud to say that I became a certified asthma educator to confidently and competently care for patients in my new career path. I am a Gainesville native, born right here at Shands Hospital. I have four boys at home; a husband and 3 sons. I am a busy woman who holds many jobs outside of work including being very active in my church, caring for my parents, and raising a family. I enjoy weekend getaways (when time allows), being a sports mom, and nursing because being a nurse...it's a way of life!



### Tay Gandy, LPN, Triage Nurse

I'm a Florida native and I'm married to my high school sweetheart. We have 3 amazing boys together & a pet turtle. I've been in the pediatric nursing world for 15 years now & it's forever changed my life. I help with refill requests, provide resources for patients, and handle phone calls & urgent matters that arise. So thankful to be working with an amazing group of people that I consider family!



### Ticea Cannon, LPN, Triage Nurse

I act as a liaison between family and Providers. I assist team members with scheduling appointments and triaging patients. I live in Fort White, I have a horse (Savanna), and two dogs, a German Sheppard (China), and a Belgian Sheppard (Rambo). I've only been with Peds Pulmonary for two weeks, I look forward to great things!



## Why Participate in Research?

Studies (or clinical trials) are important ways of contributing to new treatments for cystic fibrosis. If you think you or your child may be interested in participating in a clinical trial it is important to consider the risks and benefits. Some trials involve an intervention (such as medication) while other studies may involve completing questionnaires. Clinical trials are a major part of CF research and take place at Cystic Fibrosis Foundation-accredited care centers (UF is an accredited center). If you want to learn more about Cystic Fibrosis Research, check out the link below, where you will find out which trials are recruiting.

<https://www.cff.org/Trials/finder>



If you have any further questions, please contact Dawn Baker at (352) 273-8380. You will start to see more of Dawn during clinics in the coming months as she reviews current trials with you and your family.

## Syvanna Shake

Are you looking for a delicious, high-calorie shake recipe? Try this one, contributed by Syvanna!

### Ingredients:

- 1 packet banana flavor Scandishake powder
- 1 cup whole milk
- 1 tablespoon Nutella
- 2 tablespoons strawberry syrup

### Directions:

Mix together in a blender or shaker bottle and enjoy!!!

Calories: 770



Scandishakes are available in vanilla, strawberry, banana, and caramel! They are delicious mixed with whole milk, or try mixing the vanilla flavor with orange juice or sports drink! CMS Medicaid and the Healthwell Foundation Program will cover Scandishakes. Ask for a sample next time you are in clinic! And if you haven't heard about the Healthwell Foundation Program, check it out here: <http://healthwellfoundation.org>.

# University of Florida Pediatric Pulmonary Center

## Family Corner

### Is Your Voice Being Heard?

Do you feel we are hearing you when you have concerns or suggestions for how we can do things better? Our CF team wants to know that they are giving you great care and meeting the needs of you and your child so that your child lives the best possible life with Cystic Fibrosis. Here are some ways to give us feedback.

### Patient Surveys

Surveys are taken very seriously. Every comment is read. We appreciate the time you take to complete them. We have been working to make filling them in take less time. If you are asked to complete a survey either during a hospital stay or at a clinic visit, thank you for taking the time to complete it. Surveys that come to you in the mail are also important. Your privacy is protected so surveys about UF Health are returned to an independent organization who puts them all together before they come back to the hospital. If you have any comments about the barriers to filling in a survey, I would love to hear from you.

### Patient and Family Advisory Councils

UF Health is engaging patients and families to help make things better in the hospital and in our clinics by listening to our patients and families at advisory council meetings. In Peds Pulmonary we are interested in starting a CF Advisory Council. Would you be interested in participating? Call or email and I will give you all the details.

### Family Traineeship

You are a great advocate for your child! If you would like to help make things better for all children and would like to be trained as a family leader, we would love to hear from you.

Angela Miney, Family Partner  
aminey@peds.ufl.edu  
352-273-8508



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### Nurses:

Chris Mullally, BSN, RN  
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Tay Gandy, LPN  
Ticea Cannon, LPN

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Jennifer Hillan, MSH, RD, LD/N

### Social Worker:

Susan Horky, LCSW

### Clinical Psychologist:

David Fedele, PhD

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Shands/UF Pediatric Respiratory  
Care Team

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