

CF Connection

Summer 2019

University of Florida Pediatric Pulmonary Center

Are You Ready for Hurricane Season?

Hurricane season started June 1st and will end November 30th. Having a child with CF makes it especially important to have a plan in place for emergencies. You don't want to be without needed medications or equipment! The CF Foundation has helpful guidelines at <https://www.cff.org/Assistance-Services/Disaster-and-Emergency-Preparedness-Plan>. Follow the link to learn:

- ✓ How to be proactive and put together an emergency plan
- ✓ How to get ready for a natural disaster
- ✓ What to do during a natural disaster and how to put your emergency plan in action
- ✓ How to recover after a natural disaster



Cystic Fibrosis Foundation *Compass* can help with many concerns, including insurance, financial, and legal issues. They can also help you prepare for and recover from natural disasters. Contact *Compass* at **844-COMPASS** (844-266-7277) Monday through Friday, 9 a.m. until 7 p.m. ET. You can also email cdt@cff.org.

You may also want to talk to your power and water companies about your child's needs. Many of these companies keep a "priority reconnection service" list and you might be able to get your power restored quicker after an emergency. However, even if you get on this list, power could still be out for many days following a disaster so it's important to have backup options.

Summer Trips

If you are travelling this summer, think about how your medications should travel. Ask your pharmacist if you aren't sure. Some meds are fine at room temperature, but some might need to be in a cooler with an ice pack. Enzymes should be kept between 59-86°F, so don't leave them in the car or in direct sunlight.



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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.

Welcome Dr Veras and Dr Russo!

Dr Raymond Veras is our newest Attending Physician. Dr Veras just moved to Gainesville from West Palm Beach. He is excited to be back in Gator Country as he completed his pediatric residency here back in 2006. He enjoys spending time with his wife and two children, especially when they can be out on the water boating or fishing.



Dr Joseph Russo is our new Pulmonary Fellow. Originally from Pennsylvania, Dr Russo recently completed his residency at the University of Tennessee in Memphis. He enjoys the outdoors and likes to fish. He's also an avid sports fan! He and his family (wife Elaine and 11-year old son Antonio) enjoy going to the central Florida theme parks, especially Universal Studios.

Is Your Child Salty?

People with CF lose extra salt in their sweat, so they are at high risk for salt depletion and dehydration. This can lead to muscle weakness, fatigue, nausea, and headaches. The most severe result is heat stroke, which can cause seizures and loss of consciousness. Especially during our hot and humid Florida summer, it's important for your child to eat salty foods and drink plenty of fluids. Offer your child foods high in salt (sodium) and be generous with the saltshaker. Infants younger than 6 months should get $\frac{1}{8}$ teaspoon salt daily. Infants aged 6 months to 12 months should get $\frac{1}{4}$ teaspoon of salt daily.



People with CF who are active in sports, or play or work outside in the heat, have even higher salt and fluid needs. Sports drinks such as Gatorade® or Powerade® do not have enough salt for a person with CF during these times, so it's recommended to add $\frac{1}{8}$ teaspoon of salt to every 12 ounces of sports drink.



These foods are high in sodium and also calories, making them great choices for people with CF:

- ✓ Luncheon meat and cheese sandwich
- ✓ Salted bagel with cream cheese
- ✓ Crackers with cheese or peanut butter
- ✓ Chips and nuts
- ✓ Frozen dinners, pizza, and burritos
- ✓ Nachos with cheese, olives, beans, and avocado

Healthy Sleep Habits

Getting a good night's sleep is one of the most important things for your child's growth and development. Children's sleep quality can take a hit over the summer when your family gets off the usual school-year schedule. Here are some tips from Dr Krietsch at UF to help your child sleep well over the summer and beyond.



Adopt a sleep-positive family culture. Actions speak louder than words when it comes to parenting. Think about the attitudes your family members have about sleep, and what sleep habits you are modeling for your children. You should also be willing to make any hard changes in your bedtime habits that you ask your child to make (like leaving TVs and cell phones out of the bedroom).

Help your child create a “sleep zone.” Your child's bed should be their safe haven for sleep. Help them make the bed a “sleep zone” by making the bed and bedroom feel calming and relaxing. Make sure the room is a comfortable temperature (less than 75°F), quiet, and dark (a nightlight is OK). Importantly, your child should not do anything in their bed but sleep. When your child reads, plays video games, or does homework in their bed, it trains their body to expect to feel awake when they get in bed. Remember, we only sleep in the “sleep zone!”

Keep technology out of the bedroom. Watching TV or playing on a laptop, video game, tablet, or phone can make it more difficult to sleep. Using technology tricks our bodies into feeling alert and the light from these devices suppress the hormone in our body (melatonin) that makes us feel sleepy. Plus, scrolling on devices or watching TV is more fun than sleeping! Make it easier for everyone in the family to turn off technology one hour before bedtime and keeping devices out of the bedroom.

Follow a consistent sleep schedule. Going to bed and waking up at different times confuses our body's internal clock and puts us through jet lag. Keeping a consistent schedule helps your child fall asleep faster, stay asleep, and wake up easier.

Create a wind-down ritual. We all need time to wind down before bed. Creating a 20-30 minute routine every night before bed can help your child fall asleep. The routine should include calm activities that occur in relatively low lighting like taking a shower or bath, brushing teeth, and reading a story. Completing the same routine each night trains your child's body to know it is time to sleep.

Cut caffeine after lunch. Caffeine is a stimulant that makes the body feel awake. Caffeine can stay in the body for 8-12 hours. Your child should avoid caffeine, especially after noon.

Get enough sleep. Sleep is essential to children's learning, growth, and brain development. Pediatricians and sleep physicians recommend that children ages 6-12 get 9-11 hours of sleep each night; teens should get 8-10 hours of sleep nightly.

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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.



CF Peer Connect

Are you interested in connecting with others who understand what it's like to live with CF? The CF Foundation has two exciting opportunities to connect people with CF and their families to others who have gone through similar life transitions and milestones.

The CF Peer Connect program is a topic-based peer mentoring program for people with CF ages 16 and up and their families.

Topics for matching include dating and relationships, getting a CF diagnosis as a teen or adult, managing career decisions, starting a family, considering transplant, and coping with bereavement. Topics for family members include finding balance as a caregiver, adjusting to a new diagnosis, parenting at various ages, navigating relationships and marriage, dealing with hospitalizations and coping with bereavement.

To get started with Peer Connect, complete a request form at www.cff.org/PeerConnect. A member of the CF Peer Connect team will talk with you about what you are looking for, match you with someone who best fits your needs, and then allow you and your peer connection to talk over video, phone, email or text.

Beginning in July 2019, the CF Foundation will be creating opportunities for teens (ages 13-18) with CF to connect virtually with other teens living with CF. Teens will be able to select the type of connection opportunities they are interested in and select their preferred method of communication.

This opportunity is still in development, so if your child is interested in participating please visit www.CFF.org/TeenSignup to get more details as they become available. Parental consent for those under 18 is required.

Pediatric Pulmonary Center
University of Florida
Health Science Center
P.O. Box 100296
Gainesville, Florida 32610-0296

Phone: 352-273-8380
Toll Free: 1-800-749-7424
Fax: 352-294-8098

Physicians & Nurse Practitioners:

Silvia Delgado-Villalta, MD
Mary H. Wagner, MD
Dima Ezmigna, MD
Sreekala Prabhakaran, MD
Carmen Leon, MD
Raymond Veras, MD
Mohammed Al-Humiari, MD
Joseph Russo, MD
Dawn Baker, ARNP
Brittany Knight, ARNP
Alyssa Henry, PA

Nurses:

Alicia Hardy, RN
Tay Gandy, LPN
Ticea Cannon, LPN

Nutritionists:

Ellen Bowser, MS, RN, RD
Jennifer Hillan, MSH, RD, LD/N

Social Workers:

Susan Horky, LCSW
Tatianna Pulcini LCSW

Clinical Psychologist:

David Fedele, PhD

Pharmacist:

Kalen Manasco, PhD

Respiratory Care:

Shands/UF Pediatric Respiratory
Care Team

Family Partner:

Angela Miney—aminey@peds.ufl.edu

Office Staff:

Laura Monday
Lisa Harvey
Chris Gates
Kelly Aaronson