

Cough it Up, Spit it Out!

Pediatric Pulmonology CF Center Updates

Part of Children's Hospital of Greenville Health System (864) 454-5530

Join us at RIVERBANKS ZOO!

We have joined forces with USC in Columbia to host an educational event while your kids are enjoying the zoo.

Our theme this year is transition and we will be speaking about the transition of CF therapies to cure, school from daycare to college, responsibility from parent to patient, and our special guest of the ROCK CF Foundation.

We will have many of our

CF vendors available all morning thru lunch for you to speak with as well as pick up information from.

We ask for our patients to please wear the T-shirt we will provide to help us help you in keeping your child safe. NO CF patients will be allowed inside the education area so we may keep within the CFF Infection Prevention and Control guidelines.

Lunch tickets will be provided to your group

once the education presentation is complete. We ask that our CF children are kept at least 6 feet apart to protect them while walking the zoo and eating lunch.

Please RSVP to Lisa DuBose at 454-5530 or ldubose@ghs.org. Hope to see you there!



We are implementing CF RISE

Transition of care actually starts long before your child and family leave our practice for the adult world. We begin by gently teaching the child to take more responsibility for their own care. This is individually decided case by case with our team and your input.

The CFF along with Gilead worked together to develop a program that meets the guidelines and standards of the CFF's education committee.

We will begin piloting this

program at first with our older patients but it will soon evolve down to our 10 year olds. The purpose is to SLOWLY prepare the child as they grow into adulthood to assume full responsibility of their care and for the parent to feel comfortable as they see their child thrive given their independence.

I am including an informational page with this newsletter mailing. The program can be done on your child's smartphone either in clinic

or when away from clinic and the information is stored in a secure data area.

We are excited to be implementing this program and looking forward to its success and the affects it has on your families. For more information go to: www.CFRISE.com



Please welcome our CMA's!



You may wonder why I am welcoming Karis Sutton as she has been with us for nearly a year! She has not however gotten to tell you anything about herself.

Karis is an adoring mother of 2 girls. She has a 4-footed child as well, her dog "Charlie." Karis enjoys reading to relax. Her job as a CMA has been a welcome change as she loves kids and

caring for them. We all love to give Karis a hard time as she is NOT a football fan! Ha-ha!

Our latest pulmonary family addition is Brandi Marsh. Brandi is a proud mama of 5 and spends as much time with her kiddos as she can.

Brandi enjoys crafting and spending times outdoors. Brandi is really enjoying learning as much as she

can about pulmonology and especially CF.

We are blessed to have such enthusiastic and endearing CMA's here to care for your children. Please welcome our ladies and don't be surprised if you love them like we do!



Is it SAFE to VAPE; maybe not as safe as you think...

The glamorizing of smoking has returned with a vengeance since the introduction of VAPING.

The myth is they are safer than cigarettes. Key word, MYTH!

There are multiple ingredients in VAPES that are safe for ingestion but NOT inhalation. The liquid nicotine preparations are very deadly to a child and as little as ½ tsp swallowed can kill.

The topical effects of the chemicals in vapes have also been shown to develop burns of skin that comes into contact with them.

Vapes are being used more and more by younger children with their "sweet flavors" but also have nicotine and thus

many of these children are then shifting to cigarettes with age. Vapes are legally sold to those 18 and older however are marketed via the internet as well.

There is still no research regarding the long-term effects on users and bystanders regarding vape smoke.

We have been hammered by the Surgeon General's office and public campaign adds about how unsafe passive smoke exposure is. We all know in the medical field that ANY smoke exposure is harmful to our patients. The smoke is harmful to the smoker, to those around the smoker and even to the environment of the smoker.

Think about this, paint is a porous material, meaning

if you smoke in a home the smoke is then absorbed by the paint on the walls. It is absorbed by carpets/padding, and even the ceiling tiles. Please be aware if you are renting, that a "smoke-free" complex is not always smoke-free.

So if you ARE a smoker (cigarettes or vapes) what can YOU do to protect your child? We all know that smoking is a coping mechanism and there are free resources to help you quit, "1-800-QUIT NOW." You can limit your smoking/vaping to outdoors ONLY, and NEVER in the car or house. Wear a smoking jacket over your clothes to keep your child from inhaling the smoke off your clothing. We know quitting is hard, but isn't your child worth it?



"To get FREE resources to help you quit smoking/vapes call 1-800-QUIT NOW or IPHONE: address: I QUIT and in message: QUIT."

Mental Health Minute.....

Do you wake your child up in the morning and feel like you rush the whole day trying to fit everything in? There are treatments, breakfast, getting dressed and out the door for school only to return home from school to have homework, more treatments, a battle to eat a high calorie dinner and then bath and bedtime routine – it is all so overwhelming. How do you fit it all in without having stress and anxiety? Do you feel like you want to just take a minute to breathe? Know you are not alone and it is okay and even recommended for you to take a moment

for yourself. As parents, we often feel pressured to give so much to our children that we forget to take care of ourselves. Did you know that you can have more energy and impact on your child if you do take care of yourself first? This month try to find moments to get some extra sleep, spend time outdoors, call your best friend for a long talk, read for pleasure and have some quiet time. Don't be afraid to ask your friends and family for help. Sometimes talking to a counselor can help too. It doesn't mean there is anything wrong with you or

that you have some kind of diagnosis. It simply means you will have an outlet to process your feelings. We can help you find a counselor in your area who accepts your insurance. If you don't have insurance for yourself or if your insurance doesn't cover counseling, there is a new CF counseling resource that will pay for five counseling sessions for parents or caregivers.

Article courtesy of:
Christy Clarke, LMSW



Loving ourselves is one of the hardest jobs of a parent

RECIPE corner: TACO dip

Ingredients:

8 oz. package cream cheese
8 oz. sour cream
1 package taco seasoning
1 cup chopped tomato
1 cup chopped onion
1 lb. browned hamburger
1 cup chopped lettuce
1 cup sliced black olives
1 bag tortilla chips

Directions:

- 1) Mix together with cream cheese, sour cream and taco seasoning and spread on a serving plate.
- 2) Combine tomato, onion, hamburger, chopped lettuce and black olives and spread over cheese mixture.
- 3) Scoop dip onto the tortilla chips and ENJOY!

Nutrition Information:

(NOT counting chips!)

Serving size: 1 cup
Calories: 325
Protein: 18 g
Fat: 26 g
Carbohydrate: 5 g



This is a great snack to take to barbeques, family get-togethers or when watching ball games and fairly healthy too. Spice it up as your family desires!

GREAT STRIDES is coming SOON!



Okay all you CF Great Striders, let's lace up those sneakers and walk to find a CURE!

You can register online at www.fightcf.cff.org. If you would rather speak to someone about the walk you may call the CFF at 866-324-2242 to reach Megan Onysko or one of her colleagues. The goal is to try to do your

fundraising on-line so there is no loose money at the event, but please speak to Megan if this is an issue.

Our walk will again take place at Greer City Park on May 20, 2017 and you can register at 9:00 am. Our walk is ALWAYS such a great event and a wonderful way to affirm that you are not ALONE in

your family's CF journey. We are all looking forward to seeing as many of you there. Please remember the Infection Prevention & Control policy suggesting that patients are at least 6 feet apart at outdoor events to lessen potential bacterial transmission. Get psyched Upstate and get those sneakers moving!

What's the big deal about OGTTs?

My child's not pregnant so why does he/she need an OGTT?

Our CF Registry data has shown that our children are at a heightened risk of development of CF related diabetes mellitus. CF Foundation recommends that by age 10 ALL

children are given an OGTT.

This test involves: 2 blood draws and; consumption of some seriously sweet but, flat-tasting liquid, kinda' like orange Fanta.

Your child should NOT take their overnight formula via gtube the night

prior to testing and should not eat or drink anything after midnight or the morning of the test. Wake up, get dressed and come to our lab! We will know the results of the test typically by the next day. CF related diabetes needs to be diagnosed early for the best outcome.

Are your meds cool enough while traveling?



It is ALMOST time for summer vacation! Pools, mountain lakes and the ridiculously hot temperatures we Southerners just ADORE!

Please remember when traveling that many of your child's medications must be kept cool or they will not work well.

Pancreatic enzymes should be less than 82 degrees so being in a pocket, purse or your car will NOT work!

This is also the case for Pulmozyme, Cayston, tobramycin and insulin. Please be sure you have a cooler to carry these medications wherever you are going.

One of my favorite stories was of the child in the Grand Canyon who developed major stooling issues, and it was related to not only HOT enzymes but I think they had also gone out of date.

We want your vacations to

be awesome so take some precautions prior to your trip and be sure you have enough medications, they are kept cool and are in date.

Also remember your kids have a higher incidence of dehydration when playing out in the heat, if not drinking enough so carry water and Gatorade and encourage drink breaks.

Happy Summer and enjoy our beautiful outdoors!

Happy Birthday to our Spring peeps!

Emily S.	03/29	Emilee M.	03/12	Adalay C.	05/26
Cameron B.	04/04	Kaiden B.	02/13	Konnor W.	04/19
Brianna H.	03/04	Adam S.	05/10	Gianna F.	05/16
Areya L.	02/17	Karson C.	03/01		
Jessica D.	02/05	Liliane S.	02/22		
Lily W.	03/15	Raelyn D.	03/28		
Izabella C.	03/13	Ava W.	05/12		
Nathan P.	03/22	Madison M.	04/26		
Brynlee G.	04/14	Cameron D.	04/02		



Happy Birthday to those kids with February-May birthdays.

EXCITING news from VERTEX and CFF!

Vertex announced positive results from two Phase 3 clinical studies of tezacaftor (VX-661) and ivacaftor (Kalydeco™). I'm pleased to report that both studies met their primary endpoints with statistically significant improvements in lung function and other key measures of the disease, including exacerbations (sudden worsening of symptoms) and quality of life. These findings represent a significant milestone in our mission to develop treatments for all people with CF – and in particular, lay the groundwork for

future triple therapies that may eventually be effective for over 90 percent of our community.

[Learn more about the news on CFF.org.](#)

This positive outcome adds to our already considerable momentum, and is a reflection of the exceptional individuals – volunteers, donors, researchers, scientists, and, most of all, people living with CF and their families – who have made this work possible.

We aren't at the finish line, but today we are one step closer to achieving a cure for all people with CF.

Thank you for the work you do each day to give our community more reasons to have hope for the future. And thank you for your continued support.

All the best,
Preston W. Campbell, III,
M.D.
President & CEO

Article excerpt from CFF information email

“Groundwork for future triple therapies that may eventually be effective for over 90% of our community.”



A Father's love

Parenting is clearly the hardest job I have ever been blessed to perform. My youngest sibling has Spina Bifida, a chronic disease that affects her spine and required multiple surgeries and life modifications. Growing up in my household with her certainly has helped me identify with some of the specific issues that only those raising children with health needs deal with.

You are COURAGEOUS people and you affirm your children in all they do. We have parents who are amazing fundraisers,

parents who take their talents and educate others about CF, and we have parents that carry their child with them always (see pic of Anslee's daddy's act of love).

Like I said, parenting is hard work, but parenting a child with special health needs is simply and profoundly one of the largest acts of service you will ever do for another human being and what a blessing to know your love and support REALLY makes a difference in your child's life.

We strive here at our CF

Center to support you the best ways we can, but can always use your help knowing what else we can do. CFF sends out anonymous surveys you can complete to help us, or tell us at clinic. The key is to remember that YOU know your child better than any other human being.



About Our Organization...

Dr. Steve Snodgrass is the Medical Director Pediatric Pulmonology, part of GHS Children's Hospital and is also our CF Center director. Our vision is to transform health care for the benefit of the people and the communities we serve. Our mission is to heal

compassionately, teach innovatively and improve constantly. Our CF center is a CORE CF Center accredited by the National CF Foundation. We are continually striving to maintain the high level of care we deliver to our CF families. We have

multiple subspecialists involved in our care center. Children's Hospital is here to support our CF families to the best of our abilities.



Pediatric Pulmonology
200 Patewood Dr.,
Ste. A 300
Greenville, SC 29615

Phone:
(864) 454-5530

Fax:
(864) 241-9246

We're on the Web!

See us under:

Children's Hospital at:

[ghschildrens.org/
pediatric-
pulmonology](http://ghschildrens.org/pediatric-pulmonology)

We're also on FACEBOOK
So check us out and "like us"
[facebook.com/GHSChildrens](https://www.facebook.com/GHSChildrens)

EDITOR: LISA A. DUBOSE, NP
PEDIATRIC PULMONOLOGY
CYSTIC FIBROSIS CENTER
NEWSLETTER SUPPORTED BY A
GRANT FROM ALLERGAN.

