

Cough it Up, Spit it Out!

Pediatric Pulmonology CF Center Updates

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

Special Interest Articles:

- Get your FLU shot!
- How are ya' sleeping?.
- New drug approvals.

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Children's Hospital Radiothon a Success!

Many of you may be reading this and questioning why I would include it in the CF Newsletter. If you have participated in our Children's Hospital Radiothon in the past we thank you from the bottom of our hearts. If not, let me tell you a little more about it and why the \$3 million dollars raised over the last 10 years matters to YOU.

Children's Hospital provides MANY things to try to make hospital stays less "sterile and scary."

Our goal is that our children and our families are able to feel comforted and the children experience the least amount of anxiety, fear and pain we can provide. We have a variety of programs from our Child Life department, Facility Dog division, to even small things like numbing cream for shots/IV placement that insurance does NOT cover. We work very hard to provide these very important services and Radiothon and our Children's Miracle Network staff & Children's

Hospital Philanthropy department strive tirelessly to support the mission of Children's Hospital and how we care for kids. If you would like more information you can visit:

<http://www.ghschildrens.org/ways-to-help/>



It's Riverbanks ZOO time!

Okay all you FOOTBALL fans, we chose a NON-HOME GAME weekend for both Carolina and Clemson to bring you some fun and some education! We should be finished by 1 pm so you shouldn't miss a bit of your team in action!

We will once again be meeting at the Riverbanks zoo in Columbia, SC for a morning of fun, food and education. We are being sponsored by many of the companies whose drugs,

equipment and services work together to make life with CF livable.

The education portion is INDOORS so no patients with CF may be inside; instead we ask families to bring another adult to escort your children around the zoo. CFF will be providing you with T-shirts/beads so you can determine which families to stay 6 feet away from as per the Infection Prevention & Control guidelines.

A formal invite will follow but we have some great talks prepared, free admission to the zoo for your family, free lunch and lots of extras from our reps! Hope to see many of you there.

Date: October 6
RSVP: ldubose@ghs.org



Fever, chills? Did you get your flu shot???



We never know when flu season will be upon us, SO we have to be prepared!

The CF Foundation guidelines strongly recommend influenza vaccine for all children and family members every year.

The American Academy of Pediatrics agrees with this recommendation.

Neither of these groups

recommends the nasal flu vaccine as it contains LIVE virus and has adverse consequences for our patients and children in general.

Please plan to get your family vaccinated by their Primary Care Providers late Sept-November is ideal but most providers have vaccine well past that date given the variability in the timing of flu epidemics.

We do not make flu vaccine ONLY visits, but if your child is scheduled to be seen during late September into the end of the year we may have vaccine available.

Cystic Fibrosis puts children at higher risk of developing adverse reactions from flu. We appreciate everyone being proactive to protect their families!

Why are there so many school forms?

“Medication notes are required by STATE law, we promise the school nurse is not trying to get on your nerves!”

The relationship you have with your school nurse can make or break your child’s school success. The school nurse is often the ONLY person at your school who even knows what Cystic fibrosis is and he/she is the person, in addition to yourself, who can advocate most for what your child needs.

School nurses are bound by SC State law to have forms for EVERY

medication that is at the school whether it is in their office or in your child’s backpack.

Just for clarification, there are routine drug checks in the middle and high schools and if a medication is found without the proper documentation, the child can be severely penalized.

Please let us know if you need forms for enzymes, bronchodilators or CF 504 Accommodation notes.

Some of our children also have intermittent homebound forms BUT these must come from the guidance office at your school.

We are looking forward to another successful school year.

If you think about it, give your school nurse a little love, they really are a special group of people!

Okay, so yes I am biased because I am a nurse, but I know far too many school nurses to not completely believe they keep our kids safe!



Mental Health Minute

With the beginning of a new school year, it is a great time to establish a bedtime routine and make sure your kids are getting enough sleep. It is important for their mental and physical health, safety, and quality of life. Adequate sleep duration and quality help your kids concentrate, learn, react quickly, make decisions, create memories, and function optimally. Children with CF are at greater risk for sleep disruptions due to coughing, medication side effects, illness, infection, shortness of breath, and pain (to name just a few). For these reasons, it is vitally important to discuss sleep with your CF care team.

According to the National Sleep Foundation, sleep needs are highly individual. Babies need as many as 16 hours of sleep a day, children ranging from 10-12 hours of sleep per night, while teenagers - 8-10 hours. It is important to pay attention to your child's needs by assessing how

they feel on different amounts of sleep.

Tips from the experts for better sleep

1. Find your child's ideal bedtime and allow them the full amount of sleep needed.
2. Make bedtime a special time. Read and interact with your child.
3. Establish a simple routine. It should not last too long and should take place primarily in the room where the child will sleep. It may include a few simple, quite activities such as a light snack, bath, cuddling, saying goodnight and a story or lullaby. The kinds of activities in the routine will depend on the child's age. Children like to know what to expect.
4. Put them to bed at the same time every day. It is best to keep the same waking times, meal times and nap times daily.
5. Create a quiet, dark, relaxing, and cool environment in their bedroom. Sound machines and night-lights can be helpful.
6. Avoid electronics or TV as it will over stimulate the brain and make the transition to sleep more difficult.
7. Avoid caffeine in the afternoon and evening hours.

If you feel you have tried the above suggestions for **better sleep** for your child and still have sleep problems, please reach out to the care team. We are here to help!



*“Hey parents,
YOU need
plenty of
sleep TOO!”*



Recipe Corner: Overnight Texas Brisket



Just in time for tailgating!

Preparation time: 5 minutes to the oven, 20 minutes when cooked

Cooking time: 8-10 hours

Serves: 20 !!!!

Ingredients:

- 10 lbs. Beef Brisket
- Salt and pepper
- 1-2 oz. Worcestershire sauce

Directions:

- 1) Generously salt and pepper brisket on both sides.
- 2) Pour Worcestershire sauce on both sides.
- 3) Wrap loosely in foil and place, fat side up, in large pan.
- 4) Cook at 250 degrees

for 8-10 hours (overnight).

- 5) Cool, slice thinly. (easier with electric knife).
- 6) Serve with Easy Sauce in warm flour tortillas.

Easy Sauce

Ingredients:

- 4 oz. pickle juice, any flavor
- Two 18 oz. bottles BBQ sauce, any flavor

Directions:

- 1) In medium sauce pan, bring pickle juice to a boil.
- 2) Add BBQ sauce, and bring to a boil.
- 3) Stir and pour over sliced brisket.

Nutrition Facts per serving

Calories:	640
Total Fat	49 g
Saturated fat	19 g
Cholesterol	160 mg
Sodium	630 mg
Total carb	70 g
Dietary Fiber	<1 g
Protein	41 g



Birthday Wishes for those celebrating Sept – Nov!



Cody S.	10/24	Kamron K.	10/14	Isabella C.	9/1
Adam R.	10/8	Jesus G.	9/13	Lauren E.	11/13
Krysta H.	9/7	Piper B.	10/3	Chloe M.	10/24
Deuce W.	9/21	Rylee M.	9/20	Jack W.	11/20
Georgia K.	11/10	Ivy T.	9/28	Harper W.	10/14
Kaden G.	10/25	Aniyah J.	9/5		
Dymond G.	11/1	Yun F.	10/10		
Mason S.	10/21	Carson B.	10/11		
Zariah P.	9/4	Torin Y.	11/8		
Hunter C.	11/9	Grayson Z.	9/27		

Ask Rebecca: What is with the Annual Registry Consent?

The CF Registry is a very large research project that collects data on roughly 30,000 people in the US with CF. Cool, right?!

There are multiple Federal and State laws in place to PROTECT those subjects involved in ANY research study.

Greenville Health System has an Institutional Review Committee which is a select group of professional staff from across the system that reviews each and every research study prior to allowing the research to be done.

Our consent must also

meet with their approval and that of the CFF, again to protect your child and you.

We must update our consents with new signatures each year. Our CF center staff reviews your child's data which compares it to a CF national average and from that data we make recommendations to improve your child's outcomes.

We realize that the paperwork can be overwhelming and apologize for any stress it may cause. We do want you to realize that the data

collected from the CF Registry has literally shaped our CF Guidelines which in turns allows us to provide the most cutting edge care and in turn enhance your child's quality of life.

If you have any questions about the consents please don't hesitate to ask us and know how much we appreciate your involvement in the registry.

For more information:

<https://www.cff.org/Research/Researcher-Resources/Patient-Registry/>



CF Drug Pipeline

Many of you already know that the FDA has approved Orkambi dosing down to age 2. Kalydeco has been approved to age 2 and currently Symdeko is approved from age 12 and up. These drugs contain CFTR correctors and/or potentiators.

These drugs are utilized according to the CF alleles your child has. Each of these medications has certain alleles they treat. If you are unsure if your child is eligible, please ask us during your office visit.

Sweat tests are still the gold standard for testing/diagnosis and is

expected on all CF patients, however CF DNA is now also needed to determine if the CFTR correctors/potentiators we have are available to treat your child's disease.

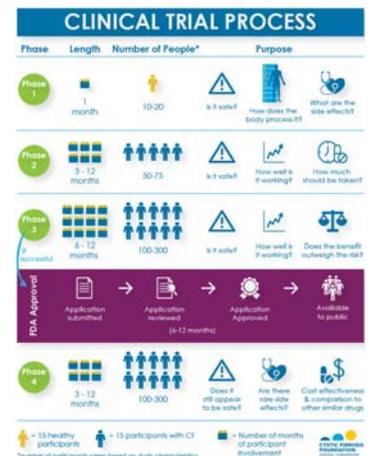
The approval process can take several weeks to months depending on the insurer. Eye exams are required as well as some lab work.

We continue to monitor each child who is started on these medications and document extensively how they respond once they start the medications. Most patients don't "feel" a change, however their

appetite improves, they have fewer exacerbations, and less hospitalizations.

There are currently several pharmaceutical companies working on more of these types of drugs to attempt to treat as many CF alleles as they can.

Research opportunities continue to exist although currently it would involve travel to MUSC or Atlanta. The reality is that our current patients are living at a great time in the history of CF care and we are all excited to see where the research will take us.



North American CF Conference 2018, Denver bound!

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We're on the Web!

See us under:

Children's Hospital at:

www.ghs.org

We're also on FACEBOOK
So check us out and "like us"
www.facebook.com/GHSChildrens

Several members of our team will be boarding planes in mid-October to attend the yearly CF conference. It is attended by professionals from all over the world. We will be presenting a quality improvement project we have been working on at the Pre-conference QI Fair. We are really excited to see the new drugs, equipment and guidelines that will be discussed.

Our CORE CF center will also have a site visit from the CFF in late September and we are proud to show them the changes we have implemented to improve our patient care. YOU have been a part of our process and YOUR feedback matters.

Please ask us the next time you are in clinic to see our posters (previous posters are on the front bulletin board) and the

current poster is still in process!

Consider logging into the 2018 CF Conference and viewing the plenary sessions as they are live-streamed so you too can share in our excitement. There is a lot of positive news we believe will be shared!

About Our Organization...

Dr. Steve Snodgrass is the Medical Director of the Division of Pulmonology of GHS's 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.



There are perks to being the editor; I get to choose the PICS!

GO TIGERS!

