

Cough it Up, Spit it Out!

Pediatric Pulmonology CF Center Updates

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

Dr. Snodgrass presents poster at NACFC

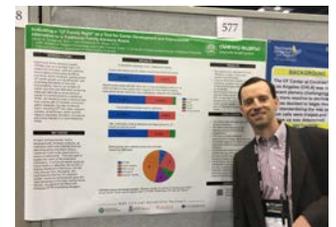
The North American CF Conference is the largest CF conference in America and is attended by people from all over the world. The CF foundation and our own drive as caretakers, motivate us to try to constantly improve patient outcomes and quality of care.

We had presented 2 posters last year and these can be viewed on the bulletin at the front of our office. This year, Dr.

Snodgrass presented an abstract about family dinners and how it was a potential viable alternative to a Parent advisory board given the complex lives our parents lead. Congrats to Dr. Snodgrass for having his abstract included in the Pediatric Pulmonology journal and presenting his poster!

Our division is constantly working on new ways to improve your child's care.

Our current quality improvement plan is trying to optimize the growth of our infant population with an improved weight to length ratio. You can look at our progress on our bulletin boards when you come in.



Welcome Yvonne Dubber!

You are all probably thinking I have lost my mind since Yvonne has been with us now since June, but I have never formally introduced you to her!

Yvonne is originally from Northwest, Ohio and is a big Ohio State fan. (ugh, Go Tigers! LOL!)

She has lived in South Carolina with her fur baby "Snoopy" for the last 4 years.

She is a Christian, and adores her time at the lake and tries to live each

day to the fullest. Yvonne has had some fun trips this year to include a visit to Graceland cause' boy oh boy does this girl love ELVIS! Her other recent trip was to Dollywood where her boyfriend surprised her by having all the family in attendance to view him proposing to her! A November wedding is planned in the Bahamas!

Yvonne has literally fallen in love with our CF patients and families. She strives to make scheduling the least stressful part of your visits here and she

hopes she is able to make your visits with us a positive experience.

Please extend warm welcomes to Yvonne, but remind her that the Tigers and Gamecocks rule!



"Hey are you getting any sleep you looked stressed out is everything ok?"

Me:



"caring for your child can be so time consuming that you forget to take care of YOU!"

Mental Health Minute

Have you heard about the flight safety instructions that are given before a flight takes off? It goes something like this: "In case of an emergency if a child is seated beside you, put on your own air mask before helping to put an air mask on the child." The CF Foundation says parents of a child with cystic fibrosis can focus so much on caring for their child that they do not notice when they are beginning to have problems themselves. The build-up of stress and anxiety can be gradual and, if you're not paying attention, can cause larger problems before you realize it.

Taking steps to take care of yourself can help you, your child, and the rest of your family. The CF Foundation gives some of the following tips that can help you avoid becoming

overwhelmed:

- 1) Respond to bills, medication instructions, and insurance forms as they arrive.
- 2) Learn as much as you can about CF if you haven't already. Connect with other parents of children with CF for general support and advice on how they handle their responsibilities.
- 3) Make time for yourself and others who are important to you, such as your spouse or partner, friends, and family. Do something you like together with your spouse or significant other (do anything not CF-related together, such as watching a movie).
- 4) Eat a healthy diet.
- 5) Practice good sleep habits. Do your best to get enough sleep. Go to bed and wake up on a consistent schedule.

Avoid staying in bed when you are not sleeping.

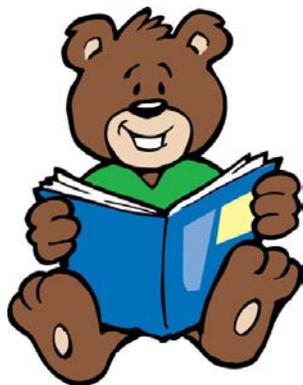
6) Get outside or in nature each day. Try taking a walk.

7) Find one person you feel comfortable confiding in who will let you vent without being judgemental.

8) Do something you like on your own (start small).

As parents it is difficult to make time for ourselves but it is important for our children to see us taking care of ourselves as an example to them. You sacrifice so much and take such great care of your kiddos. You deserve a huge pat on the back and permission to put yourself first every now and then!

CF Center a reception site for Book Donation Grant.



First Steps supports two programs called Read Greenville and Palmetto Basics. As a recipient of the books I have agreed to promote the concepts taught in these programs and plan to attend an upcoming Palmetto Basics Workshop. I listed their logos and websites below if you are interested in checking them out. Basically they encourage daily reading and parents to talk, sing, point, count,

group, compare, explore, and discuss stories with their kids.

I'm hoping that the books give our CF patients something positive to do while they are waiting in clinic or in the hospital. Hopefully they can promote learning, development, and bonding with parents. Studies show that reading can also improve mental health. © Part of my

annual psychosocial assessment includes a developmental portion where I plan to talk with the parents at that time about the Palmetto Basics concepts. **Help every child have a great start!** www.PalmettoBasics.org

Make reading daily a habit! www.ReadGreenville.com

It's not too late to get your FLU VACCINE!

Yes, yes, I know you have heard that the flu vaccine is not as effective as they had hoped. The reality of the fact is the vaccine protects against 4 different flu vaccines and those that receive it, even if they get the flu do NOT have as severe an illness as those who do NOT get the vaccine.

The CF foundation tracks how many of our patients receive the flu vaccine thru the registry. We recommend it as a practice because it is good medicine and will help to protect your child.

We also strongly recommend the ENTIRE family receive the yearly flu vaccine.

We are starting to see an uptick in the number of diagnosed cases over the last couple of weeks but the season is early so you still have time. The hospital has officially asked that children do not visit there due to the risk of flu.

Please reach out to your PCP or our office to get your child vaccinated. Adults can go to most pharmacies, health departments and often

your own employers.

Please do not minimize the severity of influenza. Children and adults with underlying pulmonary diseases are at heightened risk for severe infection.



Recipe Corner: Heavenly Hash browns

Preparation Time: 10 min
Cooking time: 45 minutes
Serves: 8

Ingredients:

1 Big bag frozen shredded hash browns
12 oz. sour cream
12 shredded cheddar cheese, ½ for topping
1 can cream of mushroom soup
¼ cup butter
Salt and pepper to taste

Directions:

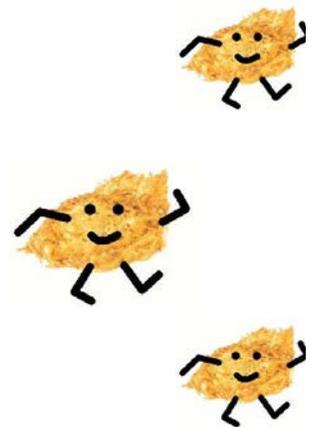
- 1) Mix all ingredients (reserve ½ the cheese for the top)
- 2) Bake in a 12 inch by 9 inch baking dish for 45 minutes at 350 degrees.
- 3) During the last 10 minutes sprinkle with remaining cheese

Nutrition Facts per serving:

Calories:	520
Total fat:	38 g
Sat. fat:	19 g
Cholesterol	90 mg
Sodium:	840 mg
Total carb.:	32 g
Dietary fiber:	3 g
Protein:	15 g

This recipe could easily be lightened with light sour cream and low fat soup, or you could even use less cheese! Another option to add flavor would be to add veggies (peppers, onion) or meat (sausage, ham, or bacon).

Lots of options for this great winter morning breakfast or even better as a breakfast for dinner meal! ENJOY!





New Program for the Upstate

Our local chapter, along with several families and interested community members has put together a program dubbed "Greenville's Finest."

This program has had success across the country with bringing education and awareness about CF while also

providing young adults an avenue for networking with a taste of philanthropy thrown in!

We will be nominating our first class of Greenville's finest soon and winners will be named in March.

If you are interested in learning more or helping in any way please contact

Megan Onysko at monysko@cff.org or 1-866-324-2242.

We are hopeful this will be the first of many years and many classes to come!

Remember to RENEW your insurance and programs

It is the start of a new year and every year we have panicked calls from parents who have let their child's insurance or program renewals run out.

Please, please respond to mailings, emails or phone calls about insurance, Healthwell, Live to thrive

or CF Care Forward.

Every insurance program requires yearly renewal and it is up to YOU to be sure this is done in a timely manner so your child is not without medications or supplements. If you have questions regarding your

child's Healthwell renewals you can speak with Christy Clark, LMSW at 454-5530.

Thanks in advance for taking such great care of your kids!

Great Strides is just around the corner!

Have your registered your team yet? It is TIME!

Our Great Strides walk will be held in APRIL this year.

We will again be at Greer City Park, on April 21, 2018.

This year will be the 30th anniversary of the CF Foundations largest fundraising event!

You can register at: www.CFF.org/GreatStrides!

If you have questions you can also contact our local CFF in Mt. Pleasant, SC at 1-866-324-2242.

Hoping this year will be a bit cooler than last and with twice as many participants.

The CFF has many ideas of things you can do to raise money toward a cure

and these are found on the CF website.

Many of our families have themes for their teams each year to make it fun. I still haven't gotten over the men dressed as bumble bees and unicorns from last year (you know who you are!)

Looking forward to seeing lots of familiar faces in Greer!



NACFC plenary sessions very EXCITING!

The CF Foundation continues to work to try to communicate all the excitement of the conference to anyone interested in the information. The plenary sessions are now being live-streamed and then uploaded to the CF website for you to view from home.

My favorite of the Plenary sessions was the first. I have been caring for people with CF since 1989 when I was still in nursing school. The average lifespan was 16 and NOW we have a median lifespan in the early 40's; and this number continues

to rise every year!

The first plenary addressed the various therapies we have had, now have and what is coming. The future is VERY bright for all people with CF and those that love them.

I strongly recommend sitting down as caretakers with your older children and family members to view this session.

If you are anything like me, you will cry a little, but will end the session with such feelings of hope and excitement about what lies around the corner.

Please remember it is because of you and your willingness to trust our center, to participate in the registry and your amazing care and love of your children that these new therapies will come to fruition.

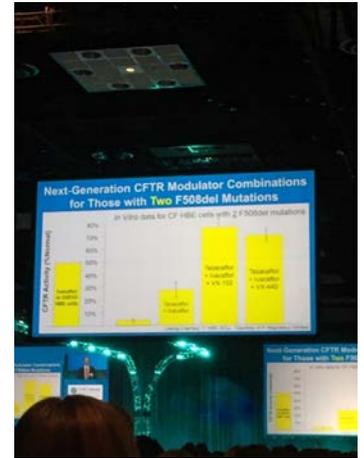
HOPE

DREAMS

FUTURE

And someday, a cure.

If you have questions about what you see on the plenary please write them down and bring them to your next visit and we will do what we can to answer them.



New therapies on the horizon!

Angels with Roses: Make a Wish with Jason!

Children with CF are eligible for Make A Wish, but the wish must be completed by age 18.

Jason was signed to a one day contract with the Pittsburgh Penguins Ice Hockey team. He had breakfast with team and then had the opportunity to receive individualized hockey training by his favorite player, Sidney Crosby.

"While getting to know Jason, the Simpsonville, SC native excitedly told Crosby this his dog is named Sidney Crosby,

although Jason just calls him Sid. Although the dog didn't make the trip, Jason did bring some pictures of his pet. Jason, who shares the same birthday with Crosby, August 7, had a nice moment with his favorite player when he proudly showed Crosby a photo of his dog and took a picture with the superstar once they got off the ice." Jason's mom said, "It's been awesome, crazy and way better than we could've ever expected." Information courtesy of Pittsburgh Post Gazette author Sam Warner.



Happy Birthday to those celebrating from Sept-March!

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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/GHSCchildrens

Areya L.	2/17	Rylee M.	9/20	Chloe M.	10/24
Jessica D.	2/5	Ivy T.	9/28	Jack W.	11/20
Lily W.	3/15	Blaise B.	12/25	Harper W.	10/14
Kaden G.	10/25	Hanna M.	10/17		
Logan T.	1/26	Owen G.	1/20		
DyMond G.	11/1	Kaiden B.	2/13		
Mason S.	10/21	Yun F.	10/10		
Zariah P.	9/4	Carson B.	10/11		
Hunter C.	11/9	Torin Y.	11/8		
Kamron K.	10/14	Grayson Z.	9/27		
Izabella C.	3/13	Karson C.	3/1		
Jesus GS	9/13	Jacob H.	1/21		
Heath R.	12/5	Liliane S.	2/22		
Nathan P.	3/22	Raelyn D.	3/28		
Piper B.	10/3	Isabella C.	9/1		
Emilee M.	3/12	Jude T.	12/13		
		Lauren E.	11/13		

We hope your birthdays
are as special as each
of you is to us!



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. The Children's Hospital is here to support our CF families to the best of our abilities.

