

# Cough it Up, Spit it Out!

## Pediatric Pulmonology CF Center Updates

A Division of Prisma Health Children's Hospital-Upstate (864) 454-5530

### Special Interest Articles:

- Meet King & the rest of our supportive care team!
- Congrats Garrison!
- Great milkshake recipe.

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## Great Strides brings in \$65,000!

Our Upstate teams showed up in full force in May as they SHOWED CFF the MONEY!!! We were honored to have National CFF staff present and I believe our families and center showed her WHY each of you is so incredibly special!

It is always so special to see our patients "outside" the office and especially when they are wearing super hero gear. Y'all know we think our kids and young adults are

super heroic in their journeys with CF. Logan's capes, the masks and the amazing array of T-shirts was extraordinary.

J & I's League raised over \$10,000, way to go! Georgia's crew \$7000 and newcomer team Emilia over \$5000. It is astounding to be able to raise these kinds of monies, but remember EVERY PENNY helps and we are excited for any amount, but even more important is your

participation as we come together to WALK FOR THE CURE and the initials CF will soon mean CURE FOUND.

I have included some pics from the walk below and hope if you walked, you come out again and if you did not, consider joining us. For more information contact:

Megan Onysko at [monysko@cff.org](mailto:monysko@cff.org)

1-843-388-5968



### Introducing Ms. Pauline Lloyd,



Ms. Pauline joined us in early spring as our new nurse. She was born in New York, raised in Connecticut and attended UofSC for her nursing degree. She has 3 kids, 2 grandkids and 2 dogs. Her fur babies are a Golden retriever “Milo” and a Bassett hound “Harry.”

She enjoys traveling and had been all over Europe and the USA. She also enjoys knitting and going

to concerts. She has a varied nursing career, encompassing pediatrics, pediatric oncology, well baby newborn, NICU, PICU, L& D, and most recently (last 20 years) GI. She went from a staff nurse in GI to Manager of GI at Parkway Regional Medical Center to director of GI at Cleveland Clinic Florida, and Aventura Hospital and Medical Center. Pauline said retirement was NOT for

her, and she joined the GI staff at MMOB at GHS in admitting and recovery but then opted for a change.

Pauline is very happy to call Pediatric Pulmonology her home and we are all quite happy she has joined us.

Pauline has taken a leadership role with CF Rise and may be on the other end of the phone if you call. Please join us in welcoming her.

*“We provide a foundation for expressing emotions involved with chronic illness.”*

### Supportive Care team is here for YOU...

The Supportive Care team is an interdisciplinary team of physicians, nurse practitioners, child life specialists, a pediatric psychologist, nurse navigator and a facility dog. Members of the team are trained within the field of pediatric palliative medicine, with their overall focus is to improve the quality of life for patients and their family. Supportive Care works with all types of pediatric patients with chronic and complex medical

conditions. Supportive Care focuses to improve:  
-Physical symptoms and concerns a patient can experience during treatment or hospitalizations

-Psychosocial problems including emotional symptoms including fear, anxiety, depression and others related to a disease

-Communication with the primary and other subspecialty teams so the patient’s voice can be heard clearly

The Supportive Care team strives to foster hope and provide an empathetic presence through unbiased discussions which appreciate a family’s spiritual beliefs, thereby providing a foundation for expressing the emotions involved with chronic illness which are unique to each patient/family.



## Back to School is almost here!

Please, please, please do yourselves a favor and do NOT wait until the first day of school to fax us your child's school forms. We are actively working on filling out forms as we receive them NOW. Please fax your child's forms to 241-9246 today!

We promise, the school nurse is not out to be your child's enemy, in fact the school nurse is typically your child's number one advocate at the school. Prescriptive medications must be in their original containers with the instructions on them. Do

not take an inhaler by itself to the nurse as it is against state law for her to be able to accept it.

Also remember that you have more knowledge about your child that the nurse does and you can work to help establish a great relationship.

If you or your child has never met the school nurse try to arrange a meeting PRIOR to the night of registration as that night is typically very busy. We have brochures at the office for you to share with school staff. We also encourage school staff to

visit the [www.cff.org](http://www.cff.org) site to learn more.

Most of our kids will need a form for rescue inhaler, pancreatic enzymes, 504 plan and some of our kids may need intermittent homebound (we will tell you during a visit if we think your child needs this).

Guidance counselors have the intermittent homebound paperwork for each district but WE have standard forms for the other items that most districts will accept, if yours does not please bring/send the form to us.



We need the school forms as soon as possible.

## Please welcome Jennifer Hipwell, CMA!

Jennifer joined our team in early spring. She has lived in the Upstate for about 4 years and hails originally from Marlette, Michigan.



(We will have to tell her we are ACC and SEC fans here! LOL).

Jennifer loves working with children. She has 6 of her own, 3 girls and 3 boys. She homeschooled her children for 15 years prior to returning to work.

Jennifer enjoys traveling, dancing and working out BUT her most favorite activity is spending quality time with her children.

Jennifer has 4-footed children as well; a dog named Mylie and 2 cats named Mia and Mazie.

Jennifer's favorite foods are DESSERTS.

Our team has enjoyed getting to know Jennifer and much like the rest of us, she enjoys decorating our office!

Jennifer is learning more about Cystic Fibrosis every day, so when she asks you to take the clothes off your newborn, it is only so she can be as precise as possible with their weights.

We are excited to have her on our team and hope you will each make her feel welcome!





## VERTEX has BIG news about Symdeko

We received some great news in June as the FDA approved Symdeko use for children with 2 copies of F508 del or one of 26 specified mutations. This means that an additional 2000 children would qualify for modulator therapy. Tezacaftor/ivacaftor is now available for those

who did not tolerate Orkambi (lumacaftor/ivacaftor).

The CFF has provided some financial support to Vertex in the development of both of the drugs in addition to Kalydeco and the latest triple therapy combination which was recently submitted to the

FDA for approval. This medication requires the patient to have only 1 copy of F508del and thus would treat a larger number of patients.

We are hoping to hear more about the triple therapy combination soon. Please see [www.cff.org](http://www.cff.org) to learn more!

## Lordy it's HOT!!!

Well band camp and fall sports conditioning and those last minute summer vacations are HERE. The lovely HEAT of August brings with it the need to keep pancreatic enzymes, Pulmozyme, Cayston and Tobii/Bethkis cool. These medications begin to break down when exposed to the heat. Please do NOT put them

in your pockets, backpacks or leave them in your car without them being in a cooler with ice packs. Enzymes need to be less than 82 degrees and the other medications need to be refrigerated so please be mindful in your travels and activities. Yeti and even Walmart's version of yeti each have items that can be used.

Be resourceful and remember your child's health and growth depend on it.



## It's nearly time...

If there is anything that is a bit unpredictable in our world, it could certainly be when will flu season start?

Our center and the Prisma Health Children's Hospital Upstate outpatient pediatricians typically have flu vaccines available by early October.

The ONLY flu vaccine your child should receive is in the form of a shot.

The nasal flu vaccine has LIVE VIRUS in it and it is not recommended for children with CF.

The flu vaccine typically takes 14 days to become effective. If your child has never had a flu vaccine then it would need to be delivered in 2 parts about 30 days apart.

Our team and the CFF are firm believers in vaccinating your children

against influenza. Many people will report that the flu is not that bad, however children with chronic disease are at the highest risk of having severe complications. Please discuss flu vaccine with your PCP or our office during your clinic visit. It is equally important for the FAMILY to also be vaccinated.



## Congratulations to GARRISON!!!!

We have an exciting “Angels with Roses” story to tell this quarter!

Garrison has graduated from high school and has been accepted to Anderson University where he is hoping to take courses to prepare to attend Medical School!

Garrison has been raised by a very supportive and empowering family who have taught him that his CF does NOT define him.

Garrison had a very successful high school career and asked about scholarship opportunities. Christy Clarke, LMSW our social worker and our

team encouraged him early on to apply for CF related scholarships.

Ironically enough, when Garrison was in the office for a clinic visit he received a text message that he had won a scholarship from the Boomer Esiason Foundation! Our team was so excited to be able to share in that moment.

Boomer Esiason is a former NFL player and is now an announcer. He has a son with CF and has been able to bring much attention to the disease over his years in the NFL. Boomer’s

Foundation has always supported higher learning but he also supports taking physical care of yourself through diet and nutrition.

His website is accessible at [esiason.org](http://esiason.org) or you can email the foundation at [info@esiason.org](mailto:info@esiason.org)



Boomer’s foundation has scholarship opportunities yearly, just ask Christy or check out his foundation on the web.

## Recipe Corner: Becky’s Super Chocolate Shake

Preparation Time: 5 min

Cooking time: NONE

Serves: one

Ingredients:

8 oz. chocolate milk

1 large scoop chocolate ice cream

1 snack pack pudding

1 envelope hot chocolate

Directions:

Put into a blender and mix until smooth and creamy

Nutrition Facts per serving

Calories: 390

Total Fat: 14 g

Sat. Fat: 7 g

Cholesterol: 35 mg

Sodium: 320 mg

Total carb: 60 g

Dietary Fiber: 3 g

Protein: 9 g

This shake has so many ways you can individualize it to make it your own! Add Oreos, reeces, kit kat or even FRUIT! Make one and enjoy it!



**Milkshakes are easy to customize and a great way to add calories to your child’s diet. Share yours with US!**

## Birthday Bonanza for June thru September!

Krysta H.	9/7	Jacob H.	8/31	Isabella C.	9/1
Deuce W.	9/21	Rylee M.	9/20	Miles P.	7/10
Garrison W.	7/11	Ivy T.	9/28	Briasia L.	8/14
Nicholas C.	6/14	Aaylivia G.	6/10	Raylynn P.	8/18
Annslee P.	7/18	Lauren S.	7/25	Marley P.	7/24
Braydon A.	7/8	Aniyah J.	9/5		
Alyson N.	7/26	Grayson Z.	9/27		
Zariah P.	9/4	Miriam H.	7/10		
Ava W.	7/21	George W.	7/14		
Jesus G.	9/13				
Karlee E.	6/30				
Noah T.	7/10				
JR. L.	7/7				



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**We're on the Web!**

See us under:  
Children's Hospital at:  
[www.ghs.org](http://www.ghs.org)

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

### ***About Our Organization...***

Dr. Steve Snodgrass is the Medical Director of the Division of Pulmonology of Prisma Health Children's Hospital-Upstate and is also our CF Center director. Our purpose:

*Inspire health. Serve with compassion. Be the difference.*

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. Prisma Health

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

