

# 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:

- Christy's Presenting a Poster about YOU!
- ICE Cream CAKE, YUM!
- Clinical trials, are they for you?

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## Great Strides a HUGE SUCCESS!

Just in case anyone from the state of SC wants to know who has the most AWESOME CF FUNDRAISERS? It is the GREENVILLE GREAT STRIDES teams!

We are so happy and proud of our families and their friends. Your hard work not only exceeded our walk amount from last year by \$10,000, but our walk is projected to raise over \$75,000! I am quoting Megan Onysko,

"Incredible results thanks to an incredible CF Community in the upstate."

The Great Strides walk is such a unifying way for family, friends, and our center to join forces as ONE, to walk for a CURE!

We have set the bar high, so get that fundraising mentality ready for next year. Thanks so much for all of your enthusiasm and

your passion. You INSPIRE us!



## Greenville's Finest Event also EXCEEDS!

Go Greenville is all I can say! Our first annual Greenville's Finest Event finale on March 22 was a beautiful event attended by our honorees (pictured at right) and many in our community.

Our program allowed for these young professionals to experience some networking, philanthropy, and education while at the same time increasing awareness of CF in our community.

We had 13 honorees this year! Honorees were submitted to the

Greenville's Finest committee and the final 13 were selected.

The Finest event is projected to raise over \$55,000 which is about \$10,000 over goal.

We want to extend our thanks to our honorees: Gaston Albergotti, Zachary

Alley, Elizabeth Couture, Raquel Denis, Kathryn Dumas, Shannon Ellingson, Bryan Elmore, Cody Hill, Sheaffer James, Brent Pilkington, Kendall Pomeroy, Allyson Powell, and Hanna Sweatt. Looking forward to Greenville's Finest 2019!



## Welcome Catherine Thomas, RN!



We have a new face in our CF Clinic these days. Please help us to welcome Catherine. Catherine graduated in December of 2017 with an Associates degree in Nursing from Piedmont Tech. Catherine is currently planning her wedding which will take

place in December! Catherine is a sweet country gal who enjoys turkey hunting, her dogs and time with friends and family. Catherine has especially enjoyed working with children which is why our clinic was a perfect fit for her.

We are looking forward to each of you getting to know Catherine and loving her, like we do!



## Mental Health Minute: Christy Clarke, LMSW

It matters to us that you feel good not only physically but mentally and emotionally as well. You might have noticed that we've started talking to you more about mental health over the last couple of years.

Our CF Center social worker, Christy Clarke and Dr. Snodgrass have worked together to create a poster presentation for the Southeastern Symposium on Mental Health (SESMH) that reflects the mental health work with our CF patients and their families. The SESMH took place at the Hyatt Regency in downtown Greenville on May 18 and 19. The conference is hosted by the GHS Department of Psychiatry in partnership with GHS Health Science Center Partners.

The poster that Christy and Dr. Snodgrass presented is titled **"Increasing Screening for Depression and Anxiety in a Pediatric Cystic Fibrosis Clinic Population."** General CF

education is provided along with how individuals with CF are at higher risk for symptoms of depression and anxiety. The poster shows how our center was able to integrate depression and anxiety screening into routine CF care per the Cystic Fibrosis Foundation (CFF) mental health guidelines of CF patients ages 12 and above and to improve the quality and accessibility of mental health services for individuals with CF and their families.

The mental health screenings began in 2016 and consist of simple written questionnaires that the patients answer while waiting during routine clinic visits.

Based on the patient score of the screenings an individualized treatment plan is indicated and recommended to the patient and their families. The following resources are available and can be offered anytime:

- Repeat Mental Health Screenings

- Supportive Counseling from CF Social Worker
- Mental Health Education
- Coping Skills Discussions and Guides
- Counseling Referral
- Psychiatrist Referral
- Support Care Team Consultations when Hospitalized
- Mental Health Resources from CFF
- CF Social Work Visits when Hospitalized
- CF Team Consultations with Psychiatry
- Crisis Intervention
- Patient and Family Meetings with Multidisciplinary Team when Hospitalized

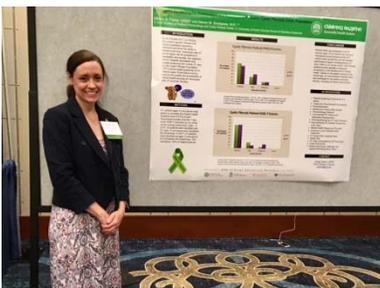
Thank you for allowing us the opportunity to walk beside you on this journey and please let us know if there are other ways we can better support you mentally and emotionally!

GHS Department of Psychiatry & Behavioral Medicine

PRESENTS



SOUTHEASTERN SYMPOSIUM  
ON MENTAL HEALTH



## New Column: "Rebecca, I have a question..."

This is a new column we are adding to the newsletter that involves YOU!

We would like you to submit your questions to Rebecca about your child's pulmonary clearance. This could be things related to their vest, treatments or anything related to the CF Registry which Rebecca coordinates.

I am going to provide you with a generic example so you have an idea what I am talking about.

Rebecca, can you please tell me in what order my inhaled medications should be administered?

Inhaled medications DO have a specified order that allows for best absorption and efficacy.

First is bronchodilator to open up the airways.

Second is hypertonic saline to promote movement of secretions.

Third is Pulmozyme which helps to thin the mucus so it can be coughed up.

Fourth are inhaled steroids or combination ICS/LABA

which decreased the inflammation in the airways and not all CF patients require these.

Lastly antibiotics (Tobi, Cayston) as we want these medications to stick to the lung tissue and work to get rid of any bacteria.

VEST can be used while taking the albuterol and hypersal ONLY. We would also prefer Pulmozyme NOT be given prior to bed as the goal is to thin the secretions and then cough them out, not sleep with them.



This sheet is available at clinic if you are interested

## Recipe Corner: Ice Cream Pie

**Preparation time:** 30 min.  
**Cooking time:** Freeze 1-2 hours

**Serves:** 15

**Ingredients:**

- 1 package Oreo cookies (36 count), crushed
- ¼ cup butter, melted
- ½ of a ½ gallon vanilla ice cream
- 1 cup smooth peanut butter
- 1 cup Spanish peanuts
- 1 cup Hershey's Hot Fudge topping
- Cool Whip (optional)

**Directions:**

- 1) Mix melted butter and crushed cookies. Press into greased pan.
- 2) Cut ice cream into thick slices and lay over cookies.
- 3) Spread with peanut butter.
- 4) Sprinkle with Spanish peanuts.
- 5) Top with hot fudge topping.
- 6) Freeze

**Nutrition Facts per serving**

Calories:	460
Total Fat:	29 g
Saturated Fat:	10 g
Cholesterol:	30 mg
Sodium:	360 mg
Total Carb:	45 g
Dietary Fiber:	3 g
Protein:	10 g

You can add anything to this recipe, like PEANUT BUTTER cups, YUM!!! Let me know what you add or delete and I can publish other ideas! ENJOY, and then go for a run!



**“Creon, ZenPep and Pertye will begin to BREAK DOWN at temperatures GREATER than 82 degrees.”**

## Keep those medications COOL!

Summer is officially upon us and with summer brings travel, camping and lots of outdoor activities. Please remember that Pancreatic enzymes will NOT work if they are kept in temperatures > 82 degrees. When traveling in cars or outside please remember to store

pancreatic enzymes in a cooler.

The same applies for inhaled medications such as Pulmozyme, Cayston, Bethkis, Tobi or Kitabis.

I also want to remind everyone to keep your kids hydrated when outdoors as they will lose salt faster than their

peers. Water and Gatorade are great options, soda is NOT.

Please remember also to apply sunscreen as this is relevant to all children to prevent sunburn and ultimately the risk of developing skin cancer.



## SAVE THE DATE: October 6, 2018



Children’s Hospital Pediatric Pulmonology CF Team will once again join forces with the CF Team in Columbia to host an Education Day at Riverbanks Zoo!

We are currently working on topics to be discussed and will have more

information regarding our event soon. There will be updates posted on our website at:

[www.ghschildrens.org](http://www.ghschildrens.org).

You can look to see further information on the Pediatric Pulmonology tab listed under specialists.

We will definitely be speaking about Symdeko and some of the current drug trials which are very promising.

Hoping to see many of you there! Remember entry into the zoo and lunch is free for the patients and immediate family members.

## CF Pipeline and what is coming!

The birth of child with Cystic Fibrosis involves many emotions. It is not typically diagnosed within the first month or so, and in the interim there is real concern. The diagnosis is a bit of a double-edged sword though; as you now have a diagnosis but you also grieve your “normal” newborn and have real concerns regarding the life your baby will lead. The Cystic Fibrosis Foundation and a multitude of pharmaceutical

companies are working harder than ever to find a cure and treatments that can limit disease progression.

If there was ever a good time to be born with Cystic Fibrosis, NOW is that time.

We currently have 3 oral agents available to assist with the functioning of the CFTR channel with another one on the way if the trials continue to progress as expected.

The trials are a vital aspect of this pipeline. If you are interested in your child being a part of a clinical trial please let us know either by phone or during your clinic visit. We can submit their records for review in a clinical trial and if accepted he/she can participate. We do not currently have trials here, but there are locations in Atlanta and Charleston. You can learn more at: [www.cff.org](http://www.cff.org).



## School forms for the 2018-2019 schoolyear

Okay, yes I know what a summer buzz-kill I am! Reality people, summer flies by and then it is time for registration and we are all in panic trying to get school forms in BEFORE the first day of school.

If your child will be attending a new school for them in the fall, I HIGHLY recommend meeting with the administration/nurse PRIOR to registration so they school and you are on the 'same page' regarding expectations.

I also strongly recommend getting their necessary school forms to bring with you to your summer visit

so we have everything in place for registration.

Most kids will need a form for enzymes (this must by state law be kept with the nurse). They may also need a form for albuterol inhaler. We typically recommend a 504 plan to adjust for absences and we have those forms at our office.

If your child is hospitalized at least once a year it is smart to have Intermittent Homebound paperwork on file. This allows for the school to have enough homebound teachers available. These forms ONLY last 9 weeks so it is

YOUR responsibility to keep them updated. We never mind filling these out.

There is a lot of information on the Cystic Fibrosis website to aid you in communicating with your school and teachers. We have some modest brochures available as well.

CFF and our division do NOT want 2 children with CF in the same classroom or in the cafeteria at the same time as per the Infection Control Guidelines. These are also available at; [www.cff.org](http://www.cff.org).



Get your Forms into our office NOW, for registration in August

## Birthday Bonanza for those celebrating birthdays from April-August!

Garrison W.	7/11	Aaylivia G.	6/10	Giana F.	5/16
Nicholas C.	6/14	Adam S.	5/10	Khlya L.	5/13
Cameron B.	4/04	Lauren S.	7/25	Jocelyn S.	4/13
Anslee P.	7/18	Miriam H.	7/10	Marley P.	7/24
Braydon A.	7/18	George W.	7/14		
Alyson N.	7/26	Ava W.	5/12		
Ava W.	7/21	Madison M.	4/26		
Jason G.	8/07	Cameron D.	4/02		
Karlee E.	6/30	Adaley C.	5/26		
Brynlee G.	4/14	Miles P.	7/10		
Noah T.	7/10	Briasia L.	8/14		
JR L.	7/07	Raylynn P.	8/18		
Jacob H.	8/31	Konnor W.	4/19		

We would like to wish a very Happy Birthday to the kids mentioned and hope your day was/is as special as each of you are to us!



## Angels with Roses: what is Make-A-Wish?

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**We're on the Web!**

See us under:  
Specialists at:

[www.ghschildrens.org](http://www.ghschildrens.org)

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

Make a Wish is a well-known organization that puts together "wishes" for children whose life is considered to be shortened due to disease. A child must be at least 2 years of age and wish must be completed by the age of 18.

Wishes range from a variety of requests depending on what the child truly enjoys. There have been Disney trips, backstage passes/meet and greets with singers,

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

Dr. Steve Snodgrass is the Medical Director of the Division of Pulmonology of 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,

computers, and shopping sprees to name a few. We have recently had 2 of our young men receive Bass boats thru Make a Wish and Cabela's.

The wish should be something the CHILD wants to do, not just a family vacation. A child is only allotted one wish in their lifetime.

You can be thinking about a wish with your child and when ready, let us know and Christy Clarke can make the referral.

You might also consider supporting Make a Wish if it is in your budget as they do a phenomenal job with this program and with our kids.



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.

