

Cough it Up, Spit it Out! Pediatric Pulmonology CF Center Updates

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

Great Strides raised \$60,000!

We had a great day for our annual Great Strides event in Greer. The sun was shining, it wasn't too hot and there were definitely some interesting team costumes! I am not sure which was my fav, either Mackenna's Unicorn daddy or Piper's Bumblebee daddy, complete with yellow tutu!

Our upstate families again were a force to reckon with in regards to fundraising. We had 27 teams registered for the

walk! Every single dollar counts but the unity achieved when we see so many people 'striding' for the same reason is so inspiring.

I wanted to give some shout outs to some of our amazing fundraisers! The Thomas gang again topped \$10,000, and we had several teams reach the \$5000 mark to include; Team Tysinger, ESI Warriors, Georgia Caroline's Crew, Lauren's Loafers and We love

Jason. There were several more teams raising \$1000 which included: Ava & Garrison's gang, 4 Life Fitness, Rock the Ranch for Nick, Flossie's Fighters, Piper's Posse, and Princess Raelyn. Like I said before EVERY dollar counts and we were so excited to see so many of our families. You can continue to raise monies towards this year's event, if you have questions reach out to Megan Onysko at 843-352-6436.

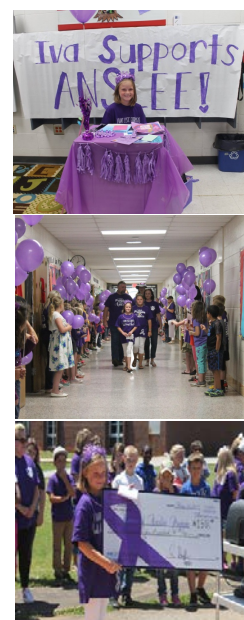
Iva Elementary School ROCKS IT!

When you live with Cystic Fibrosis and deal with the daily challenges at home and then have to also add school it can be very overwhelming.

One of our kids, Miss Anslee had a different experience. Her school decided to have a day honoring Anslee for everything she is, including her CF. Anslee is very active with a pre-school hours prayer group, in addition to being very active in her classroom. The students, faculty and community of

Iva came together to show Anslee how much she means to them. They had a fundraising day and the proceeds were donated to GHS Children's Hospital with a dedication towards helping those children who are hospitalized with CF.

Our staff was amazed at the outpouring of love and support by the Iva community, but we were not surprised as we love each and every one of 'our' kids. I am including some pics of the special day. Congrats Anslee!





"Remember that many inhaled medications and ALL pancreatic enzymes need to be kept COOL!"



It's almost SCHOOL time, are your forms updated?

Yes I appreciate that everyone is trying to enjoy their break from school, however registration will be here before you know it.

Just a reminder to have your school notes for pancreatic enzymes, bronchodilators, 504 plans if needed and intermittent homebound forms if needed ready to be given to the school AT registration.

It is South Carolina STATE LAW that a nurse may not administer medications without a signed consent and it is up to YOU to provide this. Please do not wait until the first day of school when all the fax machines will be overloaded to obtain your notes. We strongly recommend you obtain those forms NOW and either call us if it is a Greenville County school

or mail/fax them to us if your child attends a school in a district other than Greenville.

Not all patients need all forms and if you are unsure please contact us regarding what your child may need. Most kids in elementary school do not need a 504 plan or intermittent homebound unless they require frequent hospitalizations.

Travel and camp reminders

Please remember when traveling this summer and fall that some of your children's medications need to be kept cool.

Pulmozyme, Cayston, TOBI/Bethkis/Kitabis all require refrigeration. They should not however be frozen.

Pancreatic enzymes should also be kept cool as when their temperature is above 82 degrees they

begin to break down and then will not be effective when taken; hence your child will be hanging out in the bathroom! Orkambi too, needs to be kept under 72 degrees.

We recommend you store these medications in a cooler when traveling. If your child is involved in sports or band camps the pancreatic enzymes should NOT be in instrument cases,

pockets, Kavus or in the car. Pancreatic enzymes CAN be kept in a lunch box cooler and preferably stored out of the sun.

Summer is a great time to energize and prepare for fall, but your child's lungs and belly will fare much better if their medications are kept at the recommended temperatures.

Happy sun everyone!

Kalydeco has NEW indications!

We had some exciting news earlier this year with the announcement that 23 more mutations are now responsive to the therapy known as Kalydeco. Ivacaftor is the generic name of this medication that is a potentiator that allows defects of the

CFTR channel to work better and thus has been shown to improve weight, improve PFTs and lessen hospitalization. The new alleles that are now considered responsive are: A1067T, A455E, D110E, D110H, D1152H, D1270N, D579G, E193K,

E56K, F1052V, F1074L, G1069R, K1060T, L206W, P67L, R1070Q, R1070W, R117C, R347H, R352Q, R74W, S945L, S977F. The 10 previous indications are: G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N, S549R, and R117H.

Share. Educate. Encourage. CF CONNECT.

Allergan pharmaceutical is the sponsor of this newsletter and maker of pancreatic enzymes ZenPep and Ultresa; has launched a new program.

CF CONNECT is dedicated to people who CARE for people with CF. It is described as a social forum for parents, caregivers and families of people with CF as per their brochure.

There is a variety of topics available to discuss from recipes to resources. The event allows families to connect and share what worked for them and what

didn't. These types of discussions are vital in the day to day coping of a family with CF.

Our care center works very hard to achieve the best outcomes for your children but we in no way can comprehend your journey the way another parent/caretaker can.

Each CF CONNECT event is different and they are offered in varying areas. If you are interested please contact: Jerry Krise at Jerald.krise@allergan.com

Allergan already sponsors the LIVE2THRIVE

program which is available to commercially insured patients and helps to offset the cost of enzymes, vitamins and supplements along with a rewards program. Please ask us for more information at your next visit or check it out online.

IF you feel you have some information to share with other families or if you need some guidance the CF CONNECT program is a perfect fit for you. Contact Jerry with any questions.



If questions contact:
Jerry Krise at
Jerald.krise@allergan.com

Healthwell Changes

Effective April 10th there were several changes to the HealthWell Foundation CF Grant:

First, the HealthWell Foundation has separated the Grants that cover (i) nutritional products and vitamins versus (ii) co-pay assistance for CF drug therapies and approved nebulizers. For clarity, the Grants are now called the HealthWell Vitamins and Supplements Fund and the HealthWell Treatment Fund.

Second, the maximum annual Grant for nutritional products and vitamins for new enrollees and patients re-enrolling is \$1,500. The

grant amount for co-pay assistance for drugs and for nebulizers remains \$15,000.

Third, grants will be approved based on available funding. For example, a patient may be able to enroll or re-enroll in one fund but the other may be closed at that time.

The income guideline for the Healthwell vitamin and supplement fund is now 400% of the federal poverty level. For example, a household of 4 must have a gross income less than \$98,400.

The income guideline for the Healthwell Treatments fund (medication co-pays and

nebulizers) remains the same at 500% of the federal poverty level. For example, a household of 4 must have a gross income less than \$142,200.

These changes do not affect current Grants, but will affect patients who are enrolling or re-enrolling after April 10th.

Healthwell has starting doing random audits where they are requesting patients submit income verification. You will receive a letter in the mail if you are chosen for an audit.

"If you have questions about Healthwell please reach out to Christy Clarke, our social worker at 454-5568."

What is the Minnesota Protocol?



The vest therapy systems are each a little different and there is lots of misinformation on the internet.

The goal of the vest systems is to make the secretions loose enough that they can be expelled by coughing. The vests should be used at a

minimum of daily and increased up to as often as 4 times a day when sick. Each vest system uses varying Hz vibrations and pressures to obtain the optimal results. We have a handout that is available in clinic if you are interested.

The key with vest use is to

ALSO perform HUFF coughing in between frequency changes of your vest to get the best results.

If you have questions about any of this please ask Rebecca, Sherrie or Sheena when you are here. They are respiratory therapists and happy to answer your questions.

Mental Health Minute courtesy of Christy Clarke, LMSW

Did you know that reading can improve your emotional and mental health?

Reading is proven to reduce stress and increase relaxation. Our CF Center was awarded 250 children's books from the Read Greenville Summer Book Giveaway.

This is a community wide awareness program designed to help spread the word about the importance of daily reading. The donated books were geared towards ages 10 and under (sorry pre-teens and teens)! We hope these books give your

kiddos an educational activity while waiting in CF clinic or during a hospital stay. Have fun reading together as a family this summer!



CF Life Lessons....

Genentech, the makers of Pulmozyme have a new education tool that I think most of you will like. This tool speaks to those that live with CF and those that care for people with CF.

There are a variety of "witness stories" to watch that both validates feelings but also educates regarding why all these medications are needed.

There is of course special

focus on Pulmozyme. The stories can be accessed with a Blippar app if downloaded from the Apple App Store or Google play.

You may also access this information by going to CFLifeLessons.com.

Most of the drug companies that make drugs that treat Cystic Fibrosis have educational resources or programs

available on the internet. Allergan has Live2Thrive & CF CONNECT, Abbvie has CFCare Forward, and Genentech has had educational resources available on their website in addition to [CFLifeLessons](http://CFLifeLessons.com) for years.

These sites are a great way for your older child to know they are NOT alone. Consider some web surfing with your kids and check it out.



FASTPASS Review

Well yes, here I go again on my typical Infection Control rant! The office girls refer to me at the infection control Nazi, not so sure I agree with the term Nazi, but yes I am very VIGILANT with trying to protect your kids.

We started the FASTPASS program about 2-3 years ago and these cards were handed out, with masks and a page explaining our Infection Control Policies for the Health System.

These include:

1. **Having your child wear a mask**

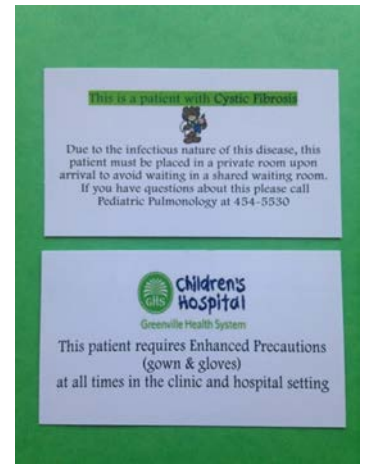
2. **Not being in a shared waiting room.**
3. **Providers and staff should gown and glove when caring for your child.**
4. **If your child is hospitalized, staying in the room as much as possible to lessen risk of picking up new bacterial colonizations.**
5. **Presenting your FASTPASS**

whenever you are seen in any office, ER, lab, x-ray, surgery or for admission.

We have had great response to this policy and continuing finding ways to try to keep your child safe.

Keep on the lookout for new things we are doing here in clinic and remember,

FLASH the FASTPASS, to keep your kids safe!



FASTPASSES are available in our office

Recipe corner: Strawberry-Kiwi Shortcakes

Preparation Time: 30 min
Cooking Time: 15 min
Serves: 8

Ingredients:

Shortcakes:

1 package grand sized refrigerated buttermilk biscuits

2 Tbsp. sugar

¼ tsp ground cinnamon

Fruit Topping:

2 pints fresh strawberries, washed, hulled and cut in bite sizes pieces (save some whole berries for top of shortcakes)

3 kiwi fruit, peeled & cut in bite sized pieces

2 Tbsp. sugar

1 ½ cup frozen whipped topping, thawed

Directions:

- 1) Preheat oven to 375 degrees
- 2) Place biscuits 1-2 inches apart on baking sheet
- 3) Sprinkle combined sugar and cinnamon evenly over top of biscuits
- 4) Bake 11-15 min
- 5) Combine fruits and sugar

- 6) Split shortcakes and place bottom half on plates
- 7) Top with fruit mixture and top half of shortcake
- 8) Add whipped cream and a whole strawberry.

Nutrition:

Calories	310
Total Fat	12 g
Saturated Fat	5 g
Cholesterol	0
Sodium	690 mg
Total Carb	46 g
Dietary Fiber	3 g
Protein	5 g



Birthday Bonanza for our summer bambinos!

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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)

Garrison W.	7/11	Lauren S.	7/25
Nicholas C.	6/14	Miriam H.	7/10
Anslee P.	7/18	George W.	7/14
Braydon A.	7/8	Mackenna T.	8/18
Alyson N.	7/26	Miles P.	7/10
Jason G.	8/7	Briasia L.	8/14
Noah T.	7/10		
JR L.	7/7		
Jacob H.	8/31		
Aaylivia G.	6/10		



We wanted to wish all of our kids having birthdays in the months of June, July and August a very HAPPY BIRTHDAY!

About Our Organization...

Dr. Steve Snodgrass is the Medical Director of Pediatric Pulmonology 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.

