

CF Connection

Summer 2010

University of Florida Pediatric Pulmonary Center

A New Inhaled Antibiotic

This spring, CF got a new tool in the toolbox with the FDA approval of Cayston®, which is the antibiotic aztreonam for inhalation. This is exciting news because the respiratory bug it is most suited to treat is pseudomonas. So when tobramycin is no longer working or that “between” month requires something to fill the gap, we’ve got a new answer.

Some things you should know about Cayston®:

- It is pricey and so it will probably require prior authorization from your insurance company before you can have it.
- It is only available from four specialty pharmacies in the country, so you can’t fill it at your local pharmacy.
- Cayston is administered with a new device called the Altera® Nebulizer System. This device is provided with the medicine, and it will not be replaced if it is lost or broken. The pharmacy provides a new “handset” with each month’s supply of medication. When you get a new one, toss the old because it works less well over time and won’t deliver the medicine correctly if it is old.
- There is a video on YouTube about how to clean and disinfect the device and soon the company will have an instruction DVD on the use and care of the machine (search Cayston on YouTube).
- The treatment only takes three minutes! I know that will be a popular idea and the immediate question will be whether you can use it for all your other inhaled medicines...but it **IS NOT** recommended. The “mesh” in the handset is designed specifically for Cayston® and wouldn’t handle other medications right. TOBI® would actually be unsafe in this device because it would deliver too much medicine making it possible to get a toxic dose that would harm your kidneys or your hearing.
- Another question might be, “why can’t I use this instead of other inhaled antibiotics?” We expect that due to cost, insurance companies aren’t going to pay for Cayston® as a first choice. Also, it doesn’t have a proven track record as a choice for eradicating pseudomonas. It might in the future, just not yet.

Cindy Capen, MSN, RN

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We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 4 or e-mail them to hillajb@peds.ufl.edu.

Thank you to Solvay Pharmaceuticals for funding the printing of this newsletter.

Fundraiser Updates

The annual **Great Strides Walk** to benefit the Cystic Fibrosis Foundation was another huge success on April 17th in Gainesville, with the largest turn out to date! Over 300 people walked for CF and raised \$46,000. Every dollar places us that much closer to a cure and we cannot stop now! We had great food from BJ's, Domino's and Tropical Smoothie and we were entertained by Carlos the Clown. The largest team this year was the Santa Fe Respiratory Club with over 80 walkers, who also came out early to help set up.

November 6th is the date of the annual **Tailgate – Kick Off To A Cure** at the Touchdown Terrace at Ben Hill Griffin Stadium at UF. This is a fabulous event where you can watch the Gators play Vanderbilt while enjoying delicious food from 20 Gainesville restaurants. For more info visit <http://www.cfftailgate.com>.

June 12th was the first annual **Poker Bike Run For a Cure**. About 50 bikes turned out for the event. At each of six stops, the riders picked a card from a deck and at the last stop the rider with the best hand got 10% of the money raised (which he donated back to CFF). At the last stop we raffled off over 60 items, including gift certificates,

tee shirts, coolers, rims, and weekend get away. A live band also entertained the riders. Although it was hot, it was a great turn out for our first year and we raised \$1500.00 to benefit the Cystic Fibrosis Foundation. We look forward to next year when we plan to hold it in the fall with cooler weather.

Hello to all our friends & family who helped with the **Ft White Car Show and Swap Meet!** It was a huge success with over 70 cars in attendance and raised a total of \$14000.00 to the CF Foundation (this includes the Home Depot match)! We have new partners & some old friends always there to help. Please visit our facebook page (Shelley Chris Brown) to see all the photos. The cake auction brought in \$2300 with Hitchcock's winning the most Valuable Bakery cake auction @ \$125 & Miss Evelyn Feagle's Coconut cake brought in \$180 for Most Valuable Homemade cake-(both received trophies). 37 trophies & plaques were given to the awesome cars! David is doing great right now, which is always a blessing to our family. We couldn't be more blessed & happy so again thanks to all of you for each part you play in our lives! Sincerely, The Brown family, Chris, Shelley, Richard, & David.



Help with Medication CoPays

If CMS has been helping with your co-pays, you have probably heard that major cuts to Shands and UF Pediatrics have taken away most of that help. Here are some ideas for filling part of the gap:

- ✓ You can still submit requests to CMS for specific needs, so talk to your case manager about your out-of-pocket expenses to see what help is still available.
- ✓ We have copay cards for Pulmozyme that will limit your co-pay to no more than \$30/month (up to a maximum of \$4000)...please ask if you need one.
- ✓ Pulmozyme Access Solutions will help you find assistance with more than just Pulmozyme. They also have a “no insurance” program for when insurance will not pay. We have the application forms if you need them and you can also visit www.pulmozymeaccesssolutions.com.
- ✓ TOBI CARE Patient Support Program is also available for copay help or for “no insurance” help in the case of insurance denial. We have those forms too! Or call TOBI Access at 1-866-598-8624 for more information.
- ✓ The Cayston Access Program will help with insurance verification, co-pay assistance and claims support. For information, visit

www.Cayston.com or call 1-877-7CAYSTON (877-722-9786).

- ✓ The CF Foundation has a website with lots of other ideas for getting help with medication costs. Visit www.cfservicespharmacy.com/PatientAssistance/ for help with medications other than the three specifically mentioned above.

I won't tell you all this is easy. In fact, the father of one sweet girl said “this is like having a full time job.” It is a sad reality made worse by the big cuts to the CMS grants. We urge you to speak up and tell your stories to the legislators that made these changes so they will better understand the impact of those cuts on your families. In the meantime, we will do what we can to help connect you with the programs that you need. We will also be happy to share any tips you might have for each other.

Cindy Capen, MSN, RN

If you want to let your legislators know how recent CMS changes are affecting you and your family, please visit the following link: <http://www.flsenate.gov/Legislators/index.cfm?Mode=Find%20Your%20Legislators&Submenu=3&Tab=legislators&CFID=217657251&CFTOKEN=82865213>

Enzyme Changes

Pancreatic enzymes now must go through testing and have Food and Drug Administration (FDA) approval, just like any other drug in the pharmacy. As of the printing of this newsletter, only Creon®, Pancreaze™ (a new form of Pancrease) and Zenpep® (a brand new enzyme) have FDA approval. If you are taking Ultrase®, you will not be able to get your enzymes once your pharmacy runs out of their supply. The next time you are in clinic, we will give

you samples of an approved enzyme that you can try. If you will run out of your prescription before your next clinic visit, please call and we will ship you some enzyme samples.

If you would like more information about the enzyme changes, please visit www.cff.org/treatments/Therapies/Nutrition/Enzymes or www.fda.gov and search for “Pancreatic Enzymes.”

Family Corner

What is Health Literacy?

Literacy means the ability to read and write. Health literacy is something different. It is defined as the degree to which we can obtain, process, and understand health information and services needed to make correct health decisions. Health literacy refers to our ability as patients and families to interact with healthcare at all levels. This includes being able to find our way to our health provider's office, understanding what our healthcare provider is telling us, and acting on this information. People working in healthcare offices, hospitals, clinics, etc don't always remember that as visitors to their offices their signs are not always clear, we don't take in all the information we hear, and when we go home we can't always follow the instructions we were given.

Here are some interesting facts:

- Research shows that today's health information is presented in a way that is not usable to most Americans.
- Nearly 9 out of 10 adults have difficulty using the everyday health information that is available to us in healthcare facilities, pharmacies, and our communities.

Without a clear understanding of information, people are more likely to skip medical tests, turn up in the emergency room more often, and have a harder time managing chronic conditions, such as diabetes or high blood pressure. Being health literate affects our health, the quality of our care, and healthcare costs. Many factors influence health literacy: the way we communicate with our healthcare team; our knowledge of our health condition; our culture; and the situation we are currently in (are we or a loved one ill or is the situation more stressful than usual?).

Here are some ways to improve communication with the healthcare team:

- ✓ Tell someone if you have difficulty finding your way to the correct office.
- ✓ Tell your healthcare provider if you do not understand the instructions you are given; and ask for those instructions to be repeated.
- ✓ Repeat back to the healthcare worker what they have said to you. For example, 'I am going to give this medication twice a day, in the morning and the evening and you are telling me it should be taken with food.'
- ✓ Ask for the instructions to be written down or write them down yourself.
- ✓ Ask for brochures in your first language. If you are more comfortable speaking Spanish, for example, ask if the information is available in Spanish.
- ✓ If you are shown how to do something, ask if you can practice it before you leave.
- ✓ Ask for a phone number to call if you have questions when you leave the office.
- ✓ Ask why it is important for you to follow the treatment plan outlined at the visit. Ask the doctor what improvements you can expect to see as a result of a change in treatment and when you should expect to see that improvement.

Being partners in our healthcare benefits all of us! If you would like to comment on this or any other article in the newsletter, please email aminey@peds.ufl.edu.

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