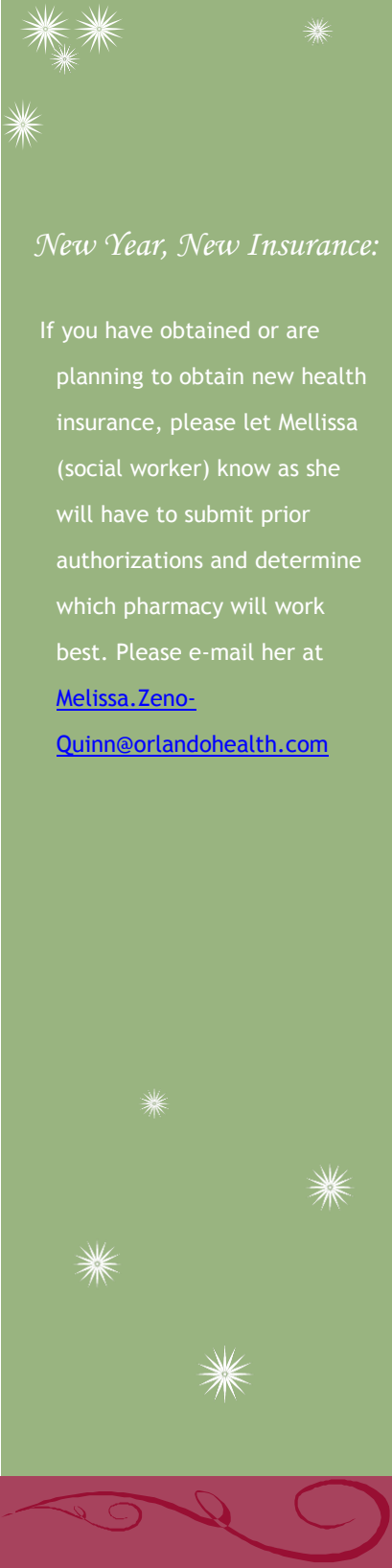




Cystic Fibrosis Newsletter

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Arnold Palmer Hospital for Children- Pulmonology (321)841-6317 aph.cfcenter@orlandohealth.com



New Year, New Insurance:

If you have obtained or are planning to obtain new health insurance, please let Mellissa (social worker) know as she will have to submit prior authorizations and determine which pharmacy will work best. Please e-mail her at

Melissa.Zeno-Quinn@orlandohealth.com



Happy holidays from our family to yours!

On behalf of the Arnold Palmer Cystic Fibrosis team we send out heartfelt wishes for a wonderful and healthy holiday season to you, your family,

and your friends. May you all enjoy a peaceful, safe, and blissful holiday season and best wishes for a happy and healthy New Year!

Flu Shot

The flu is a highly contagious respiratory illness that is caused by a virus. For individuals with CF, getting the flu may cause worse symptoms and lead to a faster decline in lung function. The flu can lead to severe lung infections, like pneumonia. The flu shot can reduce the risk of getting the flu by helping the body fight off or increase its immunity to the virus. The best time to get the flu shot is in September or October, but getting vaccinated in December or January is still helpful as the flu season can last until spring. In our CF Center, only 71% of patients obtained the flu shot so far this season. We hope that this percentage continues to increase! Other ways to reduce the risk of obtaining the flu are: cleaning your hands with soap and water or use an alcohol-based hand gel (especially after

coughing or sneezing). Always cover your mouth when you cough. Use a tissue when you cough or sneeze and if you do not have a tissue readily available, cough or sneeze into your inner elbow. Another way to prevent the flu is to stay at least 6 feet away from anyone who has a cold. Lastly, practice good health habits such as getting plenty of sleep, drink adequate amounts of fluid, eat highly nutritious food, be physically active, and manage your stress. Please call 321-841-6317 or e-mail aph.cfcenter@orlandohealth.com when you obtain the flu shot.



Equipment Checks

Equipment checks are very important. Please bring your equipment once a year to clinic with you. The purpose of these checks are to make sure vests are fitting appropriately, vest parameters are at optimal settings, airway clearance technique is being performed the best way possible, and the nebulizer compressor is strong enough to deliver all medications. Surprisingly, we have already found several nebulizers that

were not strong enough to perform the treatments in a timely fashion and needed to be replaced. So, please make arrangements to bring in your equipment and nebulizer compressor at your next office visit. We want to ensure that you are getting the most out of your respiratory equipment.



Infection Control Outside of APH CF Clinic

We recommend using infection control measures even outside of the Cystic Fibrosis Clinic. If you have CF, for your safety, please wear a mask when in common areas such as any medical related waiting area, bathroom, hallway, etc. If you are admitted to the hospital, tell your nurse that you should be on contact isolation immediately. This means that medical staff will wear a gown and gloves every time they enter the room. This helps prevent infections from being spread.

The CF Foundation recommends that other facilities also do their best to room patients' with CF as quickly as possible, even if it means having to wait longer inside of the room. This is to reduce the risk of infection. This is something that you can talk to your pediatrician and other specialists about. If this is not something they can do, ask if you can wait outside away from other sick patients. Also consider bringing disinfecting wipes to public places to clean surfaces that may be contaminated.



Recipe Spotlight: Pizza Sandwich

1 hamburger bun
2 oz. sliced salami
2 oz. pepperoni slices
2 oz. ham
2 Tbsp. canned pizza sauce
2 oz. sliced mozzarella

Layer filling ingredients on bun, heat in microwave or oven until hot



Social Media: YouTube Channels and Webcasts

Some of you may have seen a QR code within the APH Cystic Fibrosis clinic. The item to the left is a QR code. To utilize, download the QR Reader App and take a picture of this on your smart phone and you will be directly connected to our Arnold Palmer Cystic Fibrosis YouTube channel!

Once the QR reader brings you to YouTube, click on "Playlist" in the right upper corner.

If you do not have a QR code reader you can still visit our YouTube channel at https://www.youtube.com/channel/UCF-cGhA4g5Wnv-zA5_WczbQ.

The Cystic Fibrosis Foundation now has educational webcasts available for all patient's and practitioners. To view these webcasts visit the CFF YouTube channel and click on "Playlists". Here is the link:

<https://www.youtube.com/user/CysticFibrosisUSA/playlists>



Orkambi

In September, the FDA approved Orkambi for patients', with 2 copies of the DeltaF508 gene, who are 6 years and older. If you are interested in finding out more information about this medication, please feel free to contact us.



Cayston

A new, online free educational resource called My Cayston Partner has been launched recently. The online program is meant for patients taking Cayston and/or their caregivers and is filled with essential information about Cayston, interactive tools, tips and insights from other patients to help you stay on track with your treatment. This includes personalized medication and refill reminders, your refill report (available for patients enrolled in Cayston Access

Program), a lung function tracker, patient videos, and practical tips on starting and staying on Cayston. Enroll online at www.MyCaystonPartner.com<<http://www.MyCaystonPartner.com>>.



CF R.I.S.E.

Our newest quality improvement focus is on transition readiness. We will be utilizing a program called CF R.I.S.E. so please be on the lookout for this at your upcoming clinic visit.

New Team Member

The APH CF Center is currently in the process of interviewing and hiring a registered nurse to assist with answering/returning phone calls, placing orders, and assistance with patient care. We are excited to add another member to our team!

*Healthwell
Foundation Program:*

REMINDER: Each year, Healthwell requires families to reapply. To do so, please go to www.Healthwellfoundation.org or call 1-800-675-8416.

HAPPY
HOLIDAYS

