New Beginnings

Update on Pediatric and Adult CF Programs
Mary Helmers, RN BSN
Pediatric CF Nurse Coordinator
Programs Developed and Updated

- CF RISE Transition Program
- Infection Control Guidelines for Cystic Fibrosis
CF R.I. S. E.

- Gilead Transition Advisory Council
- Commenced October 2011 at NACFC
- 10 CF Centers participated in program
- Pediatric/Adult patients reviewed program
- Go Live for pilot December, 2013
- Completed pilot June, 2014
- Approved by the CFF November, 2014
The Mission of the Program

- To foster patient ownership of CF care through an educational program focused on the achievement of independence
Program Objectives

- Provide CF care teams with patient tools to help manage transition and transfer
- Help to facilitate communication between pediatric and adult care teams/patients and caregivers
November 24, 2014

Happy Fall!

We hope this letter finds everyone well. The Stanford CF Center has always considered infection control to be a critical component of safe patient care. The purpose of this letter is to inform our CF patients and families about changes in the Infection Control Guideline’s for CF patients in the Outpatient and Inpatient settings here at LPCH.

As you already know, your Healthcare team wears a gown, mask and gloves when caring for patients that are closer than 6 feet. When you come to clinic we wear all of the above items when seeing you at the clinic visit. If you are admitted to the hospital you will also see that all your care provider’s wear the same gear. The same materials we use in clinic and on the inpatient units, will be used by the all the other departments/clinics in the hospital. This is our goal!!!

We are currently working with the Infection Control Department here at LPCH to in-service and get all our ancillary and specialty clinics on board with the changes. In an attempt to do this we are asking for your help. We are beginning to educate the various departments/specialty areas, but it is a work in progress and will take time to get all the areas on board. Please do not hesitate to speak up and advocate for yourselves. We appreciate and encourage the Team approach!

Included in this letter is your CYSTIC FIBROSIS PASSPORT to carry with you at all times. The purpose of the PASSPORT is for identification and to alert all the areas that you may visit in which the CF Isolation Policy needs to be enforced. So, when you arrive at another department (for example: the lab, radiology, ENT clinic, or outpatient surgery), just present your CYSTIC FIBROSIS PASSPORT. Presenting your card will identify you as a Cystic fibrosis patient and alert the staff to our infection control policy. You will help make this a successful program!

If you have any questions or concerns please do not hesitate to contact us. Please call the RN phone line @ 650-736-1359.

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Dr. Carlos Milla                                              Mary Helmers, RN BSN
CYSTIC FIBROSIS PASSPORT

- Please escort me to a private room
- Please follow Contact/Droplet precautions (see CF Isolation Policy)
- Gown, Mask, Gloves for all Healthcare Providers
- Clean all surfaces after patient contact
- Please remember to use good hand washing/Gel/Foam cleanser before and after patient contact
Welcome Ronni Wetmore, RN MS

Adult Cystic Fibrosis Nurse Coordinator

- Coordinator, Adult Cystic Fibrosis Center of Jacksonville, Florida
- Formerly Coordinator, Adult Cystic Fibrosis Center of Albany Medical Center, Albany, New York