Pediatric CF Updates

Mary Helmers, RN BSN
Pediatric CF Nurse Coordinator
CF Education Day 2014
CF R.I.S.E.

Gilead Transition Advisory Council
Commenced October 2011 at NACFC
10 CF Centers participating in program
Pediatric/Adult patients reviewed program
Go Live started September, 2013
Program Background
Defining CF Transition and Transfer

**Transition:** the purposeful, planned movement of adolescents and young adults with Cystic Fibrosis from pediatric CF Centers to adult CF Centers

**Transfer:** the point in time in which the patient moves from the pediatric CF Center to the adult CF Center
The Landscape of CF Transition and Transfer

**A significant and growing adult CF population
Gaps in transfer and transition-related clinical care have been studied and identified**

**The ‘Emerging Adult’ (18-25) is an at-risk group of CF patients**

**A growing recognition that we need to “do more” to effectively address this issue**

**Though commonly discussed, no approach to facilitate this process has been made available nationally**

Sources:
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
Program Tools
Overview of the Tools

A resource binder for all program-related topics/tools, including printouts of the core toolset for patients in the pilot program.
Objectives: Help each patient identify opportunities to improve knowledge in 11 important aspects of CF care so that the patient and care team can work together to develop a personalized, focused plan.

Modules developed on 11 topics:

- Lung Health and Airway Clearance
- Pancreatic Insufficiency and Nutrition
- CF Liver Disease (CFLD)
- CF-Related Diabetes (CFRD)
- General CF Health
- Screening and Prevention
- Equipment Maintenance and Infection Control
- Sexual Health
- Lifestyle
- Insurance and Financial
- College and Work

Completed at: CF Center
Completed by: CF patient aged 16-25
Completed when: At every quarterly CF Center visit or at the discretion of the CF care team.
CF Skills Checklist

**Objective:** Help each patient to develop age appropriate, self-care skills by working with the CF Care Team to assess and monitor their current level of responsibility for their CF.

**Completed at:** CF Center or Home

**Completed by:** CF patient aged 16-25 or Support Person (Parent, Spouse, etc.) of a CF patient

**Completed when:** Annually or at the discretion of the CF care team
**Progress Report**

**Objective:** Help each patient track improvements in CF knowledge and skills over time and develop focused and actionable transition goals for CF patients at each visit

**Completed at:** CF Center

**Completed by:** CF care team member and CF patient aged 16-25

**Completed when:** Annually or at the discretion of the CF care team
Educational Resource Guide

Objective: Help each patient and care team member access credible educational resources to help overcome knowledge and skill gaps identified in the CF Knowledge Assessment

Completed at: CF Center or Home

Completed by: CF care team member and/or CF patient aged 16-25

Completed when: As needed
Tips for Improving Transition and Transfer Processes In General

Strive for continuous improvement

Introduce the adult CF care team to the CF patient and family before transfer

Create a Transfer Summary Form for all transitioning patients

Coordinate a formal “Transfer” meeting prior to the transfer date

Organize site visits to the adult hospital inpatient unit and adult CF center/clinic

Hold regular meetings between the pediatric and adult CF care teams
Future Goals of the Program

**Digital Portal for CF RISE**
Pilot started January, 2014

**Role out Nationally to all CF Centers with support from the CFF**
Thank you to the 5 patients and their parents for participating in the Pilot Program!!!!