Introducing CF R.I.S.E.

Speaker Name
Institution
Date 1, 2015

CF R.I.S.E. was developed in collaboration with a multidisciplinary team of CF experts and is sponsored by Gilead.
CF R.I.S.E. Program Overview
(Responsibility. Independence. Self-care. Education.)

- Help **prepare and empower** patients aged 16-25 to transition to adult care

- Identify areas for improvement in patient’s **knowledge and ownership** of their CF care

- Help to **facilitate communication** between patients & caregivers and their pediatric & adult care teams
Transition & Transfer

- A significant and growing CF population

- Adolescence and emerging adulthood is a critical time for patients to transition to caring for themselves

- Gaps in transfer and transition-related clinical care have been studied and identified
  - No consistent or standardized approach to transition nationally

- A growing recognition that we need to “do more” to effectively transition CF patients into adulthood

Sources:
CF R.I.S.E. was developed in collaboration with a multidisciplinary team of CF experts across pediatric and adult teams and is sponsored by Gilead.

<table>
<thead>
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Patrick Flume, MD
Medical University of South Carolina (adult)
CF R.I.S.E. Tools

- Tools are available in **Print format** as well as on the **Interactive Digital Portal**
- Digital Portal can be accessed on a **desktop, tablet** or **mobile** format

**CF Knowledge Assessments**  
**Responsibilities Checklists**  
**Progress Report & Educational Resource Guide**  
**CFRISE.com**

**THESE TOOLS MEET THE GUIDELINES AND STANDARDS OF THE CF FOUNDATION’S EDUCATION COMMITTEE.**
CF Knowledge Assessments

11 Assessment Topics

- CF Liver Disease (CFLD)
- CF-Related Diabetes (CFRD)
- College & Work
- Equipment Maintenance & Infection Control
- Sexual Health
- General CF Health
- Insurance & Financial
- Lifestyle
- Lung Health & Airway Clearance
- Pancreatic Insufficiency & Nutrition
- Screening & Prevention
Responsibilities Checklist for Patient & Support Person

- CF Responsibilities Checklist helps patients identify aspects of their care and where they can take more ownership
- Completed by both patient and support person (ex: parent, spouse, significant other)

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CFRISE.com Patient Website

**KNOWLEDGE ASSESSMENTS**
- Direct links to educational resources relevant to gaps
- Option to email results

**HISTORY OF RESULTS**
- History of knowledge assessments & responsibility checklists
- Track results over time

**RESPONSIBILITIES CHECKLIST**
- Identify level of responsibility around CF between patient and support person

**Why Go Digital?**
- Access the site from your desktop, tablet or mobile format
- Log in at home after clinic
- Access your results and educational materials
- Review your history of results
Protecting Your Privacy

- Each patient personally registers for the Web site
  - First Name, gender, email address and birth date
  - Patients under 18 require a parent/guardian’s consent
- Clinic code ensures that only you and your care team have access to your information
- Gilead only has access to de-identified and aggregated information
- HIPAA Compliance & Informed Consent
  - data is safeguarded with security tools including a user ID and password
  - data encryption for all personal information
Patient Introduction to Program
CF Care team discusses CF RISE program with patient to support transition

Enroll/Login to CFRISE.com
(can be accessed via smartphone, tablet, laptop or desktop computer)

Complete CF Knowledge Assessment(s) and/or Responsibilities Checklist(s)
(as directed by your care team)

Review Results and Discuss Educational Needs
(track results on the Progress Report)

Discuss & Set Measurable Transition Goal(s)
(capture goal on Progress Report and initial to indicate commitment)

Implement Transition Goal
(contact care team if you have questions)

Take Home a Copy of Your Progress Report
(place copy in your chart for reference at next visit)

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What’s Next?

- **Spring 2015**: Spanish Patient Materials
- **Winter 2015/2016**: Materials for Parents & Younger Adolescent Patients

Ask your Care team for more information on how to register on CFRise.com today!
THANK YOU!