CF Transition
Graduating from Pediatric to Adult Care
The Face of CF
CF requires multidisciplinary care

Manifestations of Cystic Fibrosis

- Lungs
  - Bronchiectasis
  - Bronchitis
  - Bronchiolitis
  - Pneumonia
  - Atelectasis
  - Hemoptyis
  - Pneumothorax
  - Reactive airway disease
  - Cor pulmonale
  - Respiratory failure
  - Mucoid impaction of the bronchi
  - Allergic bronchopulmonary aspergillosis

- Heart
  - Right ventricular hypertrophy
  - Pulmonary artery dilation

- Spleen
  - Hypersplenism

- Stomach
  - GERD

- Pancreas
  - Pancreatitis
  - Insulin deficiency
  - Symptomatic hyperglycemia
  - Diabetes

- Reproductive
  - Infertility (aspermia, Absence of vas deferens)
  - Amenorrhoea
  - Delayed puberty

- Intestines
  - Meconium ileus
  - Meconium peritonitis
  - Rectal prolapse
  - Intussusception
  - Volvulus
  - Fibrosing colonopathy (strictures)
  - Appendicitis
  - Intestinal atresia
  - Distal intestinal obstruction syndrome
  - Inguinal hernia

- General
  - Growth failure (malabsorption)
  - Vitamin deficiency states (vitamins A, D, E, K)

- Nose and sinuses
  - Nasal polyps
  - Sinusitis

- Liver
  - Hepatic steatosis
  - Portal hypertension

- Gallbladder
  - Biliary cirrhosis
  - Neonatal obstructive jaundice
  - Cholelithiasis

- Bone
  - Hypertrophic osteoarthropathy
    - Clubbing
  - Arthritis
  - Osteoporosis
In 1996, The CF Foundation recommended that all CF Centers transition at least 90% of their patients aged ≥21 years to adult providers.
The New Faces of CF
Transition: A period or process of changing from one state or condition to another

• **Barriers**
  » Logistics
  » Parents not “letting go”
  » Concerns over quality of care and poor communication
  » Family-focused care limits education, independence, and self-management skills for the adolescent

• **Consequence**
  » Patients not seeking care until a serious problem arises


Project Aim

To improve the CF transition process at UNC by creating a sustainable, streamlined, systematic approach to transition for patients beginning early in adolescence and extending to the hand off to adult clinic (age $\geq$18). We expect this will improve health literacy among patients, reduce the number of delayed CF transitions, and improve patient and provider satisfaction.
Know your 5 P’s

Percent of Eligible Patients Transferred

<table>
<thead>
<tr>
<th>Year</th>
<th>Number eligible for transfer</th>
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<tbody>
<tr>
<td>2010</td>
<td>58</td>
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<tr>
<td>2011</td>
<td>48</td>
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<tr>
<td>2012</td>
<td>43</td>
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<td>2013</td>
<td>49</td>
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<tr>
<td>2014</td>
<td>41</td>
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<td>2015</td>
<td>39</td>
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New Process Led by Transition Coordinator

- Transition Team Meetings
- Tours
- Welcome Booklet
- Feedback
- Tracking Outcomes
- Contact between appts
- CF RISE

Welcome Booklet
Tours
Tracking Outcomes
Feedback
Contact between appts
CF RISE
Transition Team Meetings
CF R.I.S.E.

LUNG HEALTH & AIRWAY CLEARANCE

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

CF R.I.S.E. was developed in collaboration with a multidisciplinary team of CF experts and is sponsored by Gilead.
CF Responsibilities Checklist

3: Living With Cystic Fibrosis

Name: _________________________________  Note: There are no right or wrong answers to this survey.

Date: _________________________________  Please provide your honest feedback below so that we can work

1. I am completely responsible  2. I am primarily responsible  3. My support person and I are equally responsible  4. My support person is primarily responsible  5. My support person is completely responsible  NA Not Applicable

Please indicate the person in your household responsible for each of the following healthcare behaviors by placing the appropriate number from 1 to 5, or NA for Not Applicable, in the boxes below:

<table>
<thead>
<tr>
<th>Behavior</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>NA</th>
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<tbody>
<tr>
<td>1. Identifying someone with whom psychological and emotional issues can be discussed</td>
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<td>2. Telling close friends, family members, teachers, administrators, etc. about CF</td>
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<td>3. Knowing how to answer or having prepared answers for questions about CF from others</td>
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<td>4. Making sure to follow infection control standards (eg, cleaning your nebulizer regularly)</td>
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<td>5. Making healthy lifestyle choices related to drugs, alcohol, and cigarettes</td>
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<td>6. Recognizing limits (eg, days you may need extra sleep)</td>
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<td>7. Making time for exercise</td>
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<td>8. Making time for fun and hobbies</td>
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<td>9. Preparing for hospital visits/tune-ups</td>
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Add all individual numbers entered for each row above and insert the total on the line below. Divide the total by 9 and enter the result in the box.
Flow Chart for Patient Transition

1. Patient ready for transition? [Y/N]
2. Y: Transition team discussion
3. N: Remains under care of Peds team
4. Y: Referral Sent
5. N: Feedback given
6. Patient attends appt
7. Reminder calls
8. Appt made
CF Transition Pathway

You’re entering a very exciting phase of life! You have been learning a lot about what it means to have CF as you’ve gotten older, and we will continue to work with you to learn everything you need to know to be an adult living with CF. Part of being an adult with CF is transitioning to the adult CF care team. Don’t panic! We’re here to usher you along in this process and make every step as easy and stress-free as possible!

Sweet 16
- Enroll in CF R.I.S.E.
- First meeting with adult CF team members

Late High School
- Meet with adult CF team yearly.
- Independent clinic visits (without your parents present).
- Communicate directly with staff by phone calls, email, or MyChart.
- Make decisions about future goals and plans (college, employment), and how they will be affected by having CF.
- Gain independence in daily CF care at home (treatments, medications).
- Discuss insurance options for after high school graduation.

Early High School
- Begin to have part of your clinic visit with the CF team without your parent present. It does not need to be the entire visit, but we want you to become comfortable about talking about your health.
- Discuss healthy lifestyle choices with your CF team. The choices you make now will have an impact on your long-term health.
- Learn what your medications are and why you take them.
- Discuss with your parents how you can take more responsibility for your care at home (cleaning equipment, organizing medications, etc.).

Oh the Places You’ll Go!
- Begin an exciting new phase of life: college, work, relationships, etc.
  - Tour the adult CF facilities.
- Have your last visit in the pediatric CF clinic.
  - First visit in the adult CF clinic.

Congratulations!
CF R.I.S.E. Enrollment

Transition Coordinator

new enrollment

total enrollment
CF R.I.S.E. RESPONSIBILITY CHECKLISTS COMPLETED

Transition Coordinator

# of Responsibility Checklists Completed per month
Patient Phone Calls

- **Number of pre-visit phone calls made**
- **Number of successful pre-visit phone call attempts**
- **Number of follow-up calls made**
- **Number of successful follow-up call attempts**
A Patient’s Story

- Looking to live independently from parents
- Completed the CF R.I.S.E. insurance & finances knowledge module and set transition goals

- **Patient:** “I feel much better about living by myself now. It is the first time I really thought about the financial side of my disease”.

- **Mother:** “My mind is more at ease now. I feel better about letting my child go.”
Spread Plan

- **Institutionally**
  - Other chronic childhood diseases
    - Pulmonary focus at first (asthma, PCD, etc.)
    - Primary Care Provider
  - Implementation toolkit and role descriptions

- **Nationally**
  - CF R.I.S.E. for age range >10
  - ATS working group
  - Got Transition and ACP Resources for Transition
Lessons Learned

• Program Champion(s)
• Institutional Buy-in
• Patient/family engagement
• Minimize work for others
Acknowledgements

- CF Transition Team
- Pediatric and Adult CF Teams
- CFF LLC2
- Patients and families
- IHQI
  - Tina Willis
  - Laura Brown
  - Jacob Reardon