WHAT TYPES OF INFORMATION CAN YOU FIND IN THE CYSTIC FIBROSIS FOUNDATION PATIENT REGISTRY?

CYSTIC FIBROSIS FOUNDATION®

DIAGNOSIS

- Age of diagnosis
- Method of diagnosis: newborn screening, respiratory and/or gastrointestinal symptoms, failure to thrive
- CFTR gene mutations
- Sweat test results

CARE RECEIVED

- Location of care: clinic, hospital or home
- Providers seen during clinic visit
- Reason for hospitalization: pulmonary exacerbation, transplant, gastrointestinal
- Length of hospital stay

DEMOGRAPHICS

- Age
- Sex
- Race
- Ethnicity
- State of residence
- Personal and parental education
- Employment status
- Marital status
- Smoking status
- Health insurance coverage

TREATMENTS

- Antibiotics
- Mucus thinners
- Bronchodilators
- Anti-inflammatories
- Airway clearance techniques
- Pancreatic enzymes
- Nutritional supplements
- CFTR modulators
- Growth hormone
- Insulin
- Oxygen

OTHER CONDITIONS AND EVENTS

- CF-related diabetes
- Asthma
- Sinus disease
- Gastroesophageal (acid) reflux disease (GERD)
- Liver disease
- Allergic bronchial pulmonary aspergillosis (ABPA)
- Osteoporosis
- Depression and anxiety
- Pregnancy
- Transplant: lung, liver, kidney

MEASUREMENTS & SCREENING TESTS

- Height and weight
- Lung function
- Cultures: *Pseudomonas aeruginosa*, *Staphylococcus aureus*, *Burkholderia cepacia* complex, nontuberculous mycobacteria
- Pancreatic function
- Screenings: mental health, bone health, CF-related diabetes
- Blood tests: glucose, liver & kidney function, vitamin levels

See the Annual Data Report for a full list of the data collected by the CF Foundation Patient Registry: **www.cff.org/Our-Research/CF-Patient-Registry**. Questions? Email us at **pfrac@cff.org**.