Behind the Scenes of a CF Clinical Trial

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Behind the Scenes of a CF Clinical Trial
Number of People in the U.S.A.

- High Blood Pressure: 68 million
- Asthma: 25 million
- Diabetes: 26 million
- CF: 30,000

Source: www.cdc.gov 2012
Safety at Multiple Levels

- Protocol Development
- National Level
- Institutional Review Board (IRB)
- MD and CF team
Behind the Scenes of a CF Clinical Trial

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FAQs About Clinical Trials

- What happens during a clinical trial?
- Who can participate?
- Will my CF care team stay involved in my care?
- What do words like protocol, placebo, randomized and control group mean?
- What are the different phases of clinical trials?
- What are some of the benefits and risks of participating in clinical trials?
- Can I leave a clinical trial after I have joined?
- How safe are CF clinical trials?
- How is my safety protected broadly?
- How long does each phase of a clinical trial last and what are the associated risks?
- How do you choose which drugs will be tested in clinical trials?
- At what age can someone join a clinical trial?
- How can I learn about CF clinical trials in my area?
- Who at my CF care center should I ask about clinical trials?
- What questions should I ask about participating in a clinical trial?
- If I’m compensated for participating in a clinical trial, will that affect my eligibility for Supplemental Security Income (SSI) or Medicaid?
- Will I get early access to drugs if I participate in clinical trials?
- What does “expanded access” mean?
- I have participated in trials and have never heard about the results. Why?
- Who decides how much money clinical trial participants are paid?
- Are there plans to collect and compare clinical trial information from outside the United States?
- Why aren’t all CF care centers involved in clinical trials?
- What can I do to help bring CF treatments to the CF community sooner?
- What does the future look like for my child with CF? Is a cure in sight?
- Other than raising enough money for research, what are the biggest challenges to finding a cure for CF?
Find a Clinical Trial

Find out about clinical trials in your area by using the CF Foundation’s clinical trial search tool. This tool has recently been updated to allow you to search for clinical trials in cystic fibrosis using three methods:

- View all trials
- View by the status of the trial (i.e. not yet recruiting, recruiting)
- View trials using “advanced search” to narrow the search

The advanced search limits the search by age, lung function (FEV1), Pseudomonas aeruginosa status, Burkholderia cepacia status, state, type of therapy, post transplant, and keywords.

Your CF care center team is a great source of news about clinical trials that are currently enrolling patient volunteers. Talk with your care center team about what trials they are involved in.

The clinical trials contained on this website have been reviewed and sanctioned by the CF Foundation’s Clinical Research Committee, Data Safety Monitoring Board and/or the Therapeutics Development Network’s Protocol Review Committee.

Learn more about CF clinical research and the benefits of participating in a clinical trial for CF.

Another resource is the National Institutes of Health website: www.clinicaltrials.gov. Visit this site and search for “cystic fibrosis.”
CF Foundation’s Clinical Trial Search Tool – Advanced Search Option

**Find A Clinical Trial**
- Care Center Network
- Drug Development Pipeline
- CF Services Pharmacy
- Make a Donation

**Find a Chapter**
- Enter zip code: [Search]

**Get Connected**
Watch Charlotte, whose son Trey has cystic fibrosis, talk about her dream for the future.

Join us on Facebook

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**OR limit search results...**

What would you like to view:
- Not Yet Recruiting
- Recruiting
- Recruiting Completed
- Trial Completed (Results may not be available for all trials)
- All Trials

**Keyword Search:**
- Select patient’s age:
- Select FEV1%:
- Select Pseudomonas Status:
- Select B Cepacia Status:
- Enter state of patient’s location:
- Limit to lung transplant studies:
  - No
  - Yes

Limit by type of therapy
- [Get Results]
- [Basic Search]
Clinical Trial Alert Tool

Sign Up for Clinical Trial Alerts

Sign up below to receive clinical trial email alerts when a trial is posted and when clinical trial results are available.

Receive Clinical Trial Alerts

* First Name: 
* Last Name: 
* Email: 
Submit
Drug Development Pipeline

Finding new medicines to fight CF and ultimately a cure is the driving force behind the Cystic Fibrosis Foundation. To achieve this goal, we aggressively invest in drug development research with the most successful and innovative biotech companies and scientists in the world. We're attacking the disease from every angle.

Click on the interactive pipeline below to learn more. You'll see nearly 30 CF drugs in development or already in use by patients — more than in the entire history of the disease. The Foundation is propelling each of these medicines forward and will not stop until there is a cure.

New: Kalydeco™ received approval from the FDA on January 31, 2012 for people with CF ages 6 and older with the G551D mutation of CF.
…for watching

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Rick Vasta and the technical crew

Melisa Kennedy and Leslie Hazle

The CF Foundation

Genentech