

# CLINICAL TRIAL BREAKTHROUGHS START HERE

Incredible breakthroughs in the treatment of cystic fibrosis have been achieved through clinical trials. Drugs and treatments that have added tomorrows — and make living with CF today better for thousands — are now available thanks to this research and everyone who volunteered to be a part of it. When you participate in a clinical trial, you are helping transform the future of CF.

## WHY PARTICIPATE?

The research community can only develop new treatments for cystic fibrosis with the help of clinical trial volunteers. As a participant, you will be leading the way to new therapies and advancements in CF care. You may also gain early access to new drugs not available to the public.

## WHO CAN PARTICIPATE

With clinical trials currently underway all across the country, there are plenty of opportunities to be part of a trial. Each clinical trial has guidelines about who can join, known as inclusion and exclusion criteria. Criteria are based on factors such as age, CFTR mutation, previous treatment history, current state of health, and other medical conditions. You can search for trials you may be eligible for using the Clinical Trial Finder at [cff.org/finder](https://cff.org/finder).



Donnita, a child with CF, and  
Mary, a CF research coordinator

## THERE ARE MANY KINDS OF TRIALS — ONE MAY BE RIGHT FOR YOU

Trials vary in length and in number of visits (if visits are even required) and can be about a treatment, a drug, or simply involve reporting about your lifestyle or emotional state. Some may offer compensation. You can participate in many different trials, though not necessarily at the same time, and can leave a trial at any point. If you choose to leave or withdraw from a trial, be sure to discuss this with your research team, as they may ask you to come for a final visit.





## POTENTIAL BENEFITS AND RISKS

Like most things in life, participation in a clinical trial comes with possible benefits and risks.

### POSSIBLE BENEFITS INCLUDE:

- Taking a more active role in your own health care
- Gaining access to new treatments not available to the public
- Getting expert medical care at leading health care facilities
- Helping others by contributing to medical research
- Receiving a treatment that works for you

### POSSIBLE RISKS INCLUDE:

- Experiencing side effects or adverse reactions to medications or treatments
- Receiving a treatment that doesn't work for you

## YOUR SAFETY MATTERS

Multiple regulatory groups, from the U.S. Food and Drug Administration to the Institutional Review Board for each particular study, help determine that every trial is safe and appropriate for participants.

CF trials have an additional safeguard — your health is monitored in real time by the Data Safety Monitoring Board, an independent committee of experts in CF clinical care and research, as well as by the study research team and your regular care team. If you or those monitoring the study note any worsening of your health, you can be withdrawn from the study, or the study may be halted altogether.

## VISITS AND SCHEDULING

Study visits vary based on the trial; some require only a quick blood draw, while others may involve multiple visits or more extensive testing. Most research teams are willing to coordinate with your CF care team so that some of your study visits may take place the same day as your or your child's regular clinic appointment. Ask your research team about the time commitment for a specific clinical trial.

## LEARNING ABOUT TRIAL RESULTS

It's only natural that after participating in a trial, you want to know the results. But it can take researchers several months or more to analyze the data. Once the trial results are available, they are posted on [cff.org/finder](https://cff.org/finder). You can also sign up for email alerts to have results sent to you directly. Your CF care team can help you learn more about what those results mean for you.

## WHAT YOU CAN DO TODAY

- Search for trials you may be eligible for at [cff.org/finder](https://cff.org/finder).
- Ask your care team about clinical trials that may be a good fit for you.
- Email [TrialNavigator@cff.org](mailto:TrialNavigator@cff.org) to get personalized assistance with the clinical trial process.
- Tell others about the importance of clinical trials and the critical role they play in transforming the future of CF treatments.

## YOUR HEALTH, YOUR IMPACT

SCAN THE QR CODE AND FIND  
A TRIAL THAT'S RIGHT FOR YOU

