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to finding new treatments
for **cystic fibrosis**

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**CYSTIC FIBROSIS
FOUNDATION**
ADDING TOMORROWS



Learn. Ask.

Join.

Help us discover and develop potential new treatments for cystic fibrosis.

Lise Courtney | Age 18

Dear Friends,

Founded more than 50 years ago by a small group of parents whose children had CF, the Cystic Fibrosis Foundation funds more CF research than any other organization and is the world's leader in the search for a cure. Nearly every CF drug available today was made possible because of Foundation support, and research to find a cure is more promising than ever before.

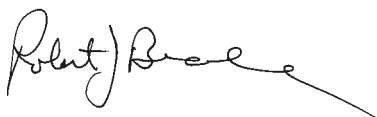
The most recent example of this progress is Kalydeco™, the first drug to treat the underlying cause of CF in a small group of those with the disease. Kalydeco has opened exciting new doors to research that could eventually lead to a cure for all people with CF. Along with other, more widely used, CF drugs — such as Pulmozyme®, Cayston®, TOBI®, azithromycin and hypertonic saline — Kalydeco would not be available today if individuals with CF had not first decided to take part in clinical trials.

You are the key to continuing this progress.

We are now testing more potential drugs in clinical trials than ever before. To help these drugs move swiftly from the research stages into the hands of those who need them, we need more people with CF to take part in clinical trials. Without volunteers — without people like you — more groundbreaking research and progress will not be possible.

We invite all people with CF and their families to learn more about clinical research, ask their doctors and CF care center teams for information about clinical trials and join in the effort to develop new treatments by volunteering for clinical trials.

As a participant, you can help our community continue to move forward so that everyone with CF can live longer, healthier lives.

A handwritten signature in black ink that reads "Robert J. Beall". The signature is fluid and cursive, with a long horizontal line extending from the end of the name.

Robert J. Beall, Ph.D.

*President and Chief Executive Officer
Cystic Fibrosis Foundation*

Learn about CF clinical trials

The Foundation and its accredited CF care centers can help you learn more about what you can expect if you join a clinical trial.

Each center uses the talents of many health experts — including doctors, nurses, researchers, respiratory and physical therapists, dietitians and social workers — to provide the best care to people with CF. Care centers also offer support as you determine which trial is right for you or your family member.

Care centers play a key role in the development of treatments. New CF drugs are available only after they have been tested by people with CF in a series of clinical trials. Results from clinical trials must then be submitted to the U.S. Food and Drug Administration (FDA) before a new drug is approved.

Learn

Patient safety comes first in every CF clinical trial

The highest priority of all trials is to protect the health and safety of the volunteer. The U.S. government has strict guidelines in place to ensure patient safety.

- The FDA must approve the clinical trial design before any new drug is tested in people. Many laws and regulations control the testing of new drugs in clinical trials and help ensure that clinical trials are as safe as they can be.
- An Institutional Review Board (IRB) must review and approve each trial before it enrolls any participants. Each CF care center has an IRB to protect the rights of people who take part in clinical trials.
- A Data Safety Monitoring Board (DSMB) — an independent group of experts in CF care — reviews activities before, during and after each clinical trial. The DSMB protects the safety and welfare of volunteers taking part in CF clinical trials and makes sure trials are done safely and ethically.



“I was nervous to have Meaghan participate in a clinical trial, but after speaking with our care center staff, I realized that we just needed to find the right opportunity. Our experience has been very positive and Meaghan feels good about helping other people with CF.”

Michelle | Mother of Meaghan, a three-year-old who has CF and is taking part in a clinical trial



“I am proud of my role as a participant in clinical trials. Even when a drug does not continue to the next phase of testing, researchers still learn from the clinical trial so that they can make a better drug in the future.”

Joan | A 52-year-old market research consultant with CF, who has been married for more than 20 years

Ask

Ask your CF care center team about clinical trials

Potential new drugs are being tested at care centers across the United States by people with CF of all ages. Your care center is a great source for news about current CF research.

Most CF care centers have a research team in charge of clinical trials. The research doctors (usually called “investigators”) and research coordinators can provide you with information about current clinical trials and answer all of your questions. The research team enrolls people with CF in clinical trials and works closely with volunteers throughout the clinical trial process.

There are always new opportunities to participate in clinical trials — be sure to ask your or your child’s CF doctor or nurse or a research coordinator to keep you informed.

More information is available on the CF Foundation website, **www.cff.org**. Here, you can find CF clinical trials in your area via an online search tool. The tool allows you to narrow your search — for example, by age, lung function or type of therapy — and provides information on specific clinical trials that you can then discuss with your CF care team.

You can also sign up to receive clinical trial email alerts, which keep you informed of new clinical trials and trial results.

To find a clinical trial:

- Visit **www.cff.org/Find**.
- Call the CF Foundation’s toll-free Clinical Trials Hotline at **1-800-FIGHT-CF**.

Join the search for new treatments and a potential cure

Today, there are more opportunities than ever to join clinical trials that test potential new drugs that could improve the health and quality of life of people with CF.

Because CF affects a relatively small group of people, those with the disease cannot simply count on “someone else” signing up to test much-needed potential CF drugs. We hope that you will consider taking part in clinical trials to help find new and better treatments for cystic fibrosis.

After you’ve learned more about CF clinical trials, you can work with the team at your care center to explore trials that you or your child might consider joining. Not every trial will be a right fit — your team will help you explore eligibility requirements for each specific trial. The team will also explain the potential benefits and risks of each clinical trial and what you could expect to take place if you join one.

Join

Joining a clinical trial is a personal decision. Your rights as a participant will be respected.

- Choosing not to participate in a clinical trial will not affect the routine care you receive at your CF care center.
- You will be given full details about the possible benefits and risks of joining any CF clinical trial.
- You can ask as many questions as you want before you make a decision.
- You must give your informed consent before enrolling in a trial. If you are a parent, you must give your consent for your child to participate.
- Your identity and medical information will be kept private, in keeping with the law.
- You can stop taking part in a clinical trial at any time, for any reason.

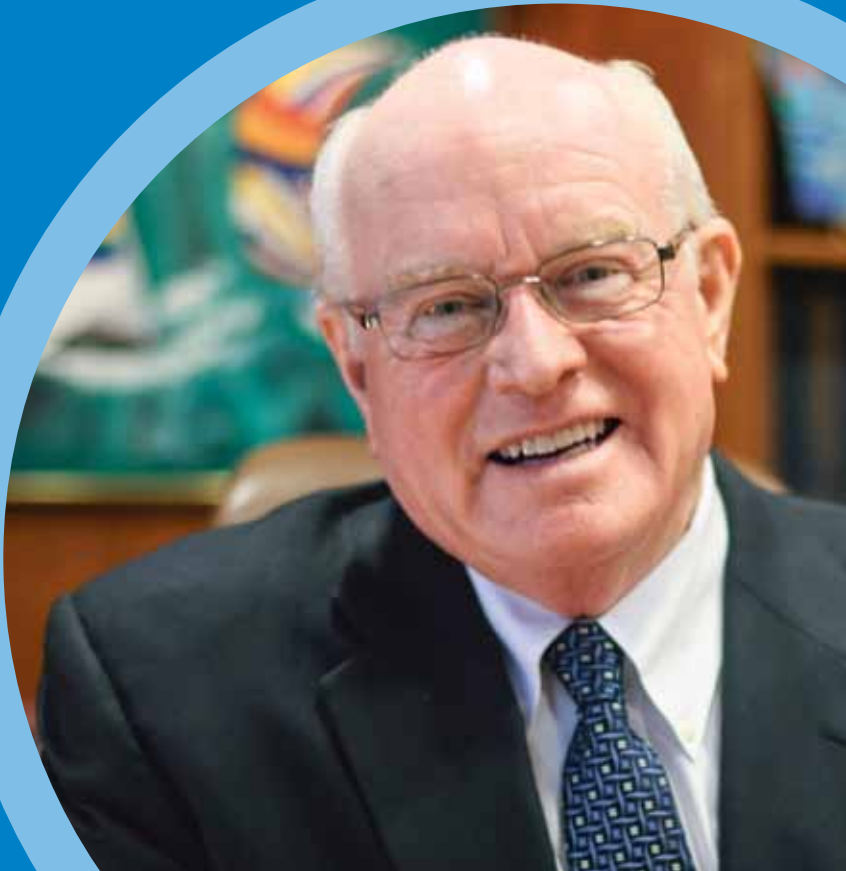


“I’ve been involved in CF clinical trials literally from the week I was diagnosed as a child. Since turning 18, it’s been my decision whether to join trials. As I see it, ‘If not me, who?’”

Brian | A 25-year-old college graduate who has CF

“You are the key to helping us move promising new treatments into the hands of people with CF. Together, we are adding tomorrows every day to the lives of those with this disease.”

Robert J. Beall, Ph.D. | President and Chief Executive Officer
Cystic Fibrosis Foundation



To learn about CF clinical research and the benefits of participating in a clinical trial:

- Visit www.cff.org/Find.
- Call the CF Foundation's toll-free Clinical Trials Hotline at **1-800-FIGHT-CF**.

The following websites also offer general information about clinical trials:

- The National Institutes of Health (NIH):
www.clinicaltrials.gov and
www.nhlbi.nih.gov/childrenandclinicalstudies
- The Food and Drug Administration (FDA):
www.fda.gov/oashi/clinicaltrials

My Care Center Contacts



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or call **1-800-FIGHT-CF**.