If you decide to take the test

- Talk to your doctor or gynaecologist
- Contact a specialized and reliable laboratory (on the **www.testfibrosicistica.it** website you can find a list of qualified laboratories)
- After taking the test, seek professional advice: depending on the result, that may be your doctor or a genetic counselor
- If the test is positive, inform your family members because they too may be carriers
- If you are considering having a child and the test was positive, communicate the result to your partner in order to evaluate together whether he or she should also take the test

About us

The Italian Cystic Fibrosis Research Foundation (Fondazione Ricerca Fibrosi Cistica) was founded in 1997. Our aims are to promote awareness of the disease and support carefully selected research projects with the potential to improve life quality and duration and ultimately to find a cure for all the people with cystic fibrosis. As Italy's pioneering hub for cystic fibrosis research, officially recognized by the Ministry of University and Research and certified by the Italian Institute of Donation, **FFC Ricerca** operates thanks to the efforts of over 980 researchers, 150 Delegations and Support Groups, and 5,000 regular volunteers.

More information, more research

YOU MAY KNOW IT ONLY BY HAVING THE TEST

1 OUT OF 30 AND YOU DON'T KNOW IT

www.testfibrosicistica.it

Help us with your 5x1000 donation.
In the Scientific Research section of the tax return form, please insert:

9 3 1 0 0 6 0 0 2 3 3

ffc ricerca *1 in 30 doesn't know it*
fibrosicisticaricerca.it

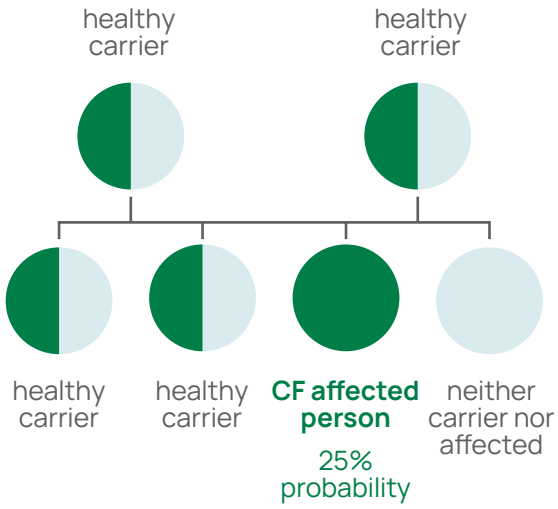
Cystic fibrosis is one of the **most common severe genetic diseases**: it reduces life expectancy and imposes time consuming daily therapies. **A definitive cure is still lacking.**
In Italy, **one in 30 people is a healthy carrier** of one of the genetic mutations that cause the disease, mostly unaware of it.
A couple of two healthy carriers has a **25% chance of having a child with CF** in each pregnancy.

CYSTIC FIBROSIS

160.000
people affected in the world

In Italy
100
new cases a year

Cystic fibrosis is one of the most common severe genetic diseases. It is caused by a mutation in a gene, called the CTFR gene. A person is born with cystic fibrosis when **two copies of a mutated CFTR gene** have been inherited, one from each parent. People with only one copy of a mutated CFTR gene are not affected by cystic fibrosis and are called **healthy carriers of cystic fibrosis**.



Cystic fibrosis manifestations are not the same for all. The body parts most severely affected symptoms are the respiratory and digestive systems. To date, **there is no cure for cystic fibrosis**, but the available treatments help to control symptoms, improve life expectancy and enhance quality of life.

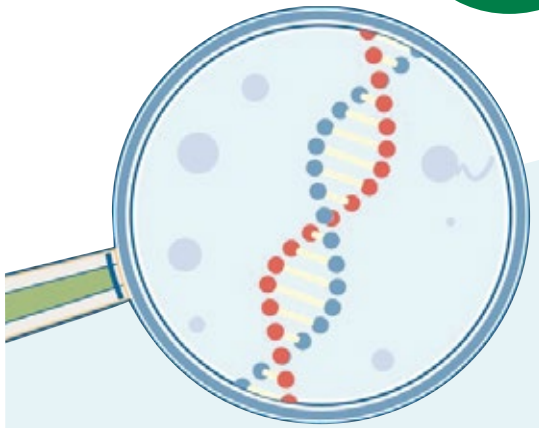
THE CARRIER TEST

Carriers are healthy and therefore have no manifestation of disease. The only way to know if one is a carrier is to have a molecular genetics test, usually called the **cystic fibrosis carrier test**. The vast majority of carriers are found by the test, but not all. Therefore, a negative test can not totally exclude the possibilty of being a carrier, but it greatly reduces it.

In Italy, healthy carriers are:

1
person in
30

1
couple in
900



Do I need to get tested?

Having or not the carrier test is an individual choice. People whose relatives are affected by cystic fibrosis or carriers have a higher risk of being carries themselves. It is advisable to consult with your doctor or gynaecologist to discuss details and available options.

How and when to take the test

The test is usually performed on a sample of blood or saliva, and you may request it to a **molecular genetics laboratory**, that will usually ask for a request from your doctor.

Being tested before a pregnancy has started, allows a wider range of possible choices if you are found to be a carrier.

How much does it cost

If you have relatives with cystic fibrosis or carriers the cost of the test is borne by the National Health Service and you will only be charged a share of the nominal price. This benefit is usually extended to couples who request medically assisted procreation, even when they do not have any relatives affected by cystic fibrosis. For everyone else, the cost is linked to different regional policies and is generally borne by citizens.