



*Fondazione per la Ricerca  
sulla Fibrosi Cistica - ETS*  
italian cystic fibrosis research foundation

# SOCIAL REPORT

## POCKET REPORT 2022

Summary of the main data of the 2022 Social Report on research, training, scientific dissemination, fundraising and awareness raising activities concerning cystic fibrosis. An opportunity to examine the Foundation's achievements in 2022 and find a new starting point for the challenges ahead.

**A CURE FOR ALL**

# ABOUT US

The Italian Cystic Fibrosis Research Foundation was established in 1997 with the following aims:



**Fostering and funding** scientific research on cystic fibrosis



**Training** young researchers and health professionals



**Contributing to the management** of research laboratories through special agreements



**Spreading information** about the disease, the general public on the disease

The Foundation is approved by the Italian Ministry of University and Research (MUR) as a body that promotes scientific research on the disease and has funded



**454**  
study projects on CF



**884**  
researchers



**264**  
research institutes in Italy and abroad

## CYSTIC FIBROSIS

It is the most common severe genetic disease in Europe, there is still no definitive cure. Those who are born with this disease have inherited a mutated CFTR gene both from their father and their mother, who are often unaware of being healthy CF carriers.

### HEALTHY CARRIERS

**2 million**  
healthy carriers

**1**  
in **900**  
couples

**1**  
in **30**  
people

At every pregnancy of the couple of carriers there is a chance that the newborn.

**25%** not a carrier and does not have CF

**25%** inherited 2 copies of the defective gene and has CF

**50%** only inherited 1 copy of the defective gene and is a healthy CF carrier

### PEOPLE WITH CF

**6.000**  
people estimated

**2**  
newborns with CF every week

**1**  
child with CF every 3,000 births/year

**2.000**  
known mutations of the gene

**+40**  
average life expectancy, requiring heavy therapy

#### AN ADULT WITH CF:

Spends up to **3** years of their life as an inpatient

Takes **700** vials of antibiotics through aerosol inhalers and **7.000** pills per year

Spends **3** hours per day doing respiratory physiotherapy

**IMPACT OF CYSTIC FIBROSIS IN ITALY**

# GOVERNANCE AND HUMAN RESOURCES

The Foundation also relies on governance and supervisory bodies that ensure efficient procedures, verify its transparency and guarantee its compliance with its Statute's declared mission goals.

## BOARD OF DIRECTORS

It defines the general directives, the final balance and social report.

*President*  
Matteo Marzotto

## THE SCIENTIFIC ADVISORY COMMITTEE

This committee includes biomedical and clinical experts who select the research strategies and priorities.

*President*  
Paolo Bernardi  
Carlo Castellani until  
03/03/2022

## THE SCIENTIFIC MANAGEMENT

It coordinates the network of researchers and is in charge of project management in collaboration with the Scientific Committee.

*Director*  
Carlo Castellani  
*Deputy-Director*  
Nicoletta Pedemonte

## THE MANAGERIAL SUPERVISORY BODY

This supervisory body oversees the operations in the areas of fundraising, administration, communication and HR.

*Director*  
Giuseppe Zanferrari

## THE SOLE AUDITOR

Alessandra Bortolomasi

## DATA PROTECTION OFFICER

Michela Maggi

## SUPERVISORY COMMITTEE

Stefano Bendinelli  
Paolo Cavaliere  
Michele Giacomelli

## WITH THE SUPPORT OF



**23**

workers  
(20\* employees,  
3 consultants)



**80%**

permanently  
employed



**99%**

university  
degree holders



**48**

average  
age

\* This number includes one person who retired, one who resigned, one replacement due to maternity leave. 40% of the employees have a part-time contract.

*To us, the Foundation is a family friend that is with us along our path towards a cure. In other words, it's another reason to hope for a better future.*



Valentina Fontana.  
Support Group from Cuneo  
called "Insieme per Giulia Sofia"

# THE NETWORK OF VOLUNTEERS

The Foundation works with a broad network of volunteers to

Inform on  
the disease



Engage in fundraising  
for research thanks to  
campaigns and events



**156**

Delegations  
& Support  
Groups



**5.000**  
Volunteers

**64%**

**17%**

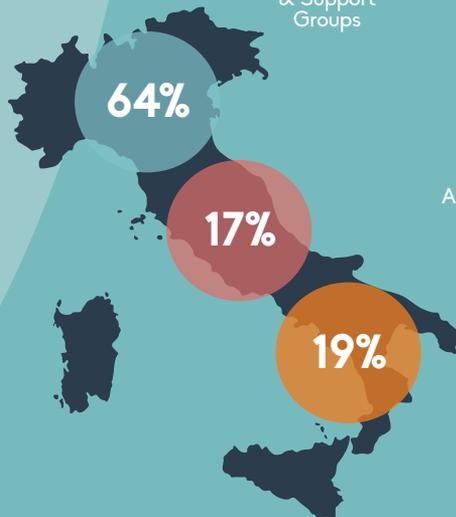
**19%**



**1**  
Advisory group  
of the  
Delegations



**48**  
Average  
age



# SCIENTIFIC RESEARCH

The studies fostered and funded by the Foundation aim at:



Improving the treatments available today, so as to **increase the quality and life expectancy** of the people with CF

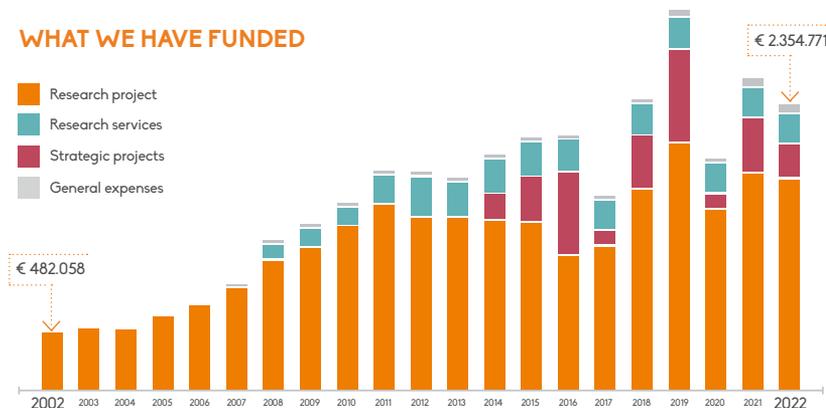


Understanding the basics of the defect that causes cystic fibrosis, to **provide a cure for all people with CF**

## 2002-2022. KEY FIGURES REGARDING OUR RESEARCH



## WHAT WE HAVE FUNDED



## HOW WE SELECT THE RESEARCH PROJECTS



## FFC RICERCA HIGHLIGHTS

Among the advances in research achieved in 2022, these are some of the most important, covered in 2022 by international scientific journals.

- CORRECTING THE BASIC DEFECT**  
Studies involved: **GMSG#1/2022**
- REDUCING THE INFLAMMATION OF THE RESPIRATORY TRACT**  
Studies involved: **FFC#25/2014, 23/2015, 4/2016, 11/2017, 8/2018**. The research work will continue with **FFC#3/2022**  
*Science Translational Medicine. Volume 14*
- ENDING THE VICIOUS CYCLE OF HYPERVISCOSITY OF THE RESPIRATORY TRACT**  
Studies involved: **FFC#9/2022**. The research work will continue in this two-year study  
*JCI Insight. Volume 7*
- COMBATING ANTIBIOTIC RESISTANCE**  
Studies involved: **FFC#23/2020**. The research work will continue with **FFC#7/2022**  
*European Respiratory Journal. Volume 60*

# ECONOMIC AND FINANCIAL TREND

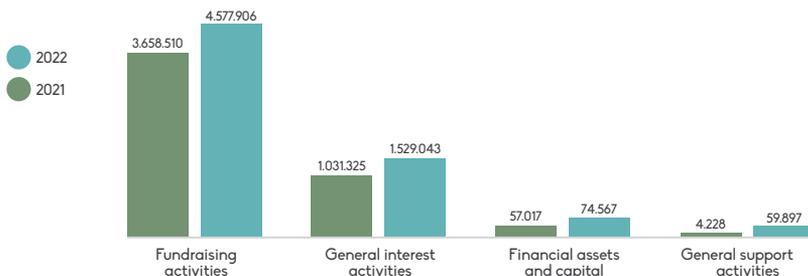
The 2022 budget result is an improvement compared to the 2019 pre-pandemic data and is proof of the commitment to supporting research projects with allocations worth close to 4 million Euros, to fund ever-more ambitious studies, supported by major scientific dissemination and awareness raising activities.

## ECONOMIC VALUE GENERATED AND DISTRIBUTED

The commitment in the management areas (business segments) leads to the economic value that the Foundation distributes in the fields of research, training and awareness.

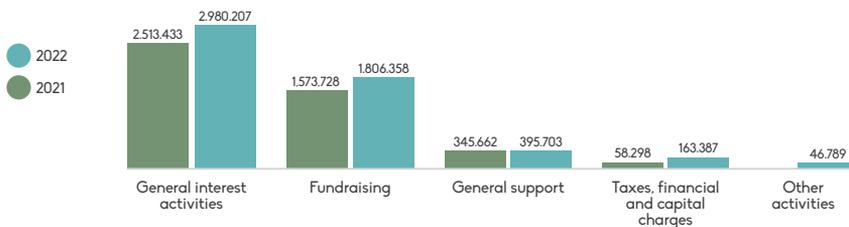
### Sources of revenue

In 2022 the Foundation recorded a revenue of over six million Euros, mostly as the result of fundraising and general interest activities, 85% of which coming from contributions of private subjects.



### Use of the funds

The main cost item is scientific research taking up, together with the other general-interest activities such as communication, training, scientific dissemination, 57% of the total charges.



## BALANCE SHEET

The net worth of the Foundation remains high: over 7 million Euros (+12% since 2021), which is proof of its ability to continue investing heavily and constantly in research, with this being the operating result of the previous and ongoing financial years.

# COMMUNICATION AND FUNDRAISING

The teamwork of the two areas to reach the budget goals has resulted in proceeds that have grown by 31% since 2022. The result of their activity helps support the Foundation's mission: funding research, training researchers and spreading awareness on cystic fibrosis among the general public.

## 2022. ORIGIN OF THE DONATIONS



## 1 NET FUNDING FOR RESEARCH

€ 2.589.699

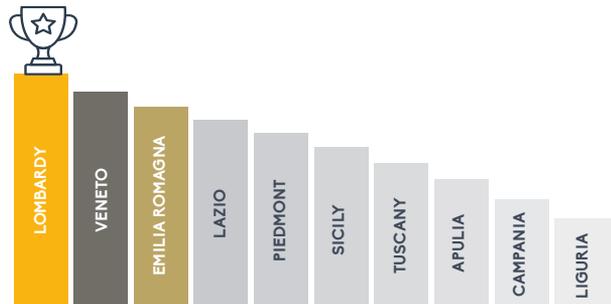
from the 3 main Campaigns



Gadgets given out

## 2 5X1000 DISTRIBUTION

10 Regions make up 89% of the donations to FFC Ricerca



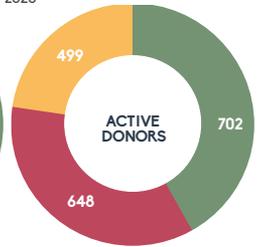
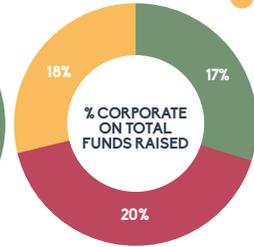
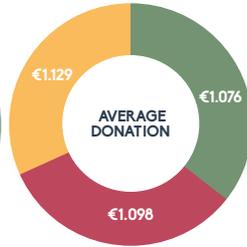
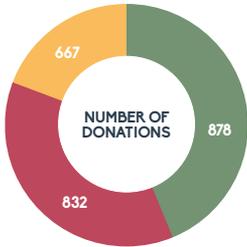
### 3 IMPORTANCE OF REQUESTS



### 4 TREND OF THE EVENTS

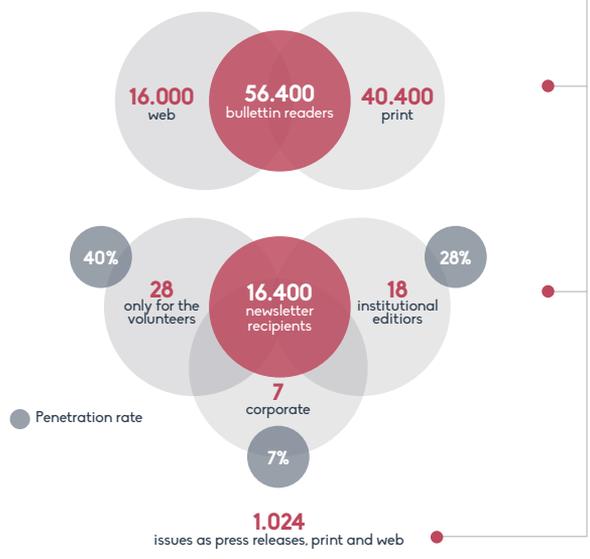


### 5 AFFINAMENTO CORPORATE

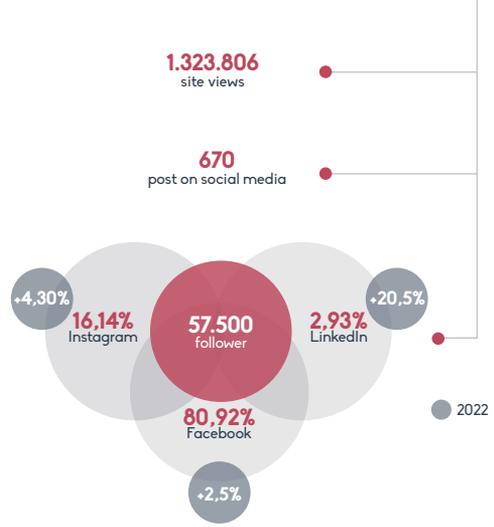


## VISIBILITY IN FIGURES

### PUBLICATIONS



### WEB





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**[fibrosicisticaricerca.it](http://fibrosicisticaricerca.it)**

For further information see the complete report  
**[www.fibrosicisticaricerca.it/i-bilanci](http://www.fibrosicisticaricerca.it/i-bilanci)**

### **To donate**

- Online on the website: [fibrosicisticaricerca.it](http://fibrosicisticaricerca.it)
- UniCredit Bank transfer (no commission at UniCredit Bank branches):  
IT 47 A 02008 11718 000102065518
- SWIFT-BIC code (for payments from abroad) UNCRITM1N58
- Banco BPM: IT 92 H 05034 11708 000000048829
- Postal account no. 18841379
- 5x1000 (0.5% income tax credit scheme) to FFC Ricerca  
tax code 93100600233



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FFC Ricerca is recognised  
by the Italian Institute of  
Donation, which certifies  
the transparent and  
effective use of funds  
raised, to protect the rights  
of donors.

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