



*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

IMPACT OF CYSTIC FIBROSIS IN ITALY

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

Constantly improving thanks to progress in research

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



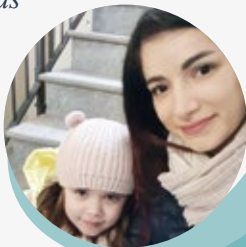
48

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%

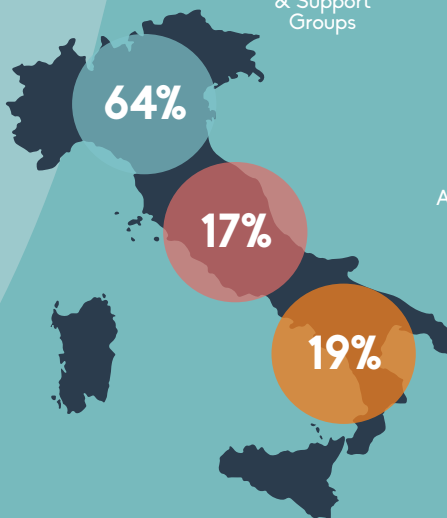


1
Advisory group
of the
Delegations



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



€ 33 million allocated for **454** Scientific projects on CF



€ 8 million given to **422** grant holders



884 researchers involved from **264** Italian and international Institutes



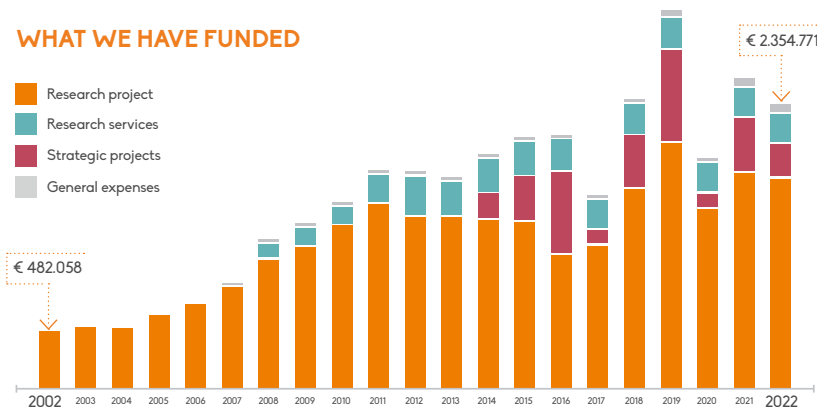
532 international referees active from **30** States



26 international patents based on our projects **10** of which co-owned by the Foundation

WHAT WE HAVE FUNDED

- Research project
- Research services
- Strategic projects
- General expenses



HOW WE SELECT THE RESEARCH PROJECTS

Step 1

Call for grant application

Every year the Foundation issues an international call
77 Proposals received in 2022

Step 2

International referees

After the assessment by the Scientific Committee, the projects are sent to international experts
76 Referees contacted

Step 3

FFC Ricerca Scientific Committee

It makes decisions on which projects to support and the funding to provide
€ 1.790.050 for 16 studies in 2022

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

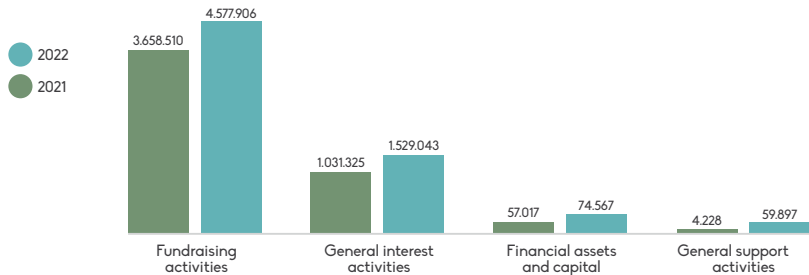
The 2022 budget result is an improvement compared to the 2019 pre-pandemic data and is proof of the commitment to supporting research projects with allocations worth close to 4 million Euros, to fund ever-more ambitious studies, supported by major scientific dissemination and awareness raising activities.

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.

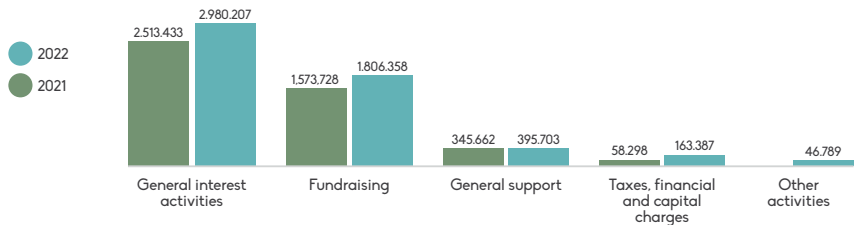
Sources of revenue

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.

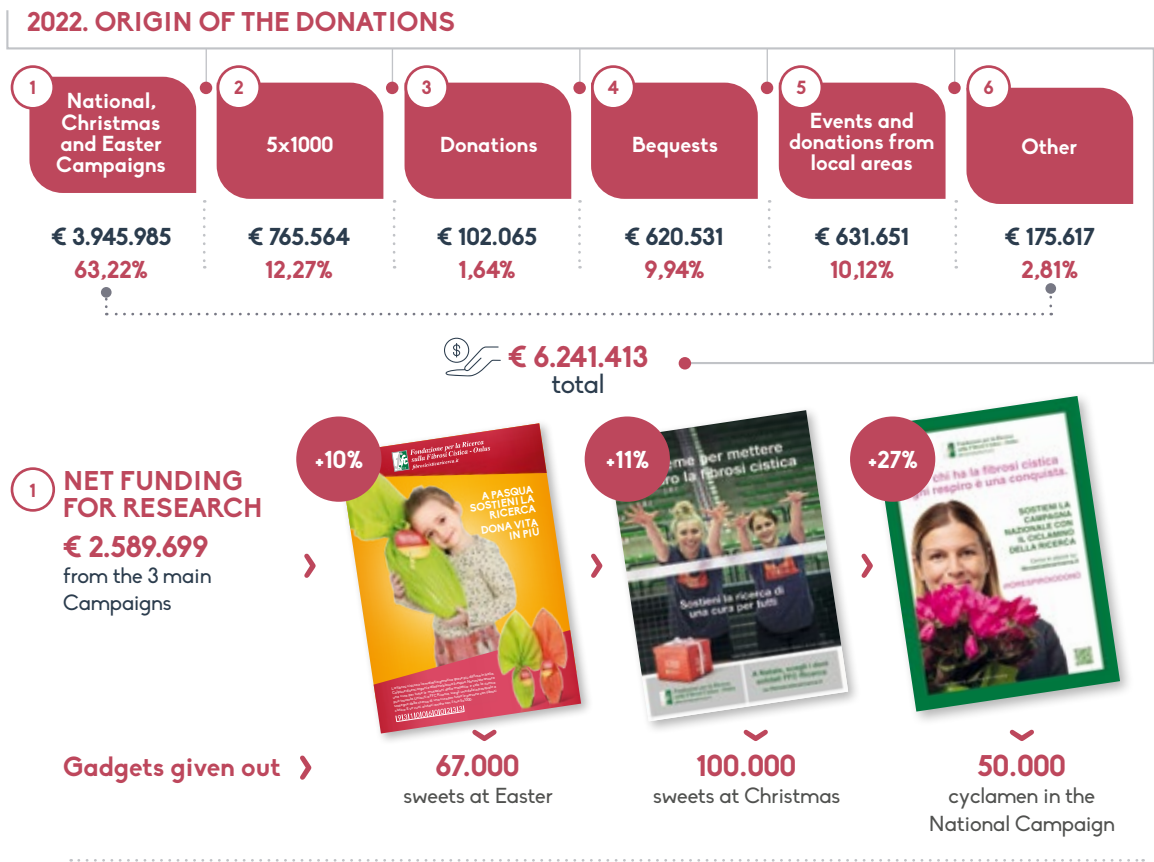


BALANCE SHEET

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.



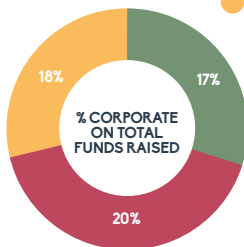
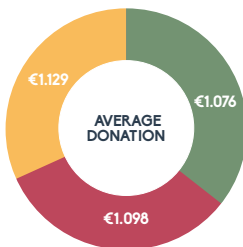
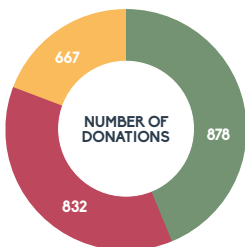
3 IMPORTANCE OF REQUESTS



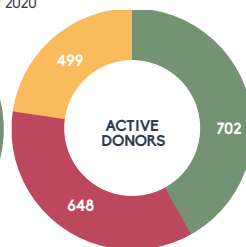
4 TREND OF THE EVENTS



5 AFFINAMENTO CORPORATE

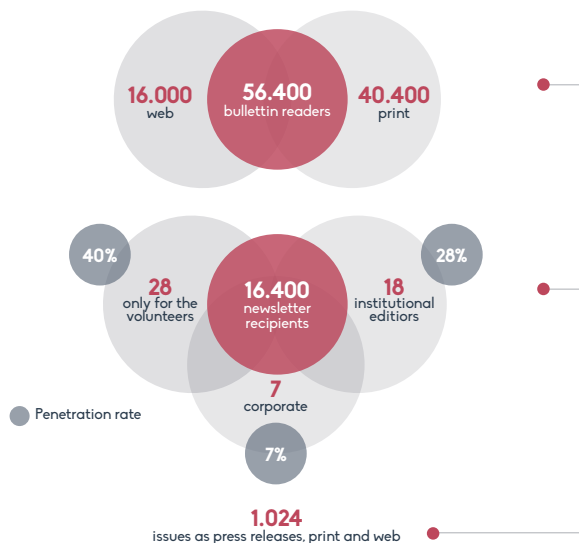


● 2022 incl. in kind
● 2021
● 2020

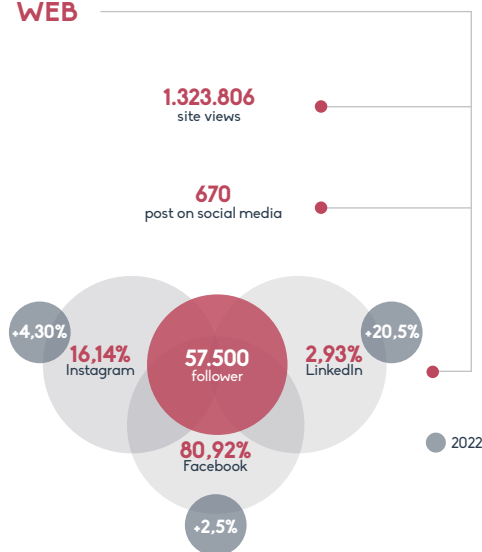


VISIBILITY IN FIGURES

PUBLICATIONS



WEB





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fibrosicisticaricerca.it

For further information see the complete report
www.fibrosicisticaricerca.it/i-bilanci

To donate

- Online on the website: 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 0000000048829
- Postal account no. 18841379
- 5x1000 (0.5% income tax credit scheme) to FFC Ricerca
tax code 93100600233



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Donation, which certifies
the transparent and
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