



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

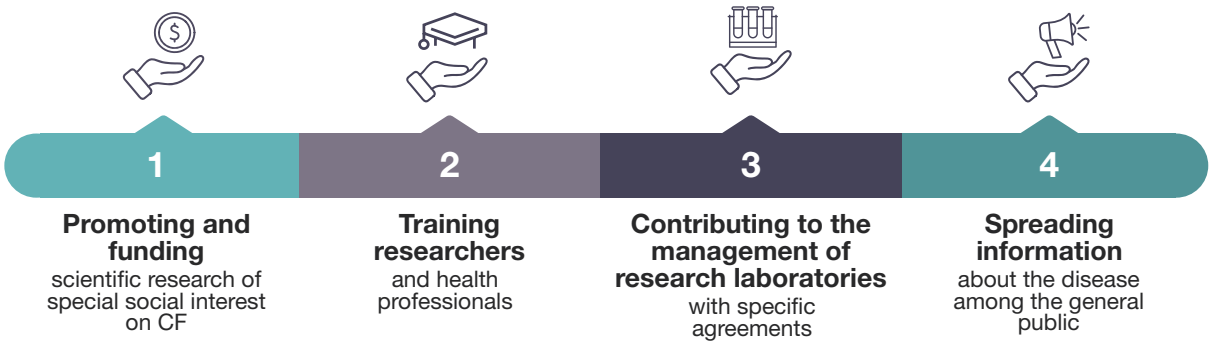
FROM THE SOCIAL REPORT POCKET REPORT 2024

Dedicated to all people
with cystic fibrosis.
Our mission, the tools to
achieve it and the results
obtained

A CURE FOR ALL

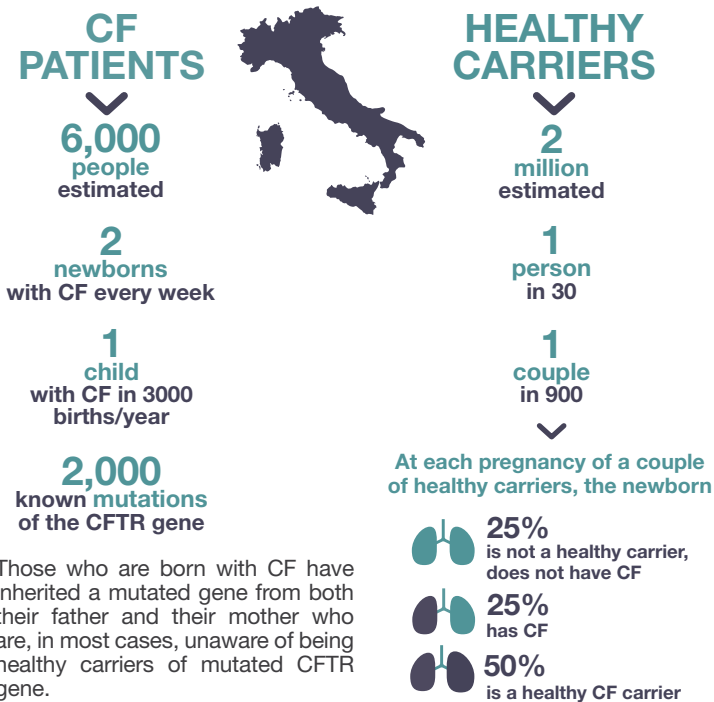
IDENTITY

The Foundation is a non-profit institution and is recognized by the Italian Ministry of University and Research (MUR) as a promoter of scientific research, training and information activities. Since 1997, it has been operating with the aim of improving the duration and quality of life of people with cystic fibrosis (CF).



CYSTIC FIBROSIS

It is one of the most widespread genetic diseases in Europe and there is still no definitive cure. The disease is present from birth and is caused by mutations in the CFTR gene that make the bodily fluids thicker, thereby impairing the normal function of pancreas, lungs and other organs. It is precisely the extent of lung damage that determines the quality of life and life expectancy of people with CF.




NOT TO BE MISSED IN THIS CHAPTER

✓ **Who the 2024 Social Report is dedicated to**

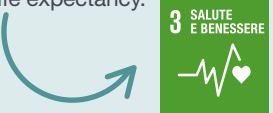
 To primary stakeholders:
People with CF

 To stakeholders supporting our mission:
the scientific community, with researchers, universities, national and international research institutions, and organizations actively working in the field of FC;

 **society at a large**, including volunteers, families and friends of people with CF, companies, donors, media, and institutions.

✓ **The new questionnaires**
To provide answers to the expectations of volunteers, supporters, companies.

✓ **Goal 3. Health and well-being for all**
Our primary contribution to the 2030 Agenda for Sustainable Development. For a constantly improving life expectancy.



GOVERNANCE AND HUMAN RESOURCES

In order to carry out its mission, the Foundation relies on governance and oversight bodies that ensure efficient procedures, verify transparency and guarantee the compliance with the objectives stated in the Statute.

BOARD OF DIRECTORS

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

President
Matteo Marzotto
Vice Presidents
Paolo Faganelli
Michele Romano

THE SCIENTIFIC COMMITTEE

It establishes research strategies with experts in the biomedical and clinical fields.

President
Paolo Bernardi

THE SCIENTIFIC MANAGEMENT

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

Director
Carlo Castellani
Deputy-Director
Nicoletta Pedemonte

THE INTERNAL MANAGEMENT DIRECTORATE

It oversees the operations in the areas of fundraising, administration, communication and HR.

Director
Giuseppe Zanferrari

THE SOLE AUDITOR AND CONTROL BODY

Alessandra Bortolomasi

DATA PROTECTION OFFICER

Michela Maggi

SUPERVISORY COMMITTEE

Stefano Bendinelli
Paolo Cavaliere
Michele Giacomelli

WITH THE SUPPORT OF



21
employees
= **17 full time resources** (FTE index, Full Time Equivalent)



85%
permanently employed

1:3
employee pay ratio (maximum allowed 1:8)



+6
contracts (project-based temporary contracts, consultancy, grants)

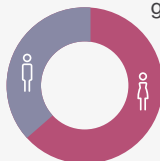


95%
university degree holders



47
average age

22%
men



78%
women

“Research – that is you: the scientists who work for us but are also present in public squares and at events, and who know how to speak a language that feels close to us.”

Cecilia Cascone, Delegation of Rome

THE VOLUNTEERS NETWORK

The FFC Ricerca works with a nationwide network of volunteers to



✓ **Raise awareness on the disease**



✓ **Raise funds for research by organizing Campaigns and Events**



158

Delegations and Support Groups

68%
North

12%
Centre

20%
South



950
regular volunteers registered in the relevant Register (31/12/2024)

49
average age



1
Delegations Advisory Group, with **9** representatives



€ 3,241,205

paid by volunteers for projects from the 2024 call for proposals and previous

FROM THE 2024 QUESTIONNAIRE

- ✓ **71%** have been volunteering for over 5 years
- ✓ **30%** for more than 200 hours/year
- ✓ **84%** are family members or friends of a person with CF
- ✓ **95%** would recommend others to join the FFCR community



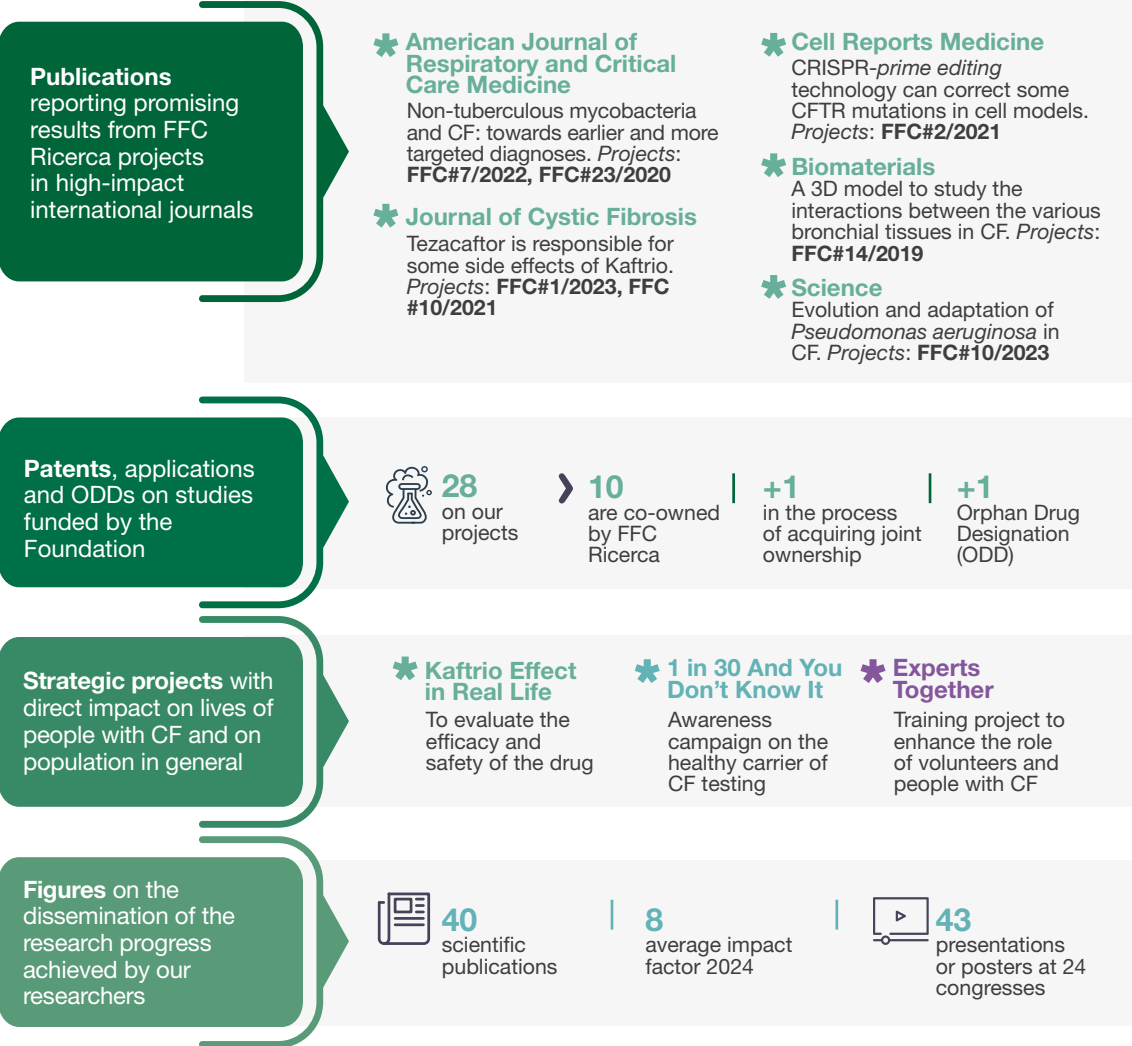
MISSION ACTIVITIES

These include the following social utility objectives, as outlined in the Statute



HIGHLIGHTS 2024

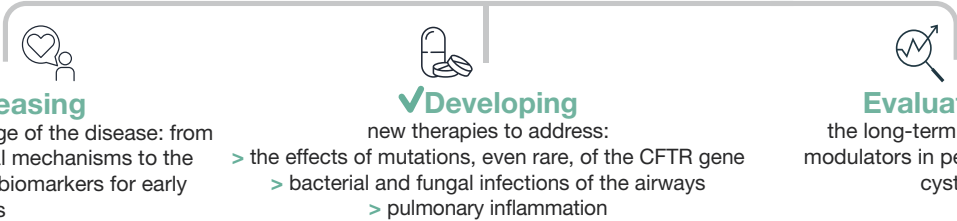
Selection of contributions shared with the international scientific community.



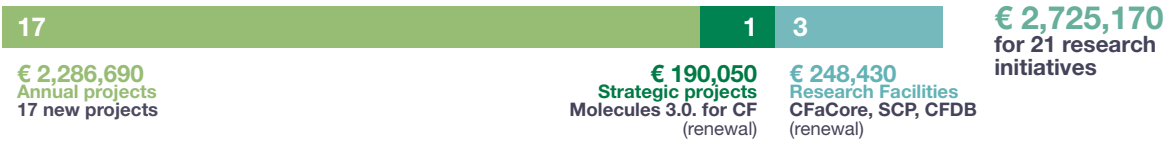
MISSION ACTIVITIES

SCIENTIFIC RESEARCH

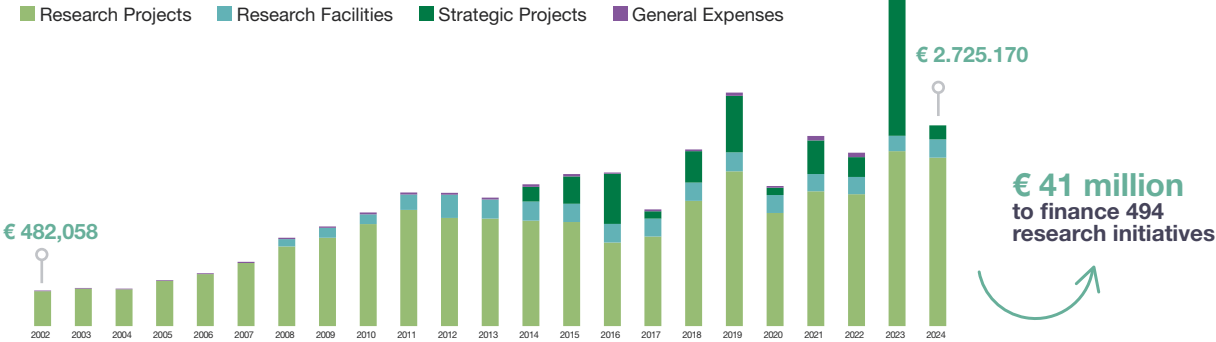
Objectives of the studies funded by FFC Ricerca



2024 Tools to promote research:



Research costs since 2002



Research network



Selection of projects from the call



MISSION ACTIVITIES

INFORMATION AND TRAINING

Awareness-raising projects and initiatives aimed at disseminating FFC Ricerca's scientific contributions and promoting broader public understanding of the disease.

Information

Training

Strategic Projects

1 in 30 and You Don't Know It

Experts Together

Awareness raising campaigns

5x1000

Bequests



Initiatives and meetings

Seminar

Researchers Convention



250 participants +25%



250 participants 76% in person

Transparent Research



69 donors received a 2024 report

Volunteers Gathering



45% of Delegations and Support Groups present

Research meets the Territory



200 participants 4 regions involved

PUBLICATIONS ON THE MISSION ACTIVITIES



WEBSITE

26 news in homepage



84% of overall news of the website / year



NEWS

41,000 readers



50% pages on a scientific topic



PRESS RELEASES

4 specifically on the mission topics



40% of releases / year



NEWSLETTER

20,700 registered



11 institutional editions



BROCHURE

500 copies distributed for the Seminar

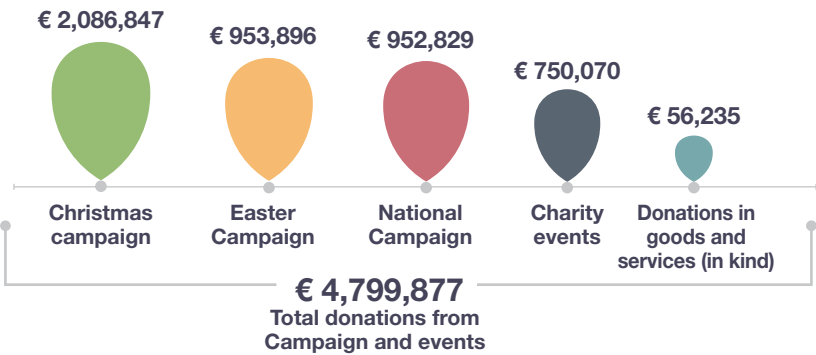


690 copies distributed for the Convention

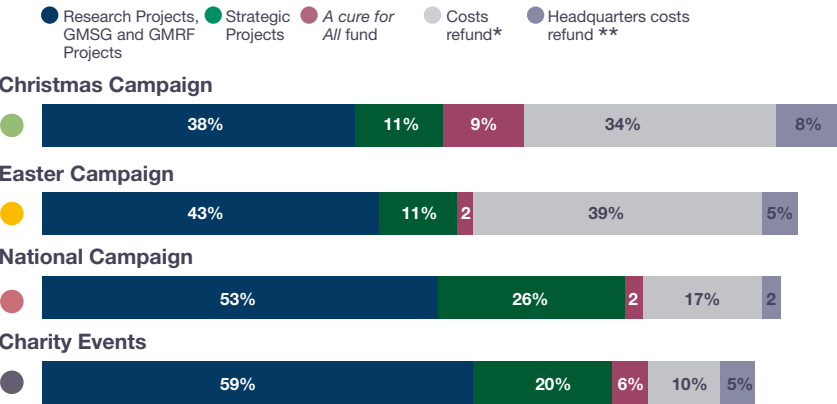
COMMUNICATION, FUNDRAISING AND RELATIONS WITH THE COMMUNITY

It covers the strategies and tools used to achieve the Foundation’s mission, the funds raised, and their allocation to research, training, and information initiatives on CF.

Funds raised during Campaigns and Events



How we distributed the donations



* Costs for acquisition of products to be distributed in Campaigns (cyclamen, sweets) and to organise Delegations and Support Group events
** Headquarters costs to organise initiatives (logistics, Campaign kits shipping, typography, paid promotion on Meta platforms)



Donating funds

Initiatives to take care of our supporters

Donor care activities to strengthen our bond with

✓ Continuing donors
+ 180 in a year

✓ Major Donors
+ 54
Major donors retained over a 2-year period

✓ All supporters through a targeted and continuous communication



FROM THE 2024 QUESTIONNAIRE FOR DONORS

- 48.5% > 50 years old
- 60.7% Women
- 69.9% Employed
- 56.8% has been donating for over 5 years
- 97.6% will continue to support FFC Ricerca

Communication in figures



Donating time



The **"Become a volunteer"** Campaign aims at motivating and involving an increasing number of people

✓ TV/radio spots and posters

with the claim:

"We do it often and gladly, but we need you to do it better!"

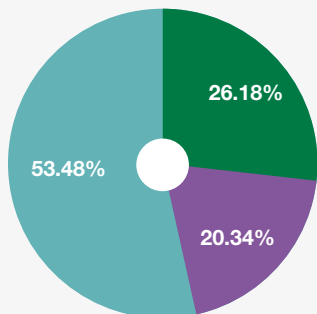
✓ 50 new volunteers

immediately joined the Volunteer Registry, bringing the total to over one thousand registered volunteers.

Corporate fundraising

€ 1,221,100

Donations in 2024 by **922** supporters



- Up to € 4,999
- From € 5,000 to € 24,999
- Over € 25,000



Website

1,400,000 views of fibrosicisticaricerca.it website

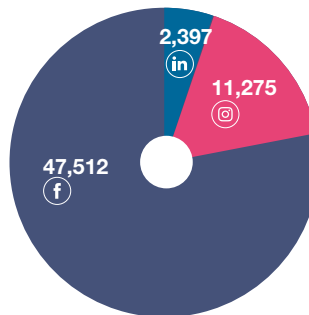
851,196 active users

130 news



Social media

61,184 follower



674 overall posts published



News

41,000 readers



25,000 paper version
↓ -34%

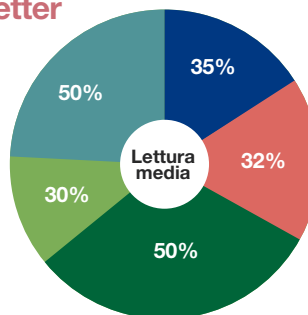
16,000 browsable, from the website, social, newsletter
↑ +60%



Newsletter

42,768 registered

77 sent



- Delegations, Support groups, volunteers
- Regular donors
- Institutional donors
- Corporate donors
- Donor journey



Press review

1,852 articles



19.71% Print
80.29% Web



Events

244 events



42.62% entertainment
24.42% sport

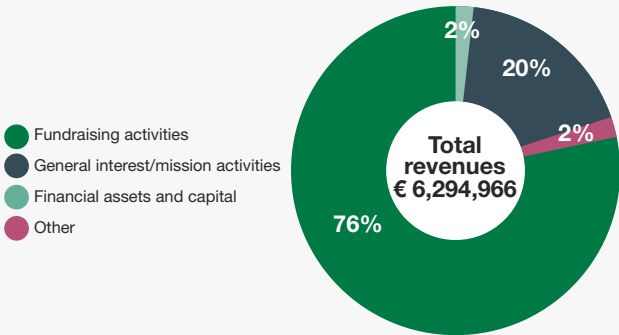
18.85% charity dinner
13.11% other

ECONOMIC AND FINANCIAL TREND

It provides information for all our supporters on how funds are raised and subsequently allocated. It shows a steady growth in support of Activities of General Interest that reflect the Foundation’s mission: +35% compared to 2023.

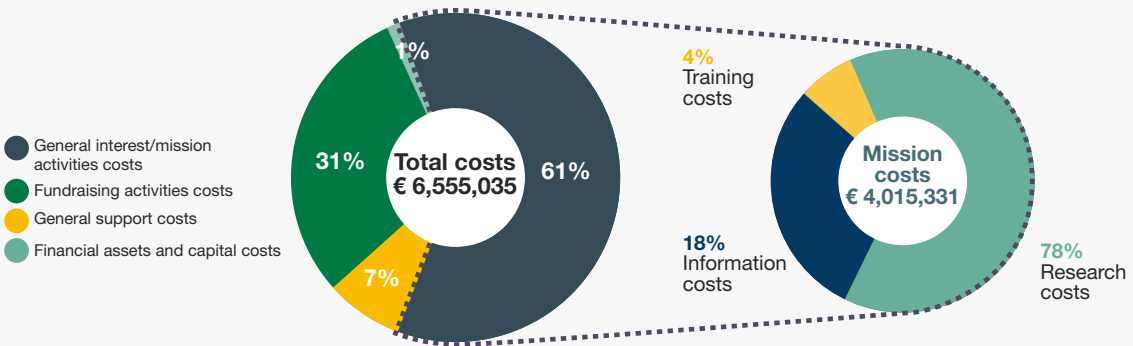
Where do resources come from

From the combined activities carried out across the five management areas, total proceeds of over six million euros were generated in 2024, primarily from fundraising activities and activities of general interest.



How we used them

The main item of expenditure is research which, together with training and information activities, accounts for 61% of total expenses, up from 54% in 2023. By contrast, fundraising costs have decreased, falling by 6 percentage points, reflecting the organization’s commitment to cost containment.



Balance sheet

Net assets, although showing a slight decrease of 3.19%, remain at a high level (€ 7,892,549), ensuring the continuity of investments in mission-related activities. Accordingly, there are no factors in 2024 that could hamper the achievement of the organization’s institutional objectives.



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fibrosicisticaricerca.com

<https://www.fibrosicisticaricerca.com/the-foundation-ffc/>

TO DONATE to the Fondazione Ricerca Fibrosi Cistica

- Online on the website: dona.fibrosicisticaricerca.it
- UniCredit Bank transfer (no commission at UniCredit Bank branches):
IT 47 A 02008 11718 000102065518
BIC SWIFT code (for payments from abroad): UNCRITM1N58
- Banco BPM: IT 92 H 05034 11708 000000048829
BIC SWIFT code: BAPPIT21008
- Postal current account nr.: 18841379
- 5x1000 (0.5% income tax credit scheme) tax code: 93100600233



DONARE CON FIDUCIA

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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