



*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).



1

## Promoting and funding

scientific research of special social interest on CF



2

## Training researchers

and health professionals



3

## Contributing to the management of research laboratories

with specific agreements



4

## Spreading information

about the disease among the general public

## 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.

### CF PATIENTS

6,000 people estimated



2 newborns with CF every week

1 child with CF in 3000 births/year

2,000 known mutations of the CFTR gene

### HEALTHY CARRIERS

2 million estimated

1 person in 30

1 couple in 900

At each pregnancy of a couple of healthy carriers, the newborn



25% is not a healthy carrier, does not have CF  
25% has CF  
50% is a healthy CF carrier

Those who are born with CF have inherited a mutated gene from both their father and their mother who are, in most cases, unaware of being healthy carriers of mutated CFTR gene.

## 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.



3 SALUTE E BENESSERE

# 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 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

## 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

## SUPERVISORY COMMITTEE

Stefano Bendinelli  
Paolo Cavaliere  
Michele Giacomelli

## WITH THE SUPPORT OF

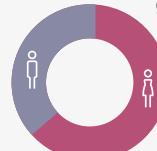
 **21**  
employees  
=17 full time  
resources (FTE  
index, Full Time  
Equivalent)

 **85%**  
permanently  
employed

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

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

**78%**  
women



 **95%**  
university  
degree  
holders

 **47**  
average  
age

*“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



 **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



Scientific research on CF



Information



Training

## HIGHLIGHTS 2024

Selection of contributions shared with the international scientific community.

**Publications**  
reporting promising results from FFC Ricerca projects in high-impact international journals

### ★ American Journal of Respiratory and Critical Care Medicine

Non-tuberculous mycobacteria and CF: towards earlier and more targeted diagnoses. *Projects: FFC#7/2022, FFC#23/2020*

### ★ Journal of Cystic Fibrosis

Tezacaftor is responsible for some side effects of Kaftrio. *Projects: FFC#1/2023, FFC #10/2021*

### ★ Cell Reports Medicine

CRISPR-prime editing technology can correct some CFTR mutations in cell models. *Projects: FFC#2/2021*

### ★ Biomaterials

A 3D model to study the interactions between the various bronchial tissues in CF. *Projects: FFC#14/2019*

### ★ Science

Evolution and adaptation of *Pseudomonas aeruginosa* in CF. *Projects: FFC#10/2023*

**Patents, applications and ODDs** on studies funded by the Foundation

28  
on our projects

10  
are co-owned by FFC Ricerca

+1  
in the process of acquiring joint ownership

+1  
Orphan Drug Designation (ODD)

**Strategic projects** with direct impact on lives of people with CF and on population in general

### ★ Kaftrio Effect in Real Life

To evaluate the efficacy and safety of the drug

### ★ 1 in 30 And You Don't Know It

Awareness campaign on the healthy carrier of CF testing

### ★ Experts Together

Training project to enhance the role of volunteers and people with CF

**Figures** on the dissemination of the research progress achieved by our researchers

40  
scientific publications

8  
average impact factor 2024

43  
presentations or posters at 24 congresses

# MISSION ACTIVITIES

# SCIENTIFIC RESEARCH

## Objectives of the studies funded by FFC Ricerca



### ✓ Increasing

knowledge of the disease: from biological mechanisms to the study of biomarkers for early diagnosis



### ✓ Developing

new therapies to address:

- > the effects of mutations, even rare, of the CFTR gene
- > bacterial and fungal infections of the airways
- > pulmonary inflammation



### Evaluating ✓

the long-term effects of modulators in people with cystic fibrosis

## 2024 Tools to promote research:

17	1	3	€ 2,725,170 for 21 research initiatives
€ 2,286,690 Annual projects 17 new projects	€ 190,050 Strategic projects Molecules 3.0. for CF (renewal)	€ 248,430 Research Facilities CFaCore, SCP, CFDB (renewal)	

## Research costs since 2002

■ Research Projects ■ Research Facilities ■ Strategic Projects ■ General Expenses



## Research network

 1,040 researchers 2002-2024	 148 in 2024	54.2% North Italy	22.9% Centre Italy	12.5% South Italy	10.4% Abroad	 198 Institutes 2002-2024	 168 Italian	 30 International	50% Universities and Polytechnics	 32 in the 2024
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## Selection of projects from the call

 Mid-December

The FFC Ricerca Calls are online.

First assessment by the Scientific Committee.

51 proposals evaluated

Sending the selected proposals to international experts.

66 Auditors consulted

The Scientific Committee makes the final decision.

33% Accepted proposals

 Beginning of September

The projects start, now available for funding.

## 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

#### Strategic Projects

1 in 30 and You Don't Know It

### Training

#### Awareness raising campaigns

5x1000

Bequests



#### Initiatives and meetings

Seminar



250  
participants

+25%

Researchers Convention



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

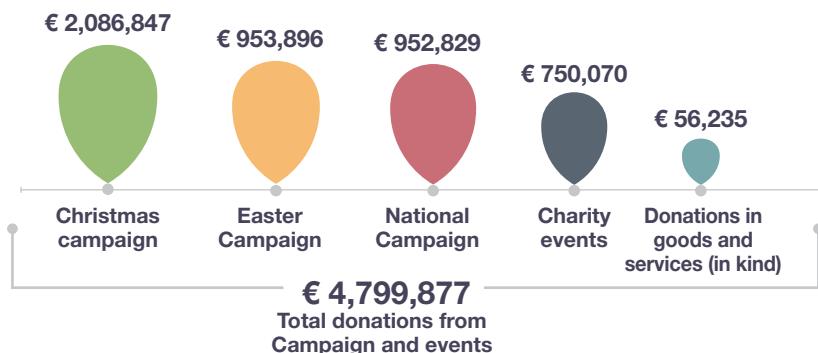
690

copies distributed for the Convention

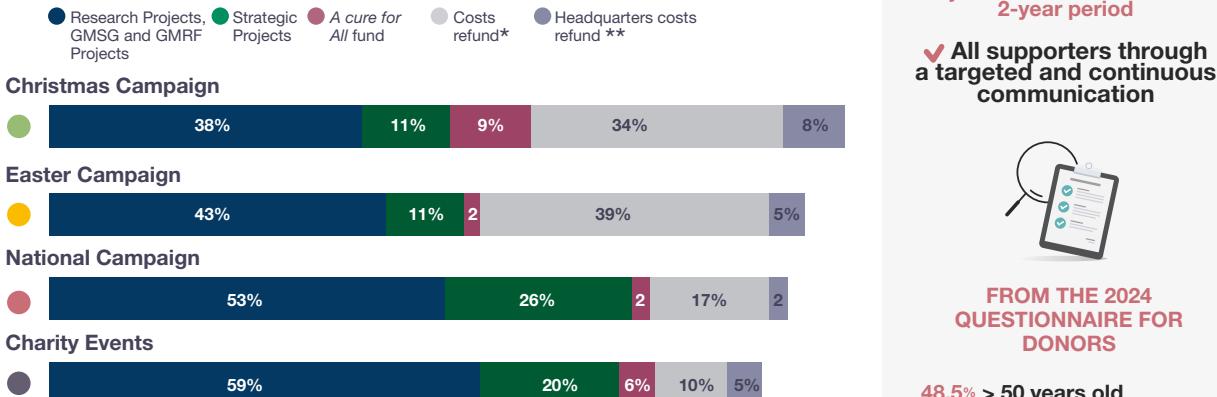
# COMMUNICATION, FUNDRAISING AND RELATIONS WITH THE COMMUNITY

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

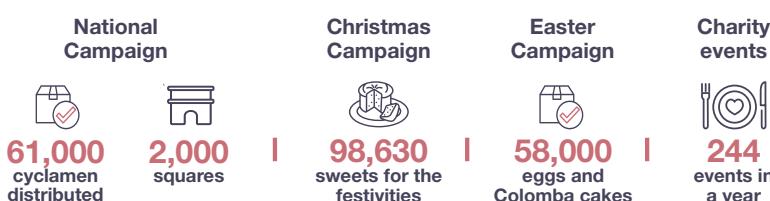
48.5% > 50 years old

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



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!"

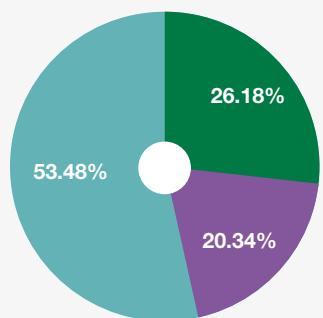
### ✓ 50 new volunteers

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

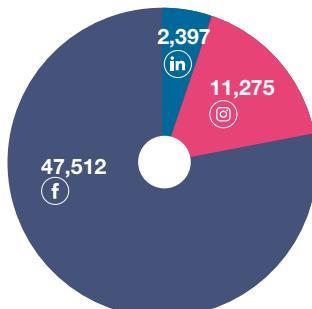
1,400,000 views of fibrosicisticaricerca.it website

851,196 active users

130 news

### Social media

61,184 follower



674 overall posts published

### News

41,000 readers



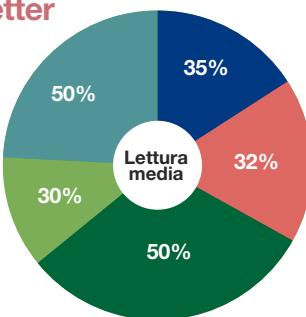
25,000 paper version  
↓-34%

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

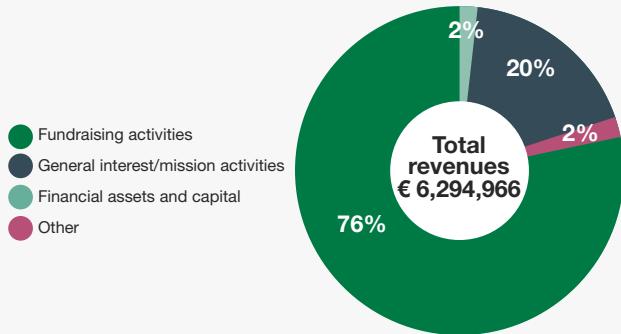
18.85% charity dinner  
13.11% other

# 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.

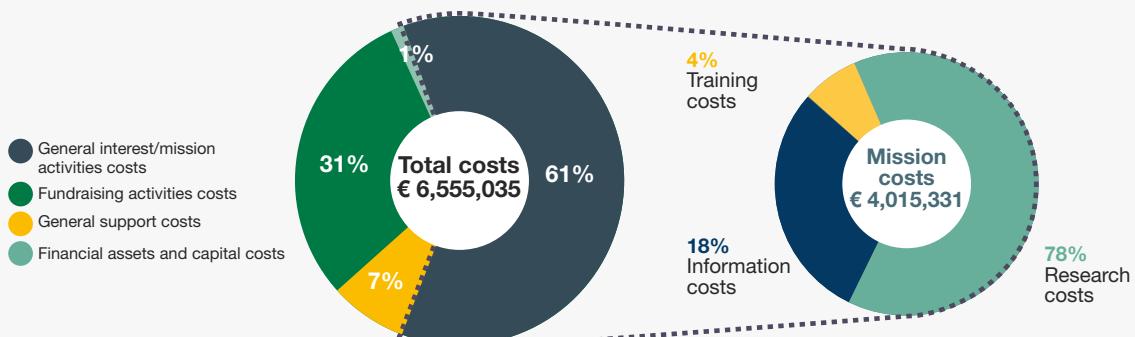
## Where do resources come from

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](http://fibrosicisticaricerca.com)

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

## **TO DONATE to the Fondazione Ricerca Fibrosi Cistica**

- Online on the website: [dona.fibrosicisticaricerca.it](http://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



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.

