



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

**FROM THE
SOCIAL REPORT
POCKET
REPORT
2023**

Dedicated to all people
with cystic fibrosis.
Our mission, tools to
reach the mission and
the achieved results in a
nutshell

A CURE FOR ALL

IDENTITY

The Foundation is a non-profit body recognised by the Italian Ministry of University and Research (MUR) as a promoter of scientific research on the disease. It was established in 1997 in order to:



Promote and fund
scientific research of special social interest on cystic fibrosis (CF)



Train
researchers and health professionals working with CF



Contribute to the management of research laboratories
with specific agreements



Spread information
about the disease among the general public

CYSTIC FIBROSIS



It is one of the most common genetic diseases and there is still no definitive cure. The disease is present since birth and is caused by mutations in the CFTR gene that make the bodily fluids more dense, thus compromising the smooth functioning of multiple organs, especially that of pancreas and lungs. It is the extent of the lungs damage that determines the quality of life and the longevity of people with CF, until they reach respiratory insufficiency.

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.

CF PATIENTS

6,000
estimated
people

2
newborns
with CF every
week

1
child
with CF
in 3,000
births/year

2,000
known
mutations
of the CFTR
gene

HEALTHY CARRIERS

2
million
healthy
carriers

1
person
in 30

1
couple
in 900

At each pregnancy, the newborn

25%

has
FC

25%

does not
have FC

50%

is a healthy
CF carrier

SOCIAL REPORT 2023

✦ Dedicated to our stakeholders



People with CF, their families and relationships.



The **scientific world**, researchers, national and international research bodies and organisations actively working with CF.



Society, with companies, donors, media, institutions and all citizens.

In order to get them involved in the project of making the CF disease increasingly curable.

✦ **Autonomy and transparency** are our values, reflected in the Code of Ethics and in our Organisational Model.

✦ Goal 3 “Good health and well-being for all”

is our primary contribution to the Agenda 2030 for sustainable development.

3 GOOD HEALTH AND WELL-BEING



GOVERNANCE AND HUMAN RESOURCES

The Foundation relies on government and supervisory bodies that ensure efficient procedures, verify their transparency and guarantee its compliance with the mission goals enshrined in the Statute.

BOARD OF DIRECTORS

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

President
Matteo Marzotto

THE SCIENTIFIC ADVISORY 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 Advisory Committee.

Director
Carlo Castellani
Deputy-Director
Nicoletta Pedemonte

INTERNAL MANAGEMENT DIRECTORATE

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

Director
Giuseppe Zanferrari

THE SOLE AUDITOR

Alessandra Bortolomasi

SUPERVISORY COMMITTEE

Stefano Bendinelli
Paolo Cavaliere
Michele Giacomelli

DATA PROTECTION OFFICER

Michela Maggi

WITH THE SUPPORT OF



20
employees
= **17 full time resources** (FTE index, Full time equivalent)



80%
permanently employed

+5
contracts (temporary contracts, consulting, grants)

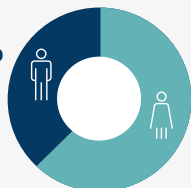


95%
university degree holders



44
average age

28%



72%

Our every gesture has the power to potentially change someone's life, it is a commitment to finding a cure for everyone, one step at a time.

Veronica Solinas,
Delegation of Siniscola, Nuoro (Sardinia)

THE VOLUNTEERS NETWORK

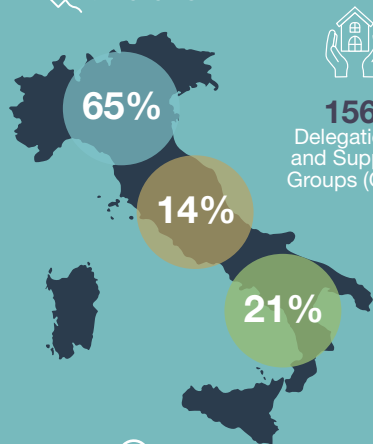
The FFC Ricerca collaborates with a broad network of volunteers in order to



Inform on the disease



Raise funds for research by organising campaigns and events



156
Delegations and Support Groups (Gds)



550
regular volunteers registered in the related Register (as on 31/12/2023)



46
average age



€ 2,375,000
raised by volunteers for the projects selected through the calls for proposal



87
sections of projects adopted by Delegations and Support Groups



1
Advisory Group of the Delegations, with **10** representatives




MISSION ACTIVITIES

These cover the goals that the Foundation was established for




HIGHLIGHTS, A SELECTION OF PROGRESS MADE IN 2023



Publications in international scientific journals with high impact factor of advances made thanks to FFC Ricerca

- * Molecular Therapy**
Genome editing to correct CFTR mutations. Projects: **FFC#3/2019, FFC#2/2021**
- * Scientific Reports**
Molecules to restore CFTR function. Projects: **FFC#4/2018, FFC#3/2020, Molecules 3.0**
- * Nature Communication**
Bacteriophage therapy for bacterial infections. Projects: **FFC#15/2021** (continues with FFC#16/2023)
- * Microbiology Spectrum**
Antibacterial properties of CFTR modulators. Projects: **FFC#15/2018** (continues with FFC#16/2021)
- * Journal of cystic fibrosis**
Secondary effects of modulators on cell lipids. Projects: **FFC#16/2021** (continues with FFC#1/2023)



Patents (or applications) on studies funded by the Foundation

> 27
on our projects

> 10
of which are co-owned by FFC Ricerca

> +1
in the process of acquiring co-ownership



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

- * Kaftrio in the real life**
A study to assess the efficacy and safety of Kaftrio
- * 1 in 30 and you don't know it**
A campaign for a better comprehension and awareness of the CF carrier test

MISSION ACTIVITIES

SCIENTIFIC RESEARCH

The Foundation selects and funds innovative studies on cystic fibrosis with the aim of:

Developing new therapies to counter:

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

Evaluating the long-term effects of CFTR modulators

Increasing the knowledge about the disease

With the following tools:

2023



18 projects selected on calls for proposals



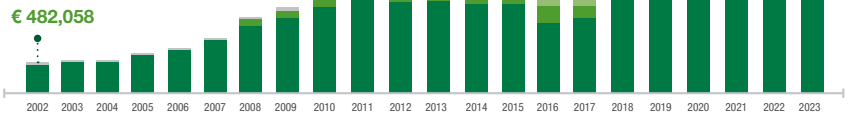
3 research services (CFaCore, SCP, CFDB)



3 strategic projects (GenDel-CF, Kaftrio unveiled, Molecules 3.0)

FUNDINGS

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



KEY FIGURES IN 2002-2023

€ 38 million to finance **477** research initiatives **5 million and 24 initiatives in 2023**

567 international referees for the selection process **93 in 2023**

984 researchers from **196** national and international research institutes **93 researchers and 24 institutes in 2023**

490 grants and **462** grant holders **68 grants and 60 grant holders in 2023**

546 conference proceedings and **915** publications in scientific journals **69 proceedings and 62 publications in 2023**

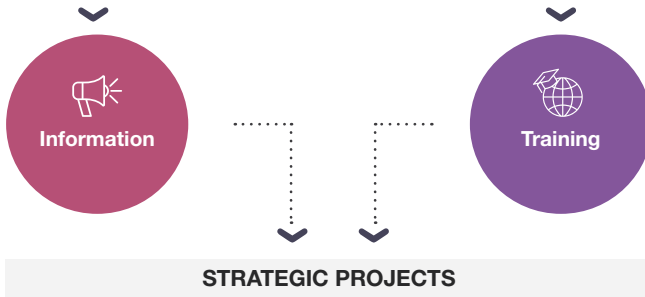
THE SELECTION OF PROJECTS PROPOSAL



MISSION ACTIVITIES

INFORMATION AND TRAINING

Strategic projects and awareness-raising initiatives that aim at informing the wider and most diverse public of the contribution given by the FFC Ricerca. These comprise



* **1 in 30 and you don't know it**

Information and awareness-raising campaign on the healthy CF carrier test

Experts together

Improving the integration and shared goals between the CF community and the research world

AWARENESS RAISING CAMPAIGNS

* **5x1000**
* **Bequests**



INITIATIVES AND MEETINGS

* **The Volunteers Gathering**



7 awards of new Delegations and Support Groups

* **Spring Seminar** *

200 participants

* **Transparent Research**



51 sponsors received the results of the research they funded

* **Convention of Investigators** *

240 participants

PUBLICATIONS ON THE MISSION ACTIVITIES



WEBSITE

28 news on the website



67% of total news 2023



BULLETIN

48,000 readers



35 pages on these topics



NEWSLETTER

19,000 registered



12 on institutional topics



BROCHURES

500 Spring Seminar brochures given

690 Convention brochures

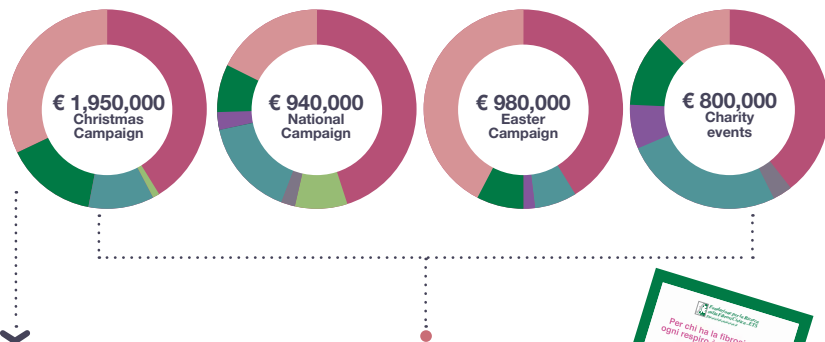
COMMUNICATION, FUNDRAISING AND RELATIONS WITH THE TERRITORY

These comprise the tools which allow the Foundation reach its goals: funding the mission activities, carrying out research, training and spreading information.

2023. FUNDRAISING FROM CAMPAIGNS AND EVENTS



USE OF COLLECTED FUNDS



- Research projects
- GM Starting Grant
- GM Research Fellowship
- Strategic projects
- Research services
- A cure for all Fund
- Reimbursement of costs

€ 4,670,000
Total net funds raised for Mission activities



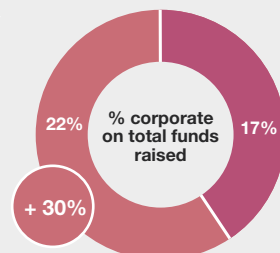
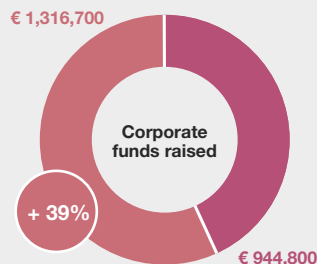
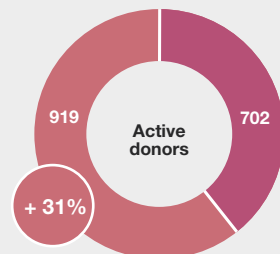
102,600
distributed Christmas sweets

60,000
cyclamen on the public squares in October

68,000
Easter sweets

250
charity events in Italy

CORPORATE DONATIONS



- 2022 with in kind
- 2023 with in kind

VISIBILITY IN FIGURES



* WEBSITE

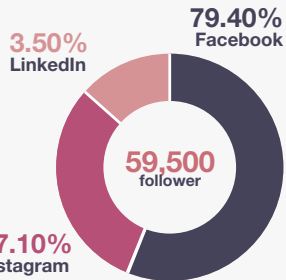
1,500,000
site views

806,600
users

159
news

* SOCIAL

666
published posts



* BULLETIN

42%
printed version

58%
ISSUU flipbook, website,
social media, newsletter



* NEWSLETTER

71 sent	sent	subscribers	reading average
Institutional	12	19,140	35%
Donor Journey	10	16,787	30%
Delegations, Gds, volunteers	37	1,636	48%
Corporate	12	1,525	30%



* PRESS RELEASES



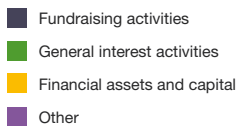
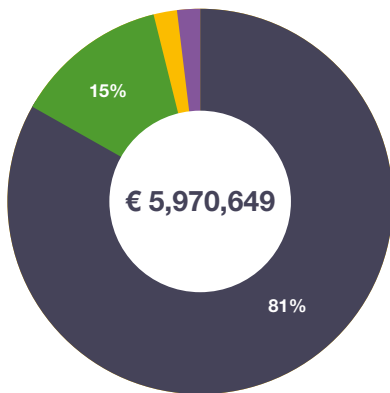
ECONOMIC AND FINANCIAL TREND

It comprises information dedicated to our supporters and volunteers on how the funds are raised and subsequently used.

It shows a constantly growing trend in support of activities of general interest that reflect the mission: research, training, information and awareness.

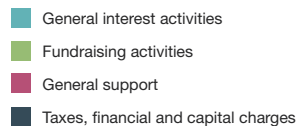
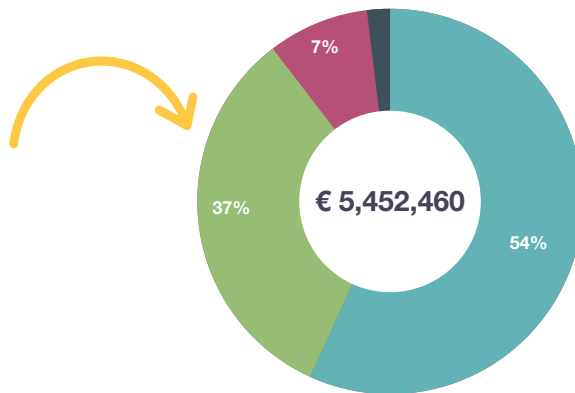
SOURCES OF REVENUES

From the combination of the activities carried out in the 5 management areas, in 2023 there were revenues of 5,970,649 euros, mainly originating from fundraising and activities of general interest.



USE OF THE FUNDS

The main item of expenditure is scientific research which, together with the other Activities of general interest, accounts for 54% of total costs, amounting to 5,452,460 euros: an indicator that has remained constant over the recent years, which testifies to the commitment to cost containment.



BALANCE SHEET

The Foundation's net assets remain high, amounting to 8,152,619 euros (+6% from 2022), guaranteeing the ability to maintain significant and constant investments in research, mainly the result of the operating result of current and previous years.



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

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For further information see the complete Social report 2023
fibrosicisticaricerca.it/i-bilanci/

TO DONATE FOR 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 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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