

22ND CONVENTION OF INVESTIGATORS IN CYSTIC FIBROSIS

XXII CONVENTION D'AUTUNNO
DEI RICERCATORI IN FIBROSI CISTICA


ESPERTI INSIEME - EXPERTS TOGETHER

An initiative to empower the role of volunteers
and people with cystic fibrosis within FFC Ricerca


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The Italian Cystic Fibrosis Research Foundation (FFC Ricerca) relies on approximately **5,000 dedicated volunteers** scattered across all Italian regions who raise funds and awareness about the disease. For reasons of identity and statute, FFC Ricerca has always paid attention to the ways in which science and research are disseminated and shared with the volunteers who support it.


FFC Ricerca dissemination initiatives:



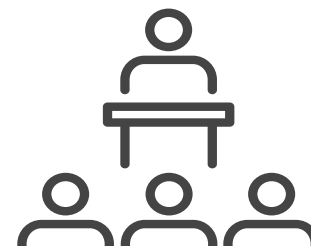
Publications




Website columns




Webinars



The annual seminar



The Transparent Research initiative



The Consultation Group

Experts Together aimed at promoting the creation of a **study group composed of 22 volunteers, people with CF, and their family members**. This group embarked on a journey of mutual understanding, cultural exchange, education, and the development of a common language. Specific tools were identified for the transfer and sharing of fundamental knowledge on **basic and clinical research methodology** regarding scientific aspects of cystic fibrosis.

The ultimate goal of the *Experts Together* group was to collaborate with the Scientific Directorate of FFC Ricerca on:

- ★ research topics
- ★ its priorities
- ★ the role of patient-parents as active research subjects
- ★ clinical research outcome measures, and
- ★ the dissemination of scientific results

THE TYPICAL STRUCTURE OF EACH MODULE

- Narration of a model case by the participants and comments by the expert speaker.
- Formulation of a question to guide research on the presented topic.
- Examination of possible sources of information; article reading followed by a discussion.
- Concluding insights from the expert speaker.
- Final discussion.
- *At home* exercises assignment.

TOPICS AND METHODS ADDRESSED

8 online meetings (modules) of 3 hours each focused on the topic of clinical research.



Respiratory Issues: randomized clinical trials and study design



CFTR: basic studies and graphics



Nutritional/Metabolic Problems: observational studies and outcomes



Physiotherapy: systematic reviews and statistics



Promising Treatments in Animal Models: databases, Pubmed, result measurements



Pharmacological Therapy Issues: guidelines and confounding



Lung Transplantation: economic studies and conflicts of interest



CF Carrier Screening: diagnostic studies, sensitivity and specificity of diagnostic tests

FINAL CONSIDERATIONS

The group coordinator of the FFC Ricerca **strategic project *Experts Together*** decided to share some final considerations of participants that indicate how these eight meetings have improved consciousness of how scientific research works:

“I bring home clarity, curiosity and willingness to make better”

“As a person with CF, I think we are used to think with our gut. However, these meeting allowed me to understand that prescription or non-prescription of some treatments have scientific reasons”

“The more we know about scientific research, the less certainties we have”

“As a FFC Ricerca volunteer, I noticed that the more people understand the complexity of CF disease, the more they approach us. I think that the same is for us with regards to scientific research”

“We now have more tools and competences to make questions to specialists”