



Funding Regulations of Cystic Fibrosis Switzerland

Originally adopted by the Board of Directors on 01.06.2018,

1st revision from 06.11.2019

2nd revision on 5.5.2022

1. Regulatory area

These Rules of Procedure describe the procedure for decision-making by the CFS Board of Directors ("Board") in cooperation with the SWGCF Research Commission ("Commission") on funding for research financed by the CFS. This is to ensure that funding applications are handled in a manner that is comprehensible to third parties at all times.

2. Background and goals

- 2.1. As a result of the 2017 strategy meeting, the Board of Directors has decided to continue to invest in the promotion of CF-specific research with high prioritization.
- 2.2. In addition to an obligation to those affected, there is also an obligation to the donors who make research funding possible. Furthermore, there is an obligation towards the researchers, who enable and secure medical progress in cystic fibrosis with their work.
- 2.3. The primary goal of the CFS research funding is to realize projects that will benefit those affected in the long term over a period of 10 years.
- 2.4. Clinical as well as experimental research projects are funded, provided that a clear relation to cystic fibrosis is recognizable. Basic research projects that serve to test general biological mechanisms or fundamental therapeutic concepts are not part of the CFS research funding.
- 2.5. No projects by scientists working exclusively abroad can be funded. Multicenter projects involving foreign researchers or institutions can be funded if the applicant's institution is located in Switzerland.
- 2.6. In the case of research projects that would exceed the budget set by CFS, partial funding may be approved, provided that the applicant can prove that the total amount required for the project can be obtained elsewhere. In this case, CFS can be supportive in arranging other funding institutions in Switzerland and abroad, with the aim of nevertheless realizing excellent projects.

3. Decision making process



- 3.1. The entire decision-making process is transparent and comprehensible to third parties. Decisions and the reasons leading to them as well as the parties involved in the decision (members of the commission or the board of directors) are recorded and made available to the applicant upon request. The review is unilaterally blinded, i.e. the applicants should not learn the names of the reviewers.
- 3.2. The scientific review level and the decision-making level are strictly separated in terms of personnel and by the procedure outlined here. On the one hand, the Executive Board explicitly refrains from a scientific evaluation of the projects, but on the other hand reserves the sole right to decide freely on research funding.
- 3.3. The decision of the Executive Board on funding is based solely on the criteria of diagnostic and/or therapeutic application perspective and scientific quality.
- 3.4. Conflicts of interest must be disclosed voluntarily and in a timely manner by all parties involved. These include direct or indirect involvement in a funding application, affiliation with the same institution (hospital, department, but not merely the same affiliation with a faculty), possible material or non-material benefits from a positive or negative funding decision, and other reasons relevant to the decision (e.g., personal conflicts or relationships). Those who have a conflict of interest should disclose this. The commission or the board of directors then decides whether or not the person in question can participate in the deliberations and voting on a funding recommendation by the commission or as an expert, or in the funding decision by the board of directors. In case of doubt, the Commission or the Board shall decide at its discretion whether a conflict of interest exists.
- 3.5. The written review will be in English only. All project proposals must be submitted in English and must also include a summary (1 page) in layman's terms in both English and a national language of Switzerland (German, French or Italian).

4. Competent scientific body

- 4.1. All applications for project funding are scientifically evaluated by the Research Commission of the Swiss Working Group for Cystic Fibrosis (SWGCF). The SWGCF Research Commission consists of 5 elected members of the SWGCF, one of whom is elected as Head.
- 4.2. Meetings of the commission can be held as face-to-face meetings or as telephone or video conferences, provided that the technical requirements are available to all members. Commission members who are unable to attend a face-to-face meeting shall submit their assessment in writing or electronically to the head of the Research Commission.



- 4.3. Decisions of the commission are made by a majority of the members, abstentions are not counted. In the event of a tie, this is recorded in the minutes and communicated to the Executive Board; in this case, the head of the commission decides whether or not to make a funding recommendation to the Executive Board.

5. Tender procedure

- 5.1. Project funding is carried out with the funding instruments "large projects" (application sum more than 20,000 CHF) and "small projects" (application sum up to 20,000 CHF). The Board of Directors may set a maximum funding amount per project for large projects in the annual call for proposals.
- 5.2. One call for proposals for research funding is issued per calendar year, covering all the funding instruments mentioned above. The Commission submits a proposal for the call for project funding to the Executive Board each year. The Executive Board shall inform the Commission by this date of the amount of funding for the planned call for proposals.
- 5.3. The Board of Directors decides on the content and scope of the invitation to tender on the basis of the Commission's submission at the following Board meeting.
- 5.4. The Board of Directors then publicly announces the grant in English with sufficient time for application submission (at least 12 weeks). Applications must be submitted on a form made available for download by CFS on the Internet (CFS as well as SWGCF website). The announced deadlines are cut-off deadlines, i.e. applications received after these deadlines will be included in the review round of the next call for proposals.
- 5.5. The incoming project applications are checked for formal correctness by the head of the commission and the managing director CFS jointly or in mutual representation. If the application is incomplete, the applicants are given a period of 2 weeks to complete it. Otherwise, the application will be rejected without scientific review.

6. Scientific review

- 6.1. In a meeting, the commission evaluates the project applications received according to the criteria of CF relevance (diagnostic or therapeutic applicability) and scientific quality.
- 6.2. Major applications and applications for the promotion of young scientists with an application amount exceeding 20,000 CHF, which are considered to be of high quality and relevant to CF, will be sent for external review to a maximum of three internationally recognized reviewers. Applicants must propose at least 3 reviewers in their application.



- 6.3. The selection of the reviewers is determined by the commission. The reviewers may not be members of the Commission or the Board. A biometric expert opinion is obtained as required.
- 6.4. At least one external review should be available for each research proposal before a decision on funding is made.
- 6.5. If, after reasonable effort, it is not possible to find an external reviewer for a project proposal, the Research Commission may decide to make the funding recommendation decision without an external review. This decision must be unanimous and include all members of the Research Commission.
- 6.6. If less than 3 members of the Research Commission are involved in the decision-making process of a project due to bias of the Commission members, it is mandatory to obtain at least one external expert opinion.
- 6.7. Each externally requested expert opinion that is complete and submitted within the deadline will be remunerated by CFS with a lump sum of CHF 200. The reviewers are to be informed of this when requesting a review.
- 6.8. Small applications can be evaluated and recommended for funding or rejected exclusively by the commission without involving external reviewers. If necessary, the Commission may call in one or more external reviewers at any time.
- 6.9. Project proposals that are CF-relevant but, in the opinion of the Commission, do not yet show sufficient scientific quality, should be returned to the applicant with proposals for revision, including recommendations for cooperation with relevant scientists, without external review. At the same time, it must be made clear that even such a revision does not entail any guarantee of funding.
- 6.10. Project proposals with no or little CF relevance will be rejected without external review, even if they are of high scientific merit.
- 6.11. After receiving the expert opinions, the commission discusses the applications in a meeting, taking into account the expert opinions received. The commission makes its funding recommendation in the categories: "Recommended for funding with priority," "recommended for funding," and "not recommended for funding."
- 6.12. Payment of the approved grant amount will be made in a one-time contribution. In advance, the applicant signs an agreement with CFS to accept the grant funds under the condition that he/she agrees to submit at least an interim report after half of the project duration, as well as a final report at the end of the project, to CFS in English or a national



language without being asked. In case of significant, relevant changes in the course of the project, it is also the responsibility of the researcher to inform CFS proactively.

7. Decision by the Board of Directors

- 7.1. The commission forwards the project applications with the funding recommendation and the external expert reports to the Executive Board for a final decision. The Executive Board decides on the applications at its reasonable discretion at the following Executive Board meeting. The head of the research commission or a representative from the commission is invited to the respective board meeting and presents the project applications at this meeting before the board reaches a decision. During the decision of the Board of Directors, the commission member steps out of the meeting. If no commission member can attend the board meeting, the head of the research commission may ask the physician representative on the board to present the projects.
- 7.2. The decision is justified by the Board of Directors on the basis of the Commission's recommendation and the Board's decision-making process. The decision is communicated to the head of the research commission and the applicants in a timely manner and is final. A new deliberation shall only take place if new aspects relevant to the decision have arisen which were not known at the time of the decision and which, had they been known, might have led to a different decision.

8. Promotion of the funded research projects for donation acquisition

- 8.1. Research projects that receive funding from CFS are actively entered by CFS into foundations for the purpose of soliciting earmarked donations, or funders are sought for the research fund.
- 8.2. Applicants are to be advised of the application by CFS as part of the funding commitment. Project funding can only be granted if the applicant agrees to the application of his or her project.
- 8.3. Communication between CFS and funding foundations is handled by the CFS national headquarters.

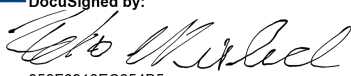
9. Interim reports, completion of the project and publication

- 9.1. Halfway through the project, the applicant prepares a short interim report on the progress of the research project (one page). After completion of the research project, the applicant prepares a final report. The reports will be sent by the applicant to the Secretariat; the Secretariat will forward a copy to the Head of the Commission, to the Board members and to the sponsors of the project. Both report templates will be available for download on the CFS and SWGCF websites.

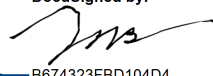


- 9.2. The applicant prepares a max. one-page layman understandable summary of the project (abstract form) in German, French or Italian, which is published on the CFS website.
- 9.3. Likewise, the applicant sends any scientific publications that have resulted from the project to the office.

Approved by the Board of Directors by circular resolution in May 2022.

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President CFS Board
10.05.2022

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Andreas Jung
CFS, Member SWGCF
10.05.2022