



CFCH research funding regulations 2019

Passed by the CFCH Board on 01/06/2018, updated 06.11.2019

1. Scope of regulations

These procedural rules describe the decision-making process of the CFCH Board ("Board") in cooperation with the SWGCF Research Committee ("Committee") regarding the funding of research that is financed by CFCH. This is to ensure that funding applications are always handled in a manner that is open to scrutiny by third parties.

2. Background and objectives

- 2.1. As a result of the 2017 strategy meeting, the Board decided to continue prioritising investment in the funding of CF-specific research in the future.
- 2.2. This constitutes not only a commitment to sufferers, but also a commitment to the donors who make research funding possible, and a commitment to the researchers whose work enables and ensures medical progress in the field of cystic fibrosis.
- 2.3. The primary objective of CFCH research funding is hereby stated as the realisation of projects with prospects of benefiting sufferers within a period of 10 years.
- 2.4. Clinical and experimental research projects alike shall hereby be funded if a clear link to cystic fibrosis is evident. Pure research projects that serve to test general biological mechanisms or fundamental therapeutic concepts are not included in CFCH research funding.
- 2.5. Projects put forward by scientists who exclusively work abroad cannot be funded. Multicentric projects with participating foreign researchers or institutions can be funded if the applicant's institution is situated in Switzerland.
- 2.6. For research projects that exceed the given CFCH budget, partial funding can be approved if the applicant demonstrates that the rest of the total sum required for the project can be obtained elsewhere. In such cases, CFCH can assist by acting as an intermediary with other funding institutions in Switzerland and abroad, with the objective of realising outstanding projects despite the budget situation.

3. Decision-making process

- 3.1. The entire decision-making process is kept transparent and open to scrutiny by third parties. Decisions, their underlying reasons and the names of those involved in the decision-making (members of the Committee/Board) are recorded in writing and these records are made available to the applicant. Single-blind assessment is conducted, i.e. the applicants are not to learn the names of the assessors.
- 3.2. The procedure described here strictly separates personnel on the scientific assessment level from those on the decision-making level. The Board expressly refrains from scientific assessment of projects, but does reserve the exclusive right to freely decide on research funding.
- 3.3. The sole criteria for the Board's funding decision are the prospective diagnostic and/or therapeutic application, and scientific quality.
- 3.4. All parties shall voluntarily reveal any conflicts of interest in good time. This includes direct or indirect involvement in a funding application, belonging to the same institution (hospital or department, but not merely belonging to the same faculty), possible material or immaterial advantages from a positive or negative funding decision, and other decision-relevant reasons (e.g. personal conflicts or relationships). Anyone with a conflict of interest shall make this known. The Committee/Board then decides whether or not the respective person can take part in the consultation and voting on a funding recommendation from the Committee, or as an assessor, or in the Board's decision-making on the funding. In cases of uncertainty, the Committee/Board uses equitable discretion to decide whether there is a conflict of interest.
- 3.5. The written assessment shall be solely in English. All project applications are to be submitted in English and must also include a (1-page) summary that can be understood by laypeople, in both English and one national language of Switzerland (German, French or Italian).

4. Competent scientific panel

- 4.1. All applications for project funding are scientifically assessed by the Swiss Working Group for Cystic Fibrosis (SWGCF) Research Committee. The SWGCF Research Committee comprises 5 chosen SWGCF members, one of whom is elected as chairperson.
- 4.2. The Committee's meetings can be held face-to-face, or else as telephone or video conferences if the technical prerequisites are met by all members. Committee members who cannot attend a face-to-face meeting submit their assessment in written or electronic form to the Research Committee chairperson.
- 4.3. Committee decisions require the support of a majority of members, regardless of abstentions. If the vote is tied, this is recorded in writing and communicated to the Board; in such cases, the Committee chairperson decides whether or not a funding recommendation is to be issued to the Board.

5. Tendering procedure

- 5.1. Project funding is realised with the funding instruments "large-scale projects" (funding request of more than CHF 20,000), "funding of young talent" (applicants aged up to 35 and a maximum of 1 peer-reviewed publication relating to CF; no defined funding request) and "small-scale projects" (funding request of up to CHF 20,000). With regard to large-scale projects and projects for the funding of young talent, the Board can set a maximum funding amount per project in the annual invitation to tender.
- 5.2. Each calendar year, one invitation to tender for research funding is issued, encompassing all aforementioned funding instruments. Each year, the Committee submits a proposal to the Board regarding the invitation to tender for project funding. Before this date, the Board informs the Committee of the financial volume for the scheduled invitation to tender.
- 5.3. The Board decides on the content and scope of the invitation to tender, on the basis of the submission from the Committee and the subsequent Board meeting.
- 5.4. The Board then publicly issues the invitation to tender for funding, which is written in English and specifies a suitable deadline for submission of applications (at least 12 weeks away). Applications are to be submitted via a form that CFCH makes available for download from the Internet (CFCH/SWGCF website). The announced deadlines are cut-off dates, i.e. applications received later are included in the assessment round for the next invitation to tender.
- 5.5. Received project applications are checked for compliance with formal requirements by the Committee chairperson and the General Manager of CFCH, either jointly, or by one acting on behalf of the other. If the application is incomplete, applicants are given two weeks for amendment. If this deadline is missed, the application is rejected without scientific assessment.

6. Scientific assessment

- 6.1. In a meeting, the Committee assesses the received project applications based on the criteria of CF relevance (diagnostic or therapeutic applicability) and scientific quality.
- 6.2. Large-scale applications, and applications for the funding of young talent, that request sums over CHF 20,000 and are classed as both high-quality and CF-relevant, are sent to a maximum of three appropriately internationally renowned assessors for external assessment. Applicants must suggest at least three assessors in their application.
- 6.3. The Committee decides on the selection of assessors. The assessors must not be members of the Committee or Board. A biometric assessment is obtained if necessary.
- 6.4. For every research application, at least one external assessment is to be obtained before the funding decision is made.
- 6.5. If, after reasonable effort is made to find an external assessor, none can be found for a project application, the Research Committee can resolve to decide on the funding

recommendation without external assessment. This resolution must be unanimous and include all members of the Research Committee.

- 6.6. If, due to bias on the part of Committee members, fewer than three members of the Research Committee are involved in the decision on the funding recommendation in a project's decision-making process, it is mandatory to obtain at least one external assessment.
- 6.7. CFCH shall pay CHF 200.- for each requested and complete external assessment submitted before the deadline. Potential assessors are to be informed of this when asked to provide an assessment.
- 6.8. Small-scale applications can be assessed exclusively by the Committee and recommended for funding or rejected without any external assessors being brought in. If necessary, the Committee can bring in one or more external assessors at any time.
- 6.9. Project applications that are CF-relevant but not yet deemed by the Committee to be of sufficient scientific quality shall be returned to the applicants without external assessment, along with suggestions for revision, including recommendations on cooperation with potentially relevant scientists. At the same time, it must also be made clear that such revision will not guarantee funding.
- 6.10. Project applications with insufficient relevance to CF, or none at all, are rejected without external assessment, even if they are of high scientific quality.
- 6.11. After receiving the assessments, the Committee discusses the applications in a meeting, taking the received assessments into account. The Committee issues its funding recommendations in the following categories: "recommended for funding with priority", "recommended for funding" and "not recommended for funding".
- 6.12. For each application, milestones are to be defined, including specification of a time horizon (schedule) for achievement of each milestone; the approved funding amount is paid in instalments, each payment occurring after the next respective milestone is achieved. The applicants must notify the Committee of achievement or non-achievement of milestones; if milestones are not adhered to, the Committee or Board can suspend or cancel payment of the outstanding instalments. The applicants are given an opportunity to explain non-achievement of milestones and to apply for an extension of the prescribed schedule.

7. Decision by the Board

- 7.1. The Committee forwards the project applications to the Board for the final decision-making, together with the funding recommendation, defined milestones, schedule and external assessments. The Board uses equitable discretion to decide on the applications at the next Board meeting. The Research Committee chairperson or a representative of the Committee is invited to the respective Board meeting and presents the project applications there, before the Board makes a decision. The Committee member does not participate when the Board is making its decision. If no Committee member can attend the Board meeting, the Research Committee chairperson can ask the medical representative on the Board to present the projects.

- 7.2. The decision is made by the Board on the basis of the Committee's recommendation and the Board's decision-making process. The decision is final and shall be promptly communicated to the Research Committee chairperson and applicants. A new consultation shall only occur if new aspects relevant to the decision arise, which were not yet known at the time of decision-making and, had they been known, might have led to a different decision.

8. Promotion of funded research projects for fundraising

- 8.1. Research projects that receive funding through CFCH are actively promoted by CFCH, so that project-specific donations can be obtained. For this purpose, interested potential donors are first contacted either verbally or in writing. The project applications, along with a summary that can be understood by laypeople, are then either forwarded to them, or presented to them in person.
- 8.2. CFCH is to inform the applicants about such promotion when funding is approved. Project funding can only occur if the applicant agrees to the promotion of their project.
- 8.3. Communication between CFCH and potential donors occurs via the CFCH office and shall be maintained by one person only, who is an experienced fundraiser. The fundraiser regularly informs the Board in a timely manner, either via the office or in person at Board meetings, of how the project-specific fundraising is progressing.

9. Conclusion of the project and publication

- 9.1. After conclusion of the research project, the applicant compiles a brief report (a CFCH template is made available for download from the CFCH/SWGCF website) and sends it to the office, which then forwards a copy to the Committee chairperson and to the members of the Board.
- 9.2. The applicant writes a project summary in the form of an abstract in German, French or Italian, which is no longer than one page and can be understood by laypeople, to be published on the CFCH website.
- 9.3. Likewise, the applicant is to send the office any scientific publications resulting from the project.
- 9.4. After conclusion of a project, the Board assesses the project's impact on the CFCH funding objectives mentioned in section 2, in reference to the report and publications.