

STICHTING USHERSYNDROOM OPENS A CALL FOR PROPOSALS



Currently no treatment is available for 400.000 “*Ushers*” worldwide. The use of the word ‘*Ushers*’ for people suffering from the Usher Syndrome is meant as a pun and refers to the meaning of the English word ‘the ushers’, the messengers. *Ushers* tell what they need, what help they require, what they think is important and how they experience their lives with the Usher Syndrome. What *Ushers* currently need is more knowledge of and research into Usher Syndrome. Therefore, Stichting Ushersyndroom [The Dutch Usher Syndrome Foundation] presents the **Usher Crusher Grant: €300.000,- for Usher Syndrome research.**

THE USHER CRUSHER GRANT

The goal of the **Usher Crusher Grant** of Stichting Ushersyndroom is to realize our moonshot goal: *“In 2030, everyone in the Netherlands and also worldwide, is familiar with the Usher syndrome, and its diagnosis, treatment, and care have been standardised”*. The **Usher Crusher Grant** aims to financially support Usher syndrome research.

The Usher Crusher Grant will award up to € 300.000,- . If there are multiple eligible projects more projects may be funded. A maximum of € 300.000 is available for funding.

Projects submitted for funding by **the Usher Crusher Grant** need to involve **research to Usher syndrome**, any form or subtype of Usher syndrome can be investigated. All submitted research proposals must fit in any of the four core values regarding research of Stichting Ushersyndroom as defined by:

1. **Treatment:** The treatment of Usher syndrome focuses on slowing down and halting its progression, improving vision, hearing, and balance, and reducing other symptoms and complaints, including sleep problems.
2. **Fundamental Research:** We aim to encourage research into all types of Usher syndrome. The research focuses on unraveling the fundamental mechanisms behind the causes of Usher syndrome, so that we can better understand them. This forms the basis for diagnosis and treatment.
3. **Biomarkers and Endpoints:** To map the clinical course of Usher syndrome and assess the effectiveness of (new) treatments, measurable indicators are needed. These biomarkers enhance the efficacy of development and determine the clinical endpoints for therapeutic studies.
4. **Diagnostics and Prognostics:** We aim for a genetic diagnosis for everyone with Usher syndrome. For individuals showing symptoms indicative of Usher but who do not yet

have a confirmed DNA diagnosis, detection and diagnostic methods need to be improved.

ELIGIBILITY AND REQUIREMENTS

The main applicant must be an **MD** or **Phd**, who is appropriately **affiliated with an academic institution**. The researcher's (applicant's) institution must **provide proof of affiliation** and **declare how it intends to support the applicant/co-applicants** with respect to his/her position, research time, lab space or access to clinical data. Collaboration, integrating knowledge, experiences and techniques with other research centres is also allowed. Participation of patient research partners is strongly encouraged to underline the importance of the project for the patients.

THE APPLICATION

The application consists of a **description of the project** (no longer than 4 pages), **budget table**, **Lay persons summary** (1-2 pages), **proof of affiliation of an academic institution** and a **resumé** of the main applicant.

DESCRIPTION OF RESEARCH PROJECT

Please indicate which research domain your project covers: Treatment, Understanding, Diagnostics or Impact. Provide the title of your research project. The research project description needs to contain an abstract, background of the research project, objective of the project, the research plan, Outcome/impact, Limitations, and Patient Participation. Below is a brief description of all these elements:

- **Abstract** – A short summary of the research project
- **Background** – The background/literature on which the project is based, please keep the amount of references limited, try to only include key references.

- **Objective** – Description the objective/research goal of the project in several sentences.
- **Research plan** – Description of how the research will be performed to reach the research objective, this includes a description of the methods and an expected timeline.
- **Outcome/Impact** – A small paragraph on what kind of impact and implications will the outcome of this project have for Usher Syndrome research and patients.
- **Limitations** – A small paragraph on what are the expected limitations or possible issues that may arise during the project and what will be done to prevent and minimize these.
- **Patient Participation** – A small paragraph on how patients are or will be involved in this project and how research results will be communicated to patients and lay persons.

The entire application should not be more than 4-5 pages in length, graphics are encouraged. (excluding the References, Budget table, Lay-man summary, Curriculum vitae and list of publications). Please keep in mind that a patient panel will also read your application, thus a readable font size/spacing etc. is very welcome.

BUDGET TABLE

A table consisting of the requested total budget for the project needs to be added. The budget should consist of a rough breakdown into salaries, supplies, services, equipment purchase, etc. There are no priori restrictions, but you will need to provide a brief justification of items that are not self-explanatory. **The Usher Crusher Grant can be used for existing projects, to start up new projects or as contributing to costs for larger projects.** In the case of multiple eligible research projects, Stichting Ushersyndroom, can also decide to partially fund multiple projects, or fund multiple projects with smaller budgets.

LAY PERSONS SUMMARY

As Stichting Ushersyndroom was founded for and by Ushers themselves, the research project will also be evaluated by a panel of Usher Syndrome patients. Thus a 1-2 A4-page Lay persons

summary is required for the application, and will be also used in the evaluation process. The use of graphics is encouraged.

PROOF OF AFFILIATION OF AN ACADEMIC INSTITUTION

The host academic institution of the main applicant and/or the academic institution where the research will be performed needs to give proof of affiliation of the main applicant for the grant application. A single letter of the host institution containing proof of affiliation and contact information of the host institution and a contact person for the host institution is needed.

RESUMÉ/CV

A resumé/CV of the main applicant also needs to be provided with the grant application. Narrative CVs are also welcome. The CV must also include a list of publications.

TIMELINE

WHAT	WHEN	DETAILS
Call open	October 8, 2024	Call is published online
Deadline project submission	February 28, 2025	Deadline for handing in all required documents
Decision/Rebuttal*	May 1 – May 31, 2025	Additional questions and/or an interview with the Usher syndrome board may be requested. Adequate time will be given to respond/prepare
Decision grant*	June 20, 2025	Official results known and published.

*Timelines may change depending on number of applications received

APPLICATION PROCESS

Applications can be sent via email to research@ushersyndroom.nl. Only complete applications will be considered. The **deadline for submission is 28th of February 2025 at 13:00 CET**. All completed applications will be reviewed by the Scientific Advice Board (WAR) of Stichting Ushersyndroom and a panel of Usher Patients. If needed external review by independent experts may be performed, if your application is sent for external review, you will be notified. The board of directors of Stichting Ushersyndroom will award **The Usher Crusher Grant** as based on the advice of the WAR, the patient panel and (if applicable) the external review panel. It may be possible that the applicant is requested for a digital interview with members of the WAR or board of directors of Stichting Ushersyndroom.

APPLICATIONS WILL BE JUDGED ON:

- **Relevance to the four core values of Stichting Ushersyndroom** – does the proposed research fit within the core values and the overarching goal of the foundation.
- **Methodology** – is the proposed methodology sound and of good quality for the proposed project.
- **Relevance & Innovation** - how innovative is the research, how will it contribute to advance the knowledge of Usher syndrome? How is/will this research be relevant for Usher syndrome patients.
- **Feasibility** – Is the proposed project feasible within the given time, budget, methodology and expertise of the main and co-applicants (does the application fit within the research and expertise of the main applicant).
- **Impact** – what will the impact of the research be on knowledge of Usher syndrome, on treatment options/development and/or the impact on Usher patients.

Winners will be announced at the International Symposium on Usher syndrome USH2025, held in Nijmegen, Netherlands on June 19th, 20th and 21st 2025. Grant awardees are expected at the start of the founded research project or at the moment of funding provide a lay-man's

summary of the project (short video summary is also allowed) in which the applicant and project is briefly introduced and which will be shared on the website and social media of Stichting Ushersyndroom

At the end of the project or funding duration an end report is requested: a brief summary of the findings of the research project and impact of the research project, also in layman terms. Additionally, **awardees are expected to present their findings before a layman audience** of Usher patients and supporters of Stichting Ushersyndroom, during a webinar organized by Stichting Ushersyndroom at the end of the research project.

PUBLICATION POLICY

Stichting Ushersyndroom is a supporter of open science and supports open access publications, thus requests (within reason) that **any scientific publication resulting from research funded by Stichting Ushersyndroom is published open access**, open access fee thus can and may be taken into account in the budget.

Furthermore, Stichting Ushersyndroom requests **that any scientific publication resulting from research funded by Stichting Ushersyndroom acknowledges Stichting Ushersyndroom in the funding section** of the scientific publication.

ADDITIONAL INFORMATION:

For previously founded projects see: <https://www.ushersyndroom.nl/en/research/>

Further questions regarding the call and the Usher Crusher Grant please contact research@ushersyndroom.nl